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Erratum

The Journal of Clinical Ethics, volume 15, number 4, includes an error in pagination: it should have begun on page 313, not page 239. Because of this error, issue 15, number 3 and 15, number 4 share some page numbers. The journal apologizes for any confusion this may have caused.

At the Bedside

Why Are They Boxing Us in Like This?

Edmund G. Howe

In this issue of *The Journal of Clinical Ethics*, in "Emancipation, Capacity, and the Difference Between Law and Ethics," Evan G. DeRenzo, Phillip Panzarella, Steve Selinger, and Jack Schwartz discuss the hospital course of TE, a 16-year-old girl who was pregnant with a 29-week-old fetus. TE had a 103° temperature, due to a kidney infection, and wanted to walk out of the hospital against medical advice (AMA). The hospital risk manager and the hospital attorney indicated to TE's careproviders that they should allow TE to leave. The core dilemma her careproviders faced was whether to let TE walk out of the hospital, knowing that, if she did, she and her fetus might well die. Since TE appeared to be lucid, the grounds on which they could keep and treat her against her will were unclear. As the authors point out, "TE's talk of leaving based on room size and the need for a bath" could reasonably be seen as not "manifesting decisional impairment."

TE's careproviders wondered what could —and should—be done in this situation. This same question applies any time that patients clearly act against their own best interests, but appear to be rational. The answer may determine whether a patient lives or dies. In the present case, TE's careproviders found bases on which they could treat her, but the authors acknowledge that it is "open to debate" whether careproviders are ethically required to protect such patients from harming themselves. They believe that TE was suffering from a dissociative disorder, and that, while this is what a "highly skilled psychiatrist would most probably have determined," a psychiatric evaluation by a psychiatrist not as skilled could "perhaps have made matters worse."

This speculation, if true, is highly troubling. In such situations, patients may die. Given this, what should careproviders do

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when a patient isn't incompetent in a way that is clear to everyone, but is making a decision that is wholly against her or his best interests and is in a dissociative state? Should careproviders let such decisions ride on the skill of a psychiatrist? What careproviders should do in this kind of circumstance is the focus of this essay. These interventions are "cutting-edge" treatments used by psychiatrists to best reach patients—I will describe them here as they can be used by ethics consultants.[1]

UNDERSTANDING PATIENTS LIKE TE

The first step in trying to help patients like TE is to try to understand them. TE had seven factors that may have affected her judgment. She was 16; she was pregnant; she was in the intensive care unit; she had recurrent high fevers; she had pain; she wasn't speaking to her baby's father; and, although she spoke to her mother, she was verbally abusive when she did.

All of these factors may have affected TE so that her intentions vacillated; sometimes she wanted to stay and be treated; sometimes she wanted to leave. This vacillation was not between two choices that made sense; rather, to choose to leave the hospital could not have benefited either TE or her baby. The difference between vacillating between two reasonable choices and vacillating between one that is reasonable and one that is not is critical. This difference probably reflects totally different psychological causes. That is, when patients vacillate between two choices that make sense, it is "normal ambivalence." When one of the choices makes no sense, however, it suggests that some part of the patients' mind, outside their control, has temporarily, as it were, "taken over."[2]

This may sound bizarre, but this kind of behavior has been well acknowledged for some time in several other contexts. In the research context, it is known as state-dependent learning. Animals may, for example, learn how to run through a maze when they have a specific drug in their system, but forget how to run the maze until they are given the same drug again. The drug causes a different part of their brain, presumably, to take over. Humans, analogously, may have more access to buried memories when they are given sodium amytal intravenously. (This is the drug commonly known as "truth serum.") Careproviders sometimes interview patients using this drug to elicit such memories. Under the influence of the drug, another part of patients' brain seems to take over. One example with which we are most familiar is alcohol. When intoxicated, persons can behave as though they are "someone else." This can happen also without drugs; it is known as a dissociated state. It can occur also when persons aren't using alcohol or drugs. The best-known example is patients who have what used to be called a multiple personality.[3]

A dissociated state in which another part of a patient's brain takes over may be what TE and patients like her experience if and when they make a choice that can't benefit them at all, in any understandable way. This is what DeRenzo and colleagues thought was the case. One part of a patient's mind, the "normal" self, may say, for instance, "I want what I need. I want to be treated and live." Minutes later, however, another part may "take over" and then the patient will say, "I don't care. It is fine with me, even if I die. In fact, I'll try to make this happen!" This other part is most likely to take over when a patient is provoked. This may have been what happened with TE. When she was asked if she cared about her pregnancy, we are told, she said she wanted to have a healthy baby, but "moments later she would act again as though she would leave." TE, or, as it were, another part of TE that could take over, may have experienced the question about her wanting to have a healthy baby as insulting. In response to this anger, this part may have emerged, taken over, and wanted to leave the hospital AMA.

Dissociation occurs in its fullest extent when patients have a multiple personality. This disorder often occurs in persons who have been badly abused during their childhood. It is believed that a "part of them" experienced overwhelming fear and anger, but,

if they expressed that openly, they would have been beaten more. Thus, their brain may have cut these fearful and angry parts "off," or dissociated them, so that those feelings were no longer part of their conscious awareness. Thus, even just moments after having been badly beaten, they would have been able to "be," and thus wholly appear, smiling and loving. If they were smiling and loving, it would have reduced the likelihood that they would have undergone further beatings.

Later on in their lives, however, these "cut off" parts of patients emerge. The angry part may come out, for example, in response to being exceptionally provoked. This is what I have suggested just above, for instance, using the example of TE. It is probably very difficult to imagine that one part of a person could say, "It is fine if I die." This is, however, often the case when patients have a multiple personality. They may have made several past suicide attempts that remain wholly unexplained. In these cases, as far as these patients or anyone else can tell, they were "happy" one minute but tried to kill themselves in the next. The most plausible explanation for this, especially if this is a repeated pattern, is that these persons have dissociated one part that wants to kill them, and that this part repeatedly takes over.

I remember interviewing such a person, who had no memory of having driven his motorcycle into a tree. He had life-threatening injuries at that time, but had survived. He had also survived similar life-threatening injuries many times before. When I first talked with him, he seemed "happy," and was very warm to me. He had no memory of his motorcycle accident. The last thing he remembered was riding his motorcycle, feeling "good." I must have said something to provoke him, for his demeanor abruptly changed. He was not happy, but angry, and could remember exactly what had happened. He had driven his motorcycle into the tree intentionally, he said. "Why?" I asked. "Because I wanted to kill the person to whom you have just spoken," he said. "But if you had, you wouldn't now be alive," I said. "Yes I would," he responded; "I didn't need his body to live before I came into existence. I don't need it now." There is only one word that best describes how his saying this affected me—it was "chilling." The individual speaking to me seemed to be another part of the "warm" person with whom I had been speaking just before the part that wanted to kill himself "took over."

This kind of "taking over" need not be complete. A renowned expert on dissociative states, John Watkins, states, "We believe that dissociation exists on a continuum. [Individuals] are a family of selves."[4] If Watkins is right that dissociation can occur to only a limited degree, this may be of utmost importance in understanding patients like TE. What this may mean is that she totally lacked control over some part of her that could take over and act against her interests, such as wanting to leave the hospital AMA. If so, the only way TE, and others like her, pregnant or not, may not die is if her careproviders do something to prevent it.

But, before we ask *how* careproviders can best do this, we might well ask, Is this all only theory? It was first speculated that dissociation like this occurred more than a century ago. William James, in the nineteenth century, noted that some persons showed behavior that suggested that another part of the brain had taken over. When this occurred, he called it an "ideo-motor act." He distinguished this behavior from a "genuinely willed act."[5] A decade or so ago, due to new electroencephalogram (EEG) and brain-imaging techniques, researchers became able to better understand what happens in the brain when this behavior occurs. As a result of these studies, they came to believe that persons have "subsystems of control" that can be "automatically activated."[6] The mind's apparent unity, they think, as a result of these studies, is, at least in part, an illusion. They theorize further how, physiologically, dissociation occurs. They believe that when an emotion such as TE's agitation reaches a certain threshold of intensity, another part of the brain is, as it were,

"unleashed."[7] They believe that when this automatic activation of a subsystem occurs, a "higher level control system" is no longer needed.[8] What this suggests is that when persons can make choices wholly against their interests (as TE did), that, at these times, they can't meaningfully reflect. This would explain why TE was willing to leave the hospital and why the patient I saw years ago was willing to ride his motorcycle into a tree.

A more recent study reports that a part of the brain can take over a function and another part of the brain, which normally is wholly in control, can shut off. For the first time, this study used persons as experimental "controls."[9] How can careproviders who are treating patients like TE, who may be experiencing a dissociative state, best proceed?

TREATING PATIENTS LIKE TE

The clinical implications of this for ethics consultants and other careproviders who treat patients like TE are obviously far-reaching. If this is true, then, although the patients may "literally" understand their options when they choose to do something that won't benefit them at all, in a deeper sense, they may not. Rather, they may be like the person I interviewed who rode his motorcycle into trees. He knew at these times, *literally,* that he could kill himself. Yet, in a deeper sense, he didn't care. This was not because he was suicidal and no longer wanted to live. This was because he—or this part of him—when it took over, didn't really know what it meant to die. He didn't know this because, at these times, a part of his brain was cut off or disembodied, as it were, from other parts. Lacking access to these other parts, he, or this part, couldn't understand what dying really means. "I will live on," this part said. "I don't need a body to live." The single most important implication for careproviders is, as I have said, that patients may not be able, by themselves, to gain full awareness when they most need it. Thus, careproviders must help them, if possible. But how?

RECOGNIZING WHAT MAY BE OCCURRING

The first step is to imagine that this may be the case. Patients may feel genuine ambivalence. If they do, they may vacillate. The distinguishing feature between these non-dissociated patients and patients like TE is as described: non-dissociated patients' choices all make *some* sense. The initial task is simply to imagine the possibility that dissociation is occurring when patients are vacillating.[10] The second task is to assess whether all of the choices have understandable goals.

Obviously, there are cases in which these two possibilities can't be distinguished. I think, for example, of a patient who had AIDS, whom I asked about advance directives. "I want to be allowed to die with utmost dignity," he first said; "Don't keep me alive after I'm no longer aware, with tubes and the like." I came back a few hours later to be sure I understood exactly what he wanted. He then said, "I want to live on as long as possible. It doesn't matter to me what they do or what condition I'm in. I just want to live as long as I can." In cases such as this, it might still be best for careproviders to respond in the ways that will be described. If, to any degree, patients' reasons for vacillating are at all the same as for patients who severely dissociate, such as those with multiple personalities, the approaches I will suggest next may be more likely to "succeed."

NOT ELICITING THE "NEGATIVE PART" OF PATIENTS

Careproviders must at all cost try to not elicit the "negative part" of these patients. They might try to anticipate, for example, how, with a patient like TE, the question, "Do you want to have a healthy child?" could be offensive. How can they best do this? Donald Saposnek states that careproviders must have an "attitudinal stance [that] includes deep mutual respect for the basic goodness of all people and for their differences. . . . "[11] This recommendation applies to all patients. It is also critically important that careproviders not

only watch what they *do,* but also watch what they *feel and think.* Saposnek goes on to describe the all-important "bottom line" of his approach, which is, indeed, the major purpose of this essay. He asserts that unless careproviders respond in the ways he suggests, "traditional therapists" will label these patients wrongly as "untreatable."[12] I will report here on Saposnek's best and most representative approach, which he refers to as a "one-down approach."[13] Careproviders who use this approach take specific initiatives to try to ensure that patients don't conclude that careproviders think they are superior. He states, for example, "The therapist anticipates resistance . . . and pre-empts it." A careprovider might say, for example, "You are probably going to think I'm stupid, but. . . ."[14] Likewise, if and when these patients' "negative parts" seem to assert themselves, a careprovider should repeatedly "redo" this.[15] In Saposnek's words, a careprovider may have to "periodically apologize for his incompetence, inadequacies, and denseness."[16] The rationale for this approach, he explains, can be conceptualized as analogous to that of the physical practice of a Japanese meditative martial art called Aikido: "Paradoxically, his power is born out of a no-power stance. . . ."[17]

FORMING A STRONG EMOTIONAL BOND

Careproviders must, if possible, form a strong emotional bond with patients. This can give the patients' "normal selves" enough support to enable them to remain in more control, perhaps in enough control to be able to choose what is best for themselves. How can careproviders do this? Leston Havens describes how to do this, in general: careproviders must convey, he says, that "I am on your side, we look out together, our search for trouble is more in the world out there than in you as a solitary being."[18] The key here is to enable a patient to no longer feel so alone. It is as if a careprovider sits next to a patient and says, "Why are they boxing us in like this?"

To respond most effectively to a patient's negative responses, whether these responses come from the patient, or, as it were, some "negative part" of the patient, careproviders first must explore *why* a patient like TE responds negatively. Only if careproviders know this can they validate the patient's basis for doing what he or she does. Richard Kluft is a psychiatrist who has had, perhaps, more experience and success in treating patients with multiple personality as anyone.[19] This illness, also called dissociative identity disorder (DID), is the most severe of the dissociative disorders. Kluft stresses the importance of respecting the negative parts of these patients by addressing them directly. He states, "To date, I have not been able to find a literature describing the successful definitive treatment of DID without addressing the alters. Therefore, the clinician who undertakes to treat DID without addressing the alters is following a path likely to prove therapeutically futile and to expose the patient to danger and excess morbidity."[20]

His explanation of the rationale for addressing these "alters" is applicable to all patients who experience any dissociation, in any context, to any degree. Kluft says, "The alters are a curious phenomena. They express the structure, conflicts, deficits, and coping strategies of the DID patient's mind. . . . Bypassing or disregarding the alters creates a therapy in which major areas of the patient's mental life and autobiographic memory *will be denied an empathic hearing.*"[21] As an example of how ethics consultants and other careproviders who lack Kluft's expertise can do this involves TE. We are told that she became verbally abusive with her mother. She did this for a reason. Careproviders should find the reason for such abusive behaviors; for example, if asked, TE might have said, "My mother didn't appreciate that they are telling me what to do."

After learning the reason, careproviders must take the initiative to support this part of the patient. If this isn't done, the patient may infer from the silence in response to the patient's disclosure that the careprovider is

negatively judging him or her. What should a careprovider say then? "I can't stand it when someone tells *me* what to do," TE's careprovider might have said to support her. Validating some aspect of the response of the negative part of the patient may decrease the source of anger that fuels the "negative part." Consequently, the "healthy" or at least healthier part of the patient may be better able to stay "in control," and, thus, be better able also to make choices, in this "emergency context," that *do* serve the patient's best interests.

As Kluft states, in regard to patients with DID, "[Strengthening] the patient as a whole and across alters . . . to preserve and enhance the patient's current level of functioning . . . often [may] allow the DID patient *to feel for the first time that he or she can be effective rather than powerless* in the face of the DID psychopathology and life events."[22] Careproviders who try to help these patients can't, however, do it only "halfway." They must be willing to acknowledge *every* way in which *any* person whom the patient experiences as having offended her or him could, indeed, have acted in a way that was "wrong." (Objectively, these other persons may have been "wrong" relative to how they might have acted if they had acted in a way that was ideal.)

How might a careprovider do this? She or he might say, "*I* would have *also* wanted *my* mother to understand this. I would feel angry, too; if she didn't!" To do this effectively, a careprovider must be willing to openly acknowledge the real, or at least relatively real, shortcomings of any other person, including family members, other careproviders, and even him- or herself. This is what makes this specific intervention unusual and maybe even radical. If a careprovider doesn't do this fully, but tries to "protect" anyone, to any extent, a patient is likely to perceive it. It may be perceived as the careprovider's willingness to implicitly deceive the patient, and the patient is likely then to not only lose trust; this may further the anger that is felt. The negative part of the patient may then be more likely to emerge, and the patient may then suffer more.

It may be feared that providing any support to a patient's negative responses may reinforce them. For example, it may be feared that supporting TE's rationales for wanting to leave the hospital AMA may make it more likely that she would do so, and then die. In one sense, this suggested approach does distort the truth. That is, persons never can act always in ways that are ideal. But patients, at some level, probably already know this. TE wanted to leave, she said, in part because her room was too small. Suppose her careproviders said, "Of course you don't want to stay in a room that feels too small! Some people, you know, have claustrophobia. The panic they feel may be as painful a feeling as there is!" Careproviders who respond in this way, rather than evoking anger, express empathy. In response to this empathy, a negative part of the TE that might "want" to leave the hospital would be *less* likely to emerge.

IF THE "NEGATIVE PART" PREVAILS

Careproviders may have no choice if they want to help patients like TE to pursue what is in their best interests. Careproviders may have to fully ally themselves with not only the patients' "normal part" that wants to live, but with other parts that are self-destructive. The question that remains is what careproviders should do if this approach fails. TE's situation is exceptional, as she was pregnant. DeRenzo and colleagues note, "at a minimum, some moral consideration is owed to the fetus."

This provides an excellent way to introduce the problem considered next. That is, in TE's case, if careproviders believe that TE's fetus is owed some moral consideration, and they tell TE this early on, it could only be expected to have a negative effect. TE might well say to herself, "I'm important too, but obviously you don't think so, so I will leave the hospital now, whereas otherwise I would not have!" Should careproviders risk having TE respond in this way? Or should they only tell TE they believe her fetus is owed consider-

ation should she definitely decide she will leave the hospital? Should careproviders be totally honest at the beginning about how fully they may later oppose a patient, or should they validate the underlying rationales of a patient's self-destructive desires in an implicitly supportive way, in the hope that this will move the patient to do what is best?

If careproviders take the second approach, they will have to decide later whether to change perspectives and wholly oppose the patient. In the case of the motorcyclist, for example, this may have meant forcefully incarcerating him once he indicated that he had planned to run his motorcycle into a tree. Careproviders might indicate earlier, as they support patients' underlying rationales, that unless the patient makes choices that seem clearly in the patient's best interests, *other* careproviders may oppose the patient, to the degree that they can. TE's careproviders could have told her, for instance, that other careproviders might do all they could to oppose her leaving the hospital AMA. This may be enough, in some cases, to shock the "part of the patient" that is refusing treatment into accepting it. That is, the patient may, like an emotionally healthier patient might, see the soundness in what other careproviders say, and comply.

This, however, begs the issue. If patients don't comply, should their careproviders, who have supported even their negative parts, now seemingly betray them? I would answer—as DeRenzo and colleagues do—unequivocally, "Yes." Since DeRenzo and colleagues give most of the strongest arguments for this already, I will mention only a few more that support them, and I will suggest *how* this should be done.

The major argument for betraying a patient at this point is that is the only way that careproviders really can respect who a patient *is*—as DeRenzo and colleagues note. Patients like TE are, like all of us, subject to dissociative states. These states can "take over" any of us. This can occur when patients have severe illnesses such as schizophrenia.[23] It can occur when patients are depressed. Psychiatrist Peter Kramer writes, "This aspect of depression is one of its most painful: alienation from feelings that accord with one's values. . . ."[24] He illustrates this most poignantly by speaking about a patient who "wanted to know why, in our discussions, I had granted an imposter—the depression—such standing."[25] Kramer continues, "I had been negotiating with an occupying government, while the legitimate ruler was in exile."[26]

Such a state may occur when patients have problems of substance abuse. One patient saw that he had a problem only after he attended Alcoholics Anonymous (AA) for other reasons (such as to find companions) *after seven years.* A dissociated self had been taking over and rejecting this reality whenever, I would suggest, this reality began to become clear and became too threatening. This dissociation occurs whenever we, in our daily life, do something that harms ourselves or others when we know, without question, we should not, and don't want to. Perhaps we have all heard from a loved one (or said ourselves): "You did this [unthoughtful act]" and then, added, wholly unnecessarily and indeed spitefully, "*again.*" Dissociation occurs even in patients who have severe dementia.[27]

When patients make choices that may greatly harm themselves, like TE's harm to herself and her fetus, which might have brought about both of their deaths, careproviders should act. They should not, as the risk manager and hospital attorney advised, let patients go after explaining the risks. They should go to court when and if necessary. If they must go to court, they should bring to the court's attention the kind of information discussed here. Judges and juries may find such patients incompetent to refuse treatment, in large part because their refusal so strongly opposes their best interests. Judges actually have much greater discretion in interpreting what they and juries may do under the law than most persons appreciate. Thomas Gutheil and Paul Appelbaum state in their authoritative text, *Clinical Handbook of Psychiatry and the Law,* now in its third edition, for instance, "It seems apparent, from a review of the law,

that the tendency has been to give the judiciary maximal flexibility in determining that an individual is incompetent. . . ."[28] They go on, "Each court tends to try to devise standards *de novo,* without relying on precedents from other courts."[29] They state, finally, "Regardless of the formal standards in place in any jurisdiction, it is likely that a sliding scale approach, with regard at least to cut-offs, is being used in practice in health care settings, and probably in courts, as well."[30] The sliding scale to which they refer allows judges to vary the requirements for determining legal competency, such that the more that patients make choices that are against their own best interests, the grounds for finding them incompetent become less.

Ethically, careproviders could tell a patient that they have changed their mind and will "go against the patient" because the patient's situation has changed. For example, the situation is changed when a patient who merely *considered* leaving the hospital AMA now *decides* to leave. But the most solid reason does not involve ethical reasoning; it is based, instead, on a presupposition of what it means to be *most human.* And this is something that careproviders should share with patients.

This is a view that comes from both Martin Buber and Emmanuel Levinas. Buber argues for what he calls inclusion: "Inclusion is . . . that one person . . . lives . . . from the standpoint of the other."[31] Levinas speaks to the moral obligation that persons have, or should have, when they live from this standpoint, especially when this is triggered by confronting another person face-to-face. Levinas says, "Here we are . . . taking a few steps outside Buber."[32] And he continues, "Ethics begins . . . as I like to put it, before the face of the other, which engages my responsibility by its human expression."[33] He goes on, "Face to face, [we experience] the defenseless nakedness, [the] misery [and the] loneliness of the face. . . . [We thus have] the categorical imperative of assuming responsibility for that misery."[34]

I think Levinas is, in one aspect, wrong. Face-to-face interaction is not necessary to trigger this most human, universal responsibility. It is rather, as Buber says, that inclusion is living from the standpoint of the other "even when they are separated in space."[35] This truth of Buber's claim came to my attention recently when I spoke in a trial in which the defendant could have been sentenced to death. (His case is now being appealed.) He sat behind me, not face-to-face. The court carried on its proceedings as if the defendant wasn't there, but he *was* there, and I was acutely aware of him and of his presence, every minute. I felt for his pain. He had committed a heinous crime, but had committed it, I feared, while he had been experiencing a dissociated state. The law often rejects a dissociated state as a defense for a criminal offense. This may be for good reason. As Buber notes, if this were not the case, it would be "likely to exonerate every person found guilty of violating the law, for every violation is occasioned by some condition . . . that paralyzes otherwise restraining tendencies. The rapist is overcome by lust; the murderer by hatred."[36]

CONCLUSION

Patients like TE may be tried in court for committing a crime. Thus, as DeRenzo and her colleagues state, when these persons are *patients,* we should respond to them as they *really* are when they become unequivocally self-destructive, due to what looks to be a dissociated state. As Levinas (and I) believe Buber would add, we have a categorical imperative not to do otherwise.

Careproviders should explain that they respond in this way because they care too much to allow the patient to be self-destructive. Judges or juries may find a patient like TE incompetent to refuse treatment. If this proves not to be the case, the patient may have one more hope: that the "betrayal" by his or her careprovider, who has gone to court to get the patient treatment, may "get through" to the patient, as it conveys how much the careprovider truly cares. The careprovider's prior support conveys this care. When a careprovider responds to a patient as an "equal," is

wholly honest regarding his or her own flaws and the flaws of others, and recognizes and supports the patient's sound (even if self-destructive) rationales, this expresses how the careprovider is committed to the patient's interests. Even when these approaches are not enough to make a patient "competent," in and of themselves, they may set the groundwork so that a subsequent "betrayal" may help the patient. At that time, the patient may be better able to see such a betrayal is, as Gutheil and Appelbaum suggest, a sincere expression of concern by a friend.

NOTES

1. For discerning and teaching such cutting-edge approaches, I am particularly indebted to Leston Havens, David Mee-Lee, and Marsha Linehan, among many others.

2. E.Z. Woody and K.S. Bowers, "A Frontal Assault on Dissociated Control," in *Dissociation,* ed. S.J. Lynn and J.W. Rhue (New York: Guilford, 1994), 52-79.

3. For an autobiographical account by a patient who experienced multiple personality, see C.Z. Sizemore, *Mind of My Own: The Woman Who Was Known as "Eve" Tells the Story of Her Triumph over Multiple Personality Disorder* (New York: William Morrow, 1989).

4. John Watkins, from a transcript of "The Splitting of the Mind," a series on the radio show *Ideas,* 22 April-6 May 1985, Canadian Broadcasting Corporation, quoted in *Mind of My Own,* ibid., 289.

5. See note 2 above, p. 60.

6. Ibid., 58.

7. Ibid., 59.

8. Ibid., 61.

9. E.L. Glisky et al., "A Case of Psychogenic Fugue: I Understand, Aber Ich Verstehe Nichts," *Neuropsychologia* 42 (2004): 1132-47.

10. ". . . [O]ne method of tracking when the bad me and not me are emerging into the patient's awareness is to look for periods of an escalation in typical interpersonal style." T.F. Van Denburg and D.J. Kiesler, "An Interpersonal Communication Perspective on Resistance in Psychotherapy," *Journal of Clinical Psychology* 58, no. 2 (February 2002): 195-205, 200.

11. D.T. Saposnek, "Aikido: A Model for Brief Strategic Therapy," *Family Process* 19, no. 3 (September 1980): 227-238, 232.

12. Ibid., 233.

13. Ibid., 231.

14. Ibid., 232.

15. ". . . [W]hen resistance is encountered, its appearance takes interventive priority." See note 10 above, p. 203.

16. See note 11 above, p. 231.

17. Ibid., 231.

18. L. Havens, *A Safe Place* (New York: Ballantine Books, 1989), 59.

19. See R. Kluft, "An Overview of the Psychotherapy of Dissociative Identity Disorder," *American Journal of Psychotherapy* 53, no. 3 (Summer 1999): 289-319.

20. Ibid., 299-30.

21. Ibid., 300; emphasis added.

22. Ibid., 291; emphasis added.

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Features

Do Elderly Persons' Concerns for Family Burden Influence their Preferences for Future Participation in Dementia Research?

Jeffrey T. Berger and S. Deborah Majerovitz

BACKGROUND

Clinical dementia research often requires participation by cognitively impaired subjects for whom informed consent is provided by surrogates. Researchers encourage the use of various surrogate decision-making methods that are well-established in clinical care. These mechanisms, however, have been imported from the clinic with little modification, even though clinical care and clinical research differ in fundamental objectives (patient care versus developing new knowledge) and primary principles (beneficence versus truth), and the ethical and legal standards for informed consent for research are more rigorous than consent for treatment. Furthermore, surrogacy in clinical care is widely recognized as highly imperfect, and its validity in research is far less well understood.

Despite these conceptual issues, researchers promote the use of research proxies and research living wills to protect incapacitated adult subjects. Practical problems also exist, and well-known challenges that are associated with directives in clinical care are likely to be amplified when these are used for research. For example, few among the public complete proxy or treatment directive documents due to sociological, cultural, and other barriers.[1] Fewer still are likely to complete less essential and more complex directives for investigational interventions. Living wills frequently use ambiguous terms and criteria, and rely on "boilerplate" documents that dubiously represent patients' authentic wishes.[2] For logistical and other reasons, living wills are often ignored during actual decision making.[3] Furthermore, statements in these directives are unlikely to be specific enough, or well enough informed, to independently satisfy rigorous consent requirements for entry into research.[4]

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Finally, the relatively few subjects who, while capacitated, complete research advance directives may ultimately bear a disproportionate share of the burden for research participation.[5] Such a skewed pool of research subjects may also threaten the validity of study findings.

Despite the promotion of research directives, research consent will likely remain the province of next-of-kin who have little specific understanding of their relatives' preferences for participation in research. These surrogates typically employ the best-interest standard or the substituted-judgment standard for decision making, although neither relate easily to research.[6] Enrollment predicated on best interest is problematic, because subjects' best interests are often irreconcilable with the structure of clinical research, in which burdens fall squarely on subjects while benefits are intended for future patients.

More often, surrogates are encouraged to replicate patients' decisions by considering patients' preferences, values, and interests, in accordance with the substituted-judgment standard.[7] However, surrogates' treatment decisions are frequently inaccurate, and concordance is poorer still for decisions about research.[8] Nevertheless, patients, little troubled by this inaccuracy, continue to depend on surrogates for both clinical and research decisions. Patients may be more concerned with fidelity and with their surrogates' comfort with the decisions that are ultimately made.[9] Some patients do not expect surrogates to follow their precise wishes, and other patients alter their preferences in response to their family members' concerns.[10] Patients' concerns about the burdens that may be placed on their families influence their preferences regarding treatment, and some patients want their surrogates' decisions to reflect these concerns.[11] Unfortunately, patients' interests in family well-being is discounted in practice and in academic discourse.[12]

Empiric study of surrogacy in research, in general, is limited. In particular, there has been scant research on subjects' concern for family burden in decisions about research participation, despite ample evidence that family burden is a central concern among ill persons.[13] Because subjects' concerns for their family remain unexamined, surrogates may consider their own burden in their substituted judgments without reference to the way that the subject preferred to consider family burden.[14] If respect for autonomy requires an accounting of all important concerns of subjects, and concern for family burden is among these, then this should be an actively considered content area in substituted judgment for research (and for treatment).[15]

More empirical data on research surrogacy is needed to address the significant ethical gaps in widely held normative positions in which the ethical basis for consent to participate in research by a third party is not clearly defined.[16] Since conventional mechanisms for consent that attempt to replicate narrowly drawn preferences of subjects are ethically problematic, a more qualitative approach to determining subjects' preferences, one that integrates a greater range of subjects' concerns, may provide a valuable and more authentic basis for consent. For example, ethical surrogate decisions for dementia research should include decisions that subjects would embrace because their participation will advance their interest in attenuating the burden on their surrogates (for example, less emotional distress by exhausting all treatment possibilities, or by creating altruistic meaning from a devastating illness). A greater understanding of the ethics of surrogate consent for research must be developed to respect subjects, to promote appropriate research involving noncapacitated subjects, and to better ethically clarify surrogates' authority.

This exploratory, qualitative study is a first step toward identifying elderly participants' specific preferences for research surrogacy and the importance of burden on surrogates in this decision-making process. The research sought to address three specific questions:

1. Do elderly persons presume that their health surrogates have authority over their

entry into research, based on trust and fidelity, rather than on replicating specific choices?
2. Is concern for family burden a widely held central interest of potential subjects of dementia research?
3. Do elderly persons want this concern to be a major consideration in surrogates' decisions regarding participation in research made on their behalf?

METHODS

In-person, semi-structured interviews were conducted with 10 older adults. Participants were recruited from among patients in a suburban, hospital-based, geriatric medicine practice. All interviews were conducted by the first author. Interviews were tape-recorded and transcribed verbatim. Participants also completed a brief written questionnaire prior to each interview. Only demographic information from this questionnaire will be reported here.

THE SEMI-STRUCTURED INTERVIEW

Participants reported whom they would rely on as a health surrogate, whether or not they had formally appointed a healthcare proxy, and the reasons for choosing that individual or individuals. The interviewer assessed subjects' preferences for different levels of care and for participation in different types of research for hypothetical conditions of moderate and severe dementia. Subjects were reassessed for their preferences for treatment and for participation in research when decisions would be made by their surrogates. For preferences regarding participation in dementia research, participants were asked to describe: (1) their direct preferences for research participation, (2) their preferences for participation if their surrogate was responsible for the decision, and, finally, (3) their preferences for their surrogate's consent for research, should their surrogate find benefits through relief of emotional burden, financial burden, physical burden, and social burden. For each scenario, subjects were asked whether they would be willing to enroll (or would want their surrogate to enroll them) in each of the following types of research study: drawing blood only, physical exam only, taking a drug approved by the Food and Drug Administration (FDA) with a low risk of side-effects, taking an FDA-approved drug with a risk of serious or irreversible side-effects, or taking a nonapproved experimental drug.

Before asking about treatment preferences, the interviewer read a definition of moderate and severe dementia based upon Reisberg's Global Deterioration Scale for Alzheimer's Disease, so that each participant would use a consistent definition of these stages of dementia when answering the interview questions.[17] The interviewer also described four types of burdens on family that are common in dementia care—emotional, financial, physical, and social—so that participants would again use consistent definitions.

DATA ANALYSIS

The authors analyzed transcripts of a subset of interviews to identify common themes. From these themes, a coding scheme was developed. The authors analyzed a second subset of interviews using the coding scheme, discussing any discrepancies and revising the coding scheme, until 100 percent agreement was achieved. Finally, all interviews were reanalyzed using the revised coding scheme.

RESULTS

SAMPLE

Ten participants were recruited through a suburban primary care geriatric medical practice. Inclusion criteria consisted of English-speaking, older adults (aged 65 or older) without cognitive impairment. The sample consisted of two men and eight women with a mean age of 73.6 years (range 67 to 80). All were White and middle-class; eight subjects had graduate degrees. Six were married; four were no longer married, three due to death and one to divorce. All but one had children.

ADVANCE DIRECTIVES, HEALTHCARE PROXIES, AND RESEARCH SURROGACY

All 10 participants had some form of written advance directive in place and most (six) had both an advance directive and a healthcare proxy. All participants chose members of their immediate family as their surrogate. All married participants (six) chose their spouse as a first choice; the others chose an adult child. Only two participants mentioned more distant relatives or friends as surrogates, and these were alternates in case a spouse was incapacitated as well.

When asked why they chose a particular individual to act as their surrogate, participants overwhelmingly cited trust and family closeness. For many, trust was based upon their family member's performance in a past crisis: "Because they love me and they're close to me and they've helped me before in a very difficult situation." Another participant described a specific trauma from the past: "We went through the loss of my oldest son, their brother and he [the son chosen as proxy] was with him [the son who died] at the time."

For other participants, trust was based purely on the family relationship and the perception that the surrogate knew the subject well: "She's most familiar with what I want, as I am with what she wants. She's really the one I trust the most." As another respondent explained, "My husband or my cousin who has been listening to me for many years, so she knows where I'm coming from." Another man discussed his confidence in his wife to anticipate his wishes: "In other words I would want her to do what she thinks I would do, and I think she knows me well enough to know that."

Several respondents spoke of a desire to avoid family conflicts in their choice of a surrogate. For example, one participant chose her husband, even though she felt that one of her sons would make better decisions on her behalf. She said that she wanted to avoid the appearance of favoritism of one child over the others: ". . . we've had these discussions, and I'll say to him, 'If anything happens to me I'll give you [her husband] three months to pull the plug.' He'll say, 'Don't pull the plug.' I think on the whole he would probably make the decisions, but I would have a talk with my son if things started, to watch over Dad. . . . We've been married 53 years, so we've developed a relationship; and with five boys, sometimes, even though there's the oldest, the other ones, I think, resent the oldest. So we have trouble: Which one do we ask to do something without upsetting the other ones? So we end up doing it ourselves."

Other respondents spoke about love and family closeness as the basis of their choice of surrogate. "They're the only ones I have. I'm a widow for 30 years and I'm very close to my girls."

Another participant combined all these concerns—love, trust, and avoiding conflict: "Even though she [her daughter] is very busy, she is very compassionate and thinks a lot like me and I feel most comfortable with her. . . . My son is very loving, too, but he's very demanding, and my youngest, who is 10 years younger than the other two, I had her 10 years later, she's too concerned about me. We are very close in a way, and she's too concerned. So that's why I picked the oldest. And being the oldest, you know the others cannot say, 'Why didn't you pick me?' I thought that would be the best."

When asked what they would want their surrogate to consider in making decisions for them, nine of 10 participants spontaneously mentioned the surrogate's welfare and burden as equivalent to, and sometimes exceeding, the subject's own welfare: "Well, I would probably want to go to a facility. I wouldn't want to be a burden." Another explained, "I would never want to be a burden to other people. That's what I dread the most. I always say, 'I hope I get hit by a truck and that's it.' " Others expressed the desire for their caregiver to go on with life: "I guess it depends on the severity of it. I would like her to not spend her ev-

ery living minute worrying about caring for me. I'd like her to have somewhat of a life of her own."

Other major concerns included the participant's own quality of life and physical comfort, and a desire to maintain personal dignity. "Like I said, I made out the living will, and if I couldn't recover and live any kind of a life, I don't want anything done. I don't want any great precautions made if my heart stops beating. I don't want anyone to bring me back. I'd rather not live that way." Some participants expressed their trust in their proxy to see to it that they would be well cared for: "She would see to it that I wouldn't be in pain. . . . I know she would take care of that." As another put it, "He should think about my dignity, my good health, a safe environment, and hopefully being placed in a place where people are really caring for you in the proper way."

Participants also were asked whether they would be willing to participate in research, and why they would choose to do so. Four respondents had participated in a clinical study in the past, and another five had considered it. When asked about their reasons for considering clinical research, participants voiced two distinct considerations: altruism coupled with the possibility of personal or family gain. Nine cited the desire to help others or further scientific knowledge in general, and nine also described personal reasons, such as access to new medications or the importance of speeding the discovery process in chronic illnesses that ran in their own families. If they themselves could not benefit, they reasoned, then perhaps their children or grandchildren would.

When subjects were asked whether or not their health surrogate should also make decisions about research, all 10 subjects presumed that these individuals would. Subjects generally saw no clear line separating acting as a health surrogate from acting as a research surrogate. One subject replied, "If I've designated him as my healthcare proxy, I'm incapacitated; it's his decision." Some subjects gave measured license to their surrogates, limiting decisions in various ways. For example, one subject gave his wife blanket authority over nontherapeutic research, while limiting her decisions about therapeutic research to lower-risk studies.

PARTICIPATION IN RESEARCH TO RELIEVE SPECIFIC BURDENS

The next set of questions asked participants whether they would want their surrogates to enroll them in dementia research if participation would relieve specific burdens for the surrogate. Table 1 shows the number of participants who were willing to be enrolled in each type of study under the various hypothetical circumstances.

The overwhelming majority of participants would be willing to have blood drawn, undergo a physical examination, or take an approved drug with a low risk of side-effects for research purposes, whether or not this participation would relieve their surrogate's level of caregiver burden. Overall, participants were reluctant to consider taking experimental drugs or those with serious known side-effects. However, some participants did express willingness to take such drugs, despite their concerns, if doing so would benefit their surrogates in some way. For example, only two would choose to take a drug with serious side-effects for research if they were making the decision themselves, and only three said they would be comfortable with their surrogate making such a decision. However, six respondents said they would definitely be willing to do so if participation in the study provided their surrogate with relief from the physical burden of caregiving, perhaps by offering some form of respite. Similarly, five participants would agree to take a drug if participation in the study relieved their surrogates' emotional burden, and four would take it to relieve social burden.

Participants were not willing to consider participating in a risky study solely for financial gain to the caregiver. Some reported that they had already planned for their own financial futures, so that their care would be cov-

ered financially. Another expressed the fear that their children would actually increase their sense of burden of guilt if they accepted money for a parent's or spouse's research participation: "But then she feels like I'm a guinea pig."

Overall, when compared to subjects' direct preferences for research participation, six of 10 subjects were prepared to accept additional research-associated risks specifically to attenuate some type of family burden.

DISCUSSION

These findings represent a first step in documenting the strong preference of older adults to have their decision-making surrogates consider their concerns for family burden when making choices about participation in dementia research. Overwhelmingly, participants expressed the primacy of close family ties grounded in love, trust, and mutual concern. Participants were adamant that they would not want to be a burden to anyone, should they become physically or mentally incapacitated. They plainly expressed their desire for their surrogates to take their personal needs into account along with the patient's.

Overall, these individuals felt comfortable with the idea of participating in low-risk dementia research, either for possible benefits to themselves and their families or for altruistic reasons. They were more hesitant to become involved in research that involved greater risk that could worsen their condition or cause them pain or discomfort. However, a surprising number of participants were willing to take on these same risks if their surrogate could derive some benefit. They expressed trust that their surrogate would continue to watch out for them, while also voicing the desire that the surrogate not find his or her duties personally overwhelming.

Given the fact that older adults, at least in this sample, consider family burden an important consideration in clinical care and research participation, how can this knowledge inform researchers and ethicists as they develop guidelines for surrogate decision making? If substituted judgments require surrogates to identify what these individuals would want if they were able to make the decision themselves, surrogates should account for subjects' concerns for family burden. Researchers may be reassured by elderly subjects' faith and trust in their family members to make these decisions. Our subjects consid-

Table 1
Number of Participants Who Would Want to be Enrolled as Subjects in Dementia Research under Various Hypothetical Conditions

	Blood Test		Physical Exam		Low-Risk Drug		High-Risk Drug		Experimental Drug	
Query Re: Type of Participation	Yes	Maybe	Yes	Maybe	Yes	Maybe	Yes	Maybe	Yes	Maybe
Would you enroll?	9	0	10	0	8	1	2	2	4	2
Should surrogate enroll you?	10	0	10	0	9	0	3	1	3	1
To relieve surrogate's emotional burden?	10	0	10	0	9	0	5	1	6	1
To relieve surrogate's physical burden?	9	0	9	0	9	0	6	2	4	3
To relieve surrogate's social burden?	9	0	9	0	9	0	4	2	4	2
To relieve surrogate's financial burden?	8	0	8	0	7	0	2	1	2	1

ered themselves embedded in a family network, and saw the possibility of future incapacity and their loved ones' responsibility for their care as an integral part of that family connection. While each one expressed it differently, all of them indicated that "what is best for my family is also best for me." As one participant put it in discussing her considerations for future treatment: "What am I concerned about? That she [her oldest daughter] takes away from her own family. I know my son-in-law deals very, very badly with sicknesses. My youngest would just be worried sick and wouldn't be able to do her job. She's not married yet. So they would take turns, I know that. And I would want to make it as easy for all three of them as possible." A second woman talked about the importance of her daughters tending to their own young children and busy professional careers, as well as considering their mother's medical condition and quality of life, in making decisions on her behalf. She concluded, "Well, I trust their decisions. They can make any decisions they want. I'll leave it to them."

LIMITATIONS

The generalizability of our study is limited for several reasons, in addition to the small size of the subject group. The participants represent a convenience sample drawn from a White, middle-class, and well-educated community. All participants already had completed one or more advance directive documents. Our subjects were atypical in that nearly all of them had participated in research or had considered doing so. Preferences and beliefs are sure to differ in the general population. Future studies should draw from a wider range of ethnic, religious, and socioeconomic groups to insure wider generalizability. We suspect that, among some minority ethnic groups in which identification with family is stronger compared to the dominant culture, preferences to participate in research may be more highly influenced by concerns for family burden.

The small number of participants makes it impossible to conduct statistical analyses. Therefore, we cannot determine whether the increased number of participants willing to participate in greater risk research to alleviate family burden is a reliable finding or due to chance.

Despite these limitations, these data offer insight into the importance of family concerns in making research and treatment decisions among older adults. Future research should explore these values with larger and more diverse samples. This information is crucial in order to strengthen our understanding of the ethics of third-party consent for research.

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The Politics of Care: Dementia and Accounting versus Caring for Mortification

Alice Stollmeyer

> A patient who refuses food is encouraged, but not forced to eat, even if the refusal might lead to a further deterioration in the patient's condition. This nursing home is reluctant to administer artificial nutrition. [The administration of] artificial nutrition is considered in cases of a disorder from which recovery is possible, but when it is given, it is given for a previously agreed period of time. If recovery does not ensue and the condition does not improve sufficiently for the resident to remain alive without artificial nutrition, this is accepted as a sign of approaching death.[1] [From a directive at Nursing Home Blauwbörgje in Gronigen, the Netherlands.]

In 1997 in the Netherlands, only 13 percent of the nursing homes had established directives relating to (some) medical decisions surrounding the final stages in the life of demented patients. Most of these directives concern the administration of tube feeding, and this reveals the existence of problems surrounding food in the final stage of Alzheimer's disease.[2] Eating is one of the skills that is affected by dementia. In the course of their disease, demented people encounter increasing difficulties with eating. In the final stage of their lives, this often results in a continuous refusal of food, which presents physicians, nurses, and relatives with the difficult decision whether, and when, to proceed to tube feeding.

In the Dutch public debate on the refusal of food by demented patients, this phenomenon is called *versterving*, which I here translate as "mortification."[3] In modern nursing homes, mortification is a quite common way that people with Alzheimer's disease die. In the public debates on mortification, two vocabularies are used alternately to account for it. From a medical point of view, mortification is described as a "disappearing need for food," the "final stage of dementia," a "natural process."[4] In these contexts, mortification here seems to be a matter of the body. From an ethical perspective, however, mortification is directly related to the question of whether

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a patient who is refusing food is still competent—a matter of the mind. In this context, food refusal, just like the refusal of other medical treatments, is considered to be an act of will, a more or less conscious choice. Some of the more intermediate positions in the debate try to take both body and mind into account, but do so by switching between the two discourses, not by integrating them. Although the parties in the debate may not be convinced that there is a dichotomy between mind and body, such a dichotomy is still reflected in the vocabularies they use to account for mortification. However, when observing the daily practices of care in a nursing home and listening to nurses' descriptions of it, neither of the two vocabularies in the discourse seem to apply. In practice, neither the mind-body dichotomy nor the competence-incompetence distinction holds.

When one is *caring* for a patient, however, neither the attribution to body or mind, nor the arbitrary distinction between competence and incompetence, is used. Nurses consider the refusal of food neither as merely the lack of a physical need, nor as a purely conscious action. In the practice of care, mortification seems more like an event, a mixture of action and behavior taking place within a network of other (human and nonhuman) "actors."[5] This may have some consequences for the notion of rational autonomy (which is considered to be the foundation of informed consent). Could we instead speak of *relational autonomy*—based on, and dependent on, social and material relations? In a case of food refusal, nurses do not assess whether a patient is still competent enough to want anything. To face a patient's food refusal, nurses check and use their entire arsenal of food, other objects, and their social skills to discover whether the patient needs anything. Good care practice might thus consist of an ongoing fine-tuning of human and nonhuman "actors" to the changing needs of the patient who refuses food, while simultaneously unraveling what her or his needs are.

ACCOUNTING FOR MORTIFICATION

Nursing Home Accused of Attempted Murder

> AMSTERDAM—Relatives of a 62-year-old man accuses the staff of psychogeriatric Nursing Home Blauwbörgje . . . in Groningen of attempted murder and reported this to the police. The wife and daughter of the patient believe that the nursing home deliberately allowed him to dehydrate, to cause him a mild death.[6]

In summer 1997, the Dutch media had a field day with the theme of mortification. A Mrs. Mulder accused Nursing Home Blauwbörgje in Groningen of attempted murder. Her ex-husband, 62 years old and demented, lived in the nursing home and gradually stopped eating and drinking. His physician and her colleagues decided, considering the circumstances and according to the directives of the nursing home, to accept this as a sign of approaching death. However, when Mrs. Mulder returned from a short holiday and discovered what had happened, she had Mr. Mulder transferred to a hospital where he was tube fed. Some newspapers reported on his first day at his home again, where he was welcomed by his ex-wife and their daughter with a meal of spinach and mashed potatoes and a dessert of custard.

Most of the confusion in the newspapers was caused by the notion of mortification itself: is "to mortify" a transitive verb (something done to the patient by the physician) or is it an intransitive or a reflexive verb: something the patient does (to himself)? The articles that use the first sense are mostly written by journalists. They describe mortification as an active intervention: the physician decides and "commits" mortification. Others (especially physicians) soon tried to straighten out this dreadful vision of mortification-as-policy. According to these writers, to mortify is not

to kill, but to die. In this medical discourse, people try to account for mortification by explaining its physical causes. They consider it to be part of dementia: the need for food and drink disappears as the illness progresses.[7] Whereas these physicians emphasize the sick body and the natural course of the disease, ethicists stress the mind and appeal to moral principles. In their contributions to the newspapers, ethicists define mortification as the refusal of food by patients. It is viewed as an act of will that is, or should be, respected by physicians.

The overall picture in the media is thus that, according to the representatives of the *medical discourse*, ceasing to eat is a matter of the body: the final stage of dementia, a natural process, the disappearing need for food. But physicians also show that an interpretation is involved. There is a process of attribution in cases when food is refused. In the first instance, one looks for temporary, physical causes that may underlie the eating behavior. The refusal of food is ascribed to the body. Only "when that refusal is not incidental and there is no clear and treatable cause to be found . . . the behavior of the patient can support the decision to not proceed to tube-feeding." Thus, food refusal is a matter of the body, in the absence of any proof to the contrary.

The mind is central to the *ethical discourse:* mortification is the refusal of food and drink. Food refusal, just like the refusal of other treatments, is an act of will, a conscious choice. Ethical problems begin when patients are incompetent; when patients can no longer be held responsible for their decisions. However, even then the starting point for ethicists is that refusers "sometimes have lucid moments" during which they can explain the reason for their refusal.

What is important, within the framework of this article, is that two dichotomies are implicitly being referred to in accounting for mortification. The first is the *mind-body* distinction. Within the medical discourse, physicians adhere as long as possible to a physical cause of mortification, whereas ethicists attribute food refusal, as long as possible, to a mental cause.[8] Behind this relatively obvious observation lays the assumption of another distinction: the *competence-incompetence* dichotomy. This distinction concerns the decision-making ability of patients, usually with respect to medical treatment. Besides medical professional norms, medical action is also guided by norms derived from patients' rights: patients' wishes and preferences, and informed consent. There can be no medical treatment without patients' permission.[9] This also holds for demented patients in nursing homes, even after enforced admission.[10] If one takes into consideration that the administration of tube feedings is a medical act, together with the informed-consent requirement, this means that there are three different decision situations regarding the treatment of mortification: (1) the patient is competent to decide, (2) there is doubt as to the patient's competence, (3) the patient is incompetent to decide.

Both dichotomies together form the heart of the account of mortification. When the refusal of food is an act of will (the patient is competent and there is no physical cause), it is a choice that should be respected. Patients are autonomous subjects who bear full responsibility for their actions. However, when mortification might not be an act of will (there might be a physical cause), matters become more complicated. Perhaps then it should be treated by administrating food artificially. As long as patients are considered competent, there's nothing wrong. The usual biomedical ethics approach is followed, which starts from the premise of a rational actor, from autonomy and self-determination, from informed consent. When patients refuse treatment, it should be respected; if they agree to treatment, they will be treated. Patients' informed consent is used as a means by which patients themselves are made responsible.

However, as soon as it is no longer obvious whether a patient really is competent, people become uncertain. Boudewijn Chabot, a psychiatrist, states: "When an old, sick cat withdraws into a corner and doesn't touch her

food, we accept that she 'wants' to die. When a demented person does the same, we get confused."[11] The participants in public or professional practices of accounting nevertheless want a clear, individual allocation of responsibilities. Hence the persistent efforts to attribute mortification to body or mind and to explain food refusal from an emphasis on body or mind. For as soon as—and as long as—an answer is found to the question, "What is going on?" the medical action and the allocation of responsibility that go with it are clear, too. As Jessica Mesman notes, "when facts are not settled yet . . . and we look at how facts are made, it appears that the moral choice is made simultaneously. Prescriptive ethics separates the questions 'What is the case?' 'How do we act?' but they are in fact answered in one and the same process."[12] I would add that, in this process, the question, "Who is responsible?" is answered as well.

However, between the lines of the newspaper articles, one can also read a few other statements—statements that do not fit into the dichotomy of body versus mind. Eating is not just a bodily need; it also has important *social* dimensions. Mrs. Mulder had welcomed her ex-husband home with a meal of spinach, mashed potatoes, and custard. And she visited him twice a day to feed him; out of love and out of a sense of duty. Stopping eating can have social causes too. Thus, Mrs. Mulder wondered whether her ex-husband was homesick. Maybe he had refused food to protest her going on a holiday? These divergent positions are amplified by a few intermediate positions. For instance, one nursing home physician writes that mortification is not about "refusal," but about "not liking" anything to eat, and a colleague describes food refusal as a "decision of the body."[13]

The (rare) occurrence of these divergent and intermediate statements, mostly made by people working in nursing homes, might point to the fact that *accounting* for mortification by using vocabularies that refer exclusively to either body or mind is not in accordance with *caring* for mortification, with experiences from actual caring practice in nursing homes. To see whether this assumption is correct, let's take a look inside a nursing home.[14]

MR. VAN DER VELDE

> I remember Mr. Van der Velde fell ill quite suddenly. And um. . . . Yes, now I remember: he had pneumonia, and then, presumably because of his fever and a lack of oxygen, his heart started to fail . . . and was not able to pump round all the blood any more and then one gets fluid behind the lungs. That played a part too, that was treated. . . . But actually it all went so fast. We talked it over with his family, that we had the impression that he . . . was not strong enough to make it. And then the very next day he was no longer communicative. However, for a description of when he actually started to refuse drinking . . . I would really need the file. That's what is important to you, of course.

This nursing home physician was right: I was doing ethnographical research on the role of food and drink in nursing homes.[15] The nursing home in question (the same one that was accused by Mrs. Mulder) specializes in psychogeriatric care: caring for, nursing, and treating aged people who suffer from dementia. Alzheimer's disease is the most frequently encountered form of dementia. It begins with loss of memory, but ultimately skills like speaking, dressing, and moving also gradually start to deteriorate. This nursing home provides care that aims at retarding the decline and preserving the skills people still have. Some of the symptoms may be treated, but this is a fatal disease with no prospect of recovery.

The brochure that this particular nursing home hands to its new residents and their relatives assures them that euthanasia (*ending* a life at the request of a patient) is not performed, nor will lives be ended without a request. The nursing home does, however, pursue a careful policy in regarding medical action that *prolongs* life. The booklet explains

that there comes a moment when medical acts aimed at improving health become pointless. Then the omission or suspension of those acts is required. The physician will discuss this with the relatives, after which medical care will concentrate on relieving pain.[16]

So what about Mr. Van der Velde? I met Mr. Van der Velde when I spent two days on one of the wards in the nursing home. He was one of the 15 residents on this ward. The first thing I noticed was that the nurses give him his coffee in a plastic cup, instead of giving him a coffee cup. And he wears a plastic bib. Every now and then he takes a sip of his coffee. But then he stares straight ahead, his head inclined. Some coffee drips from the corner of his mouth. He does not swallow. Julie, the nurse responsible for life in the living room, sits down next to him and helps him drink. After each sip she reminds him that he should swallow. And when he still does not swallow, she rubs one finger under his chin. In this way, he finally finishes the whole cup.

A few weeks later, when I came back to the nursing home to do some interviews, Mr. Van der Velde had died. When I asked his physician what had happened, he recalled all the medical details of his illness, but wondered when Mr. Van der Velde started refusing drinks. "Yes, he did that way before. . . . Sorry, I don't really remember. A lot of people have the flu, so we concentrate on treating the diseases that prevail at the moment. And then one loses sight of daily matters like this. That's what the nurses know better than us." So I decided to ask Julie, his nurse. Here is the story of Mr. Van der Velde, reconstructed with Julie's help.

For Mr. Van der Velde, drinking is connected to *knowledge.* He takes a sip of his coffee, but doesn't know what to do next. According to his psychologist, part of it is breakdown in the "neurological program" that controls swallowing. "Plus disorders of comprehension. No longer knows what to do with what's in his mouth. He'll look at a cup of tea in utter amazement without recognizing it. As a cup of tea that one can drink. It's almost Roald Dahl-ish." But the psychologist doesn't consider this stage to be food refusal yet. For now, it's just ". . . not knowing what to do with food."

Meanwhile, the nurses do everything they can to get Mr. Van der Velde to drink enough liquid. From the beginning until the very end they take *care* of his food and drink. "One tries one's utmost to get him to drink and to eat."

They soon find out that it is not a problem of taste preference. And in the meantime, the physician has had a look at Mr. Van der Velde's throat. Nothing to be seen. Could it be the liquid consistency of the food then? They try to give him thickened tea, coffee, and yogurt, which is sometimes easier to swallow. But that isn't the solution, either. Rubbing under his chin works for a while, but in the long run, Mr. Van der Velde becomes fed up (!) with it. He won't let them help him any more, and gets angry when they try anyway. Then he falls ill and becomes bedridden. The nurses go to his room dozens of times to bring him drinks. Julie says: "Even if it's just a couple of sips a day, one does try."

But Mr. Van der Velde makes it very clear that none of that's for him. Sometimes he does it verbally: "Get lost!" or "Piss off!" But usually the *communication* on (not) eating is nonverbal. He knocks the cup out of their hands. Pushes the spoon or the plate aside. Often, he communicates *by means of* food.[17] Sometimes he splutters out his drink. Or even spits it in their face. He tightens his lips; one arm stretched to ward them off, the other hand in front of his mouth. He even manages to show via his eating behavior that he prefers some people to others: he doesn't respond well to the people he doesn't like. With others, like Julie, he colluded with their actions: "Sometimes I said something to him in French, like 'Bon appetit,' and then he smiled again."

Then, when Mr. Van der Velde fell ill and became bedridden, they ran out of alternatives to make him eat or drink. Before this, he sometimes would unexpectedly drink a whole cup of Nutridrink (a special nutritious drink for sick people); but that no longer happens. He

gets pneumonia and liquid collects behind his lungs. During all this, Julie becomes increasingly convinced that Mr. Van der Velde really does not want any more. Not just because of what he shouts in his anger; she also observes it in his behavior: "Whatever we did, he really wouldn't swallow." Well, what else could they do? Eating or not eating is a matter of *autonomy*, something one has to respect. At those moments it is repugnant to Julie: ". . . to force someone, to make someone drink by coercion. If he really does not *want* to, who am I to . . . hold his nose and shove that cup into his mouth? I just can't."

What matters to the physician is Mr. Van der Velde's physical condition. The psychologist is not sure whether this eating behavior can be classified as food refusal. Losing the skill of swallowing is probably a neurological disorder. But when the elderly man starts closing his mouth and no longer even takes a sip, matters become clearer: "Then it seems more like a refusal." And in the end, Julie knows for sure that Mr. Van der Velde ". . . just doesn't *want* any more."

But what is it that Mr. Van der Velde doesn't seem to want any more? Although part of it might be due to his slowly disappearing appetite, according to Julie it is not just food he refuses. She sheds some light on another possible dimension of his refusal: when demented people become bedridden in the final stage of their illness, and especially if they develop an additional disease, they usually start declining food, and they make themselves clear, either verbally or nonverbally. Julie had witnessed this process very often. However, she thinks Mr. Van der Velde's behavior is ". . . very extreme: being so aggressive that he knocks the drinks out of your hands or even hits you. Then I think: there's so much anger in there, such a conscious . . . not wanting. Because he just doesn't want this situation." Thus Mr. Van der Velde starts to offer resistance: to the care he is being offered in the form of food and to everything that goes with it. To the whole situation. By his resistance to food he resists the whole *network* that goes with it: care, communication, location, sociality, company. He no longer wants to be part of it. As he once said when Julie brings him a drink: "Leave me alone. Can't you just let me die?"

CARING FOR MORTIFICATION

Joan C. Tronto writes, "On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web."[18] Public debates offer us words and dichotomies to account for mortification. But they do not describe what happens in daily care. Attributing Mr. Van der Velde's food refusal either to body or mind would violate the story Julie told us. And assessing Mr. Van der Velde as competent or incompetent would be to miss the point. For in daily care the point is not how to *account* for food refusal, but how to face it. How to *practice* good care?

First of all, care takes a lot of *persistence.* Julie explains: "One tries to the utmost and to the very end to get that man to drink and to eat." This does not mean that they will force Mr. Van der Velde to drink, but that they continue offering drinks, even after the decision has been made not to proceed to tube feeding. "Abstaining [from administering food artificially] does not mean that we ask the physician whether we have to stop giving food and drink. You don't even talk about that. You just carry on offering them." She repeats over and over: ". . . you just keep on trying."

When caring for a demented person who stops eating or drinking, to keep on trying has yet another sense. It consists of *experimenting* by trial and error: Is it the liquid consistency of the drinks? Is it a matter of taste? Is there a problem with Mr. Van der Velde's throat? Does rubbing his chin work? To which nurse does he respond best? Does it help to say, "Bon appetit"? All possible remedies are

tried; "the entire arsenal" is checked and used. Mr. Van der Velde's reactions are observed and his daily care is adjusted accordingly.[19] When a patient can no longer verbally communicate what he wants or doesn't want, good care consists in continuous, creative, and rich experimentation.

The experiments are not about the two options of "forcing" versus "leaving be": not about either administering artificial food as the remedy to a presumed physical cause without considering the possibility of an act of will, or the unquestioned translation of the patient's behavior into wishes, accepting food refusal as a death wish, with no further enquiry. Both options would amount to neglect. No, experimenting in care means *adding:* adding a thickening powder to Mr. Van der Velde's coffee to make it easier to swallow, adding sugar or milk to change its taste, adding a physician to see whether there is a problem with his throat, adding words to encourage and remind him to swallow, adding a finger under his chin to help him swallow, adding Julie rather than another nurse. . . . The list of possibly helpful human and nonhuman "actors" is virtually endless.[20]

Yet all these human and nonhuman actors do not make Mr. Van der Velde a helpless person, a medicalized object, or a subject with no autonomy: this would imply an individualistic conception of autonomy as being rational, free and independent. What matters in daily care is not rational autonomy (the ideal of rational choice theory), but "relational autonomy," that is based on and dependent on social and material relations.[21] Human beings are social beings: agents are socially embedded and their identities and capacities, like autonomy, are constituted in interactions with other agents. Moreover, agents are not only embedded socially, but also materially, in interactions with nonhuman actors.[22] This becomes especially clear in the context of care practices. Mr. Van der Velde's story illustrates that his autonomy is produced and sustained by experimentation, adding other human and nonhuman actors: nurses, bibs, words, plastic cups, physicians, thickening powder, fingers, tastes. . . . Together they create the conditions for *prolonging his autonomy.*

Besides producing and prolonging autonomy by adding possibly helpful actors, experimentation has another advantage: it *avoids both under-* and *overinterpretation.* It does not immediately reduce action to behavior (by looking for physical causes only), nor does it interpret any behavior instantly as action (by paying attention only to mental causes). Experimentation helps to *suspend a definite attribution* of mortification to either body or mind. Or, in other words, good care neither objectifies nor subjectifies—it humanizes.

This is why in daily care drawing a distinction between competent and incompetent is not even needed: as long as there is no doubt as to the ability of Mr. Van der Velde to reason, or at least to express a preference or choice, for the nurses there is no motive to consider the possibility of incompetence.[23] And when Mr. Van der Velde's cognitive and communicative skills start to decrease, a definite attribution of action-behavior to only mental or only physical causes is postponed. Even in the end, when Julie is sure that Mr. Van der Velde "just doesn't want any more," she continues to offer him drinks and keeps on trying. She does not diagnose Mr. Van der Velde as either competent or incompetent, once and for all; she doesn't reduce him to either a subject or an object, but up to the very end continues to experiment and add to prolong his relational autonomy—his *humanity.*[24]

RELATIONAL AUTONOMY

Over the last few decades there has been a development toward more patient autonomy in healthcare. Dutch law no longer allows any justification for coercive treatment: the right to self-determination overrules considerations of protecting a patient's well-being. The principle of autonomy has replaced the principle of beneficence.[25] Competence is seen as the main precondition for making an autonomous

choice. Two other preconditions are listed in the doctrine of informed consent: did the patient receive enough information, and did he or she really grasp this; is the patient not being forced to make a choice that is actually not the patient's. Informed consent is considered to be *the* means to achieve and respect autonomy.[26] Autonomy refers here especially to self-determination, patients' right to decide whether or not they agree to a treatment. Thus, competence and participation in decision making are central to mainstream biomedical ethics.

This classical style of ethics takes the wishes of patients literally. Wishes are interpreted as acts of will that should be respected without further questioning. However, in daily care, especially as applied to people with Alzheimer's disease, the limitations of this approach are revealed: immediately interpreting food refusal as an act of will and respecting this without taking pains to nurture the resident would be gross neglect. On the other hand, dismissing food refusal as mere behavior based on incompetence, and administering tube feeding without any responsiveness to what the resident may try to communicate, would also be neglect. How can one deal with the principle of autonomy without risking either kind of neglect?

During the brief visit to the nursing home described above, I defined autonomy as based on and dependent on social and material relations. Using this relational conception of autonomy allows one to avoid the shortcomings of the received views that were mentioned above. Theorizing relational autonomy on the basis of ethnographies of daily care for demented people does not focus on competence and decision-making moments. The nurses do not definitely assess whether a resident is still competent enough to *wish* anything; until the very end they add all kinds of human and nonhuman actors to check by trial and error whether patients *need* anything. In this way they prolong residents' relational autonomy—not a given asset, but a continuous achievement.

This observation is in line with an approach of ethics called an *ethics of care*.[27] This growing body of theory shifts attention from wishes to needs, and from decision-making moments to the context and content of nonlinear, collective caregiving and care-receiving processes. Reflecting on psychiatry, the care ethicist Marian Verkerk pleads for the introduction of "compassionate interference" as a form of good psychiatric care, because it may help to overcome the dichotomy between coercion and autonomy.[28] It prevents situations in which only two strategies remain: leaving patients as they are or using coercion. Likewise, the care given to Mr. Van der Velde was to avoid the two extremes of forcing versus leaving be; objectification versus subjectification; too much versus too little care.

This compassionate interference seems to me a good way to face food refusal, and the people who are trying to account for mortification might learn something from the people who are caring for it. This does not mean that they should never conceptually distinguish between body and mind, or competence and incompetence. But, within daily care itself, and within an alternative kind of accounting that better allies with providing care, it is more helpful to realize that attributions to body or mind are never finite, and that autonomy is not given *a priori,* but is a continuous accomplishment. So I would enter a plea that moral discussion concerning mortification should no longer confine itself to autonomous decision making, to develop a more relational account of autonomy, and to open its mind—and heart—to an ethics of care. My objective in this article is to support care ethics, as well as to add some nonhuman actors to it. I hope this compassionate interference of mine will be fruitful, not only for an ethics of care, but also for the daily care of people with Alzheimer's disease.

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NOTES

1. From the directives of Nursing Home Blauwbörgje in Groningen, the Netherlands.

2. Alzheimer's disease is the most frequently occurring form of dementia. Both terms are often used to refer to the same disease, and so do I in this text.

3. In the English medical vocabulary, the word "starvation" is used. However, I prefer to translate *versterving* more literally, in order to retain some of the Roman Catholic connotations of mortification: abstaining from food and drink—earthly pleasures—to be able to better attend to spiritual matters.

4. These quotations are from articles in Dutch newspapers: "Verpleeghuis ontkent bewust uitdrogen van Alzheimerpatïent," *De Volkskrant,* 25 July 1997; "Kwaliteit leven moet zwaarder wegen dan durer," *De Volkskrant,* 7 August 1997; "U gaat moeder toch niet uitdrogen?" *Trouw,* 27 September 1997; "Rusdie en 't Blauwbörgje," *Het Parool,* 14 August 1997, and a magazine: "Versterven in Nederland," *De Groene Amsterdammer*, 20 August 1997.

5. On the notion of "event" as a mixture of action and behavior, of making happen and letting happen in a socio-material network, see E. Gomart and A. Hennion, "A Sociology of Attachment: Music Amateurs, Drug Users," in *Actor Network Theory and After,* ed. J. Law and J. Hassard (Oxford, U.K.: Blackwell, 1999): 221-47. This is also where philosophy of action comes in. See for example J. Raz, "When We Are Ourselves: The Active and the Passive," in *Engaging Reason: On the Theory of Value and Action* (Oxford, U.K.: Oxford University Press, 2000): 5-22. For a good overview, see A.L. Mele, ed., *The Philosophy of Action* (Oxford, U.K.: Oxford University Press, 1997).

6. "Verpleeghuis beschuldigd van uitdroging," *De Volkskrant,* 24 July 1997.

7. They do not specify whether this need is physical or psychological, but by linking it to "illness" and "natural course," the need appears to be of a more bodily kind.

8. This reflects the guidelines of the Dutch Board on Decision-Making with Dementia Patients, which say that one should not conclude too quickly that a dementia patient is no longer competent and would no longer have the capability to practice the right to self-determination and—hence—would be incompetent. "Everyone is considered competent until the contrary has been proved." Commissie Besluitvorming bij Dementerende Patiënten (Board on Decision-Making with Dementia Patients), *Medische zorg met beleid; Handreiking voor de besluitvorming over verpleeghuisgeneeskundig handelen bij dementerende patiënten (*Utrecht, the Netherlands: Nederlandse Vereniging van Verpleeghuisartsen, 1997), 15.

9. There are some exceptions to this rule, for example, in case of emergency, but mortification is not considered to be a case of this kind. Further, several varieties of autonomous consent can be distinguished, and surrogate decision making is a way—although not an unproblematic one—to reach decisions for incompetent patients. See T. Beauchamp and J. Childress, *Principles of Biomedical Ethics,* 5th ed. (New York: Oxford University Press, 2001).

10. D.P. Engberts, "De dienstbaarheid van het recht: Het juridische kader van complexe behandelbeslissingen" (The servitude of justice: The legal framework of complex treatment decisions), in *Medisch-ethische casuïstiek; Complexe behandelbeslissingen aan het einde van het leven,* ed. H.M. Dupuis (Leiden, the Netherlands: Boerhave Commissie voor Postacademisch Onderwijs in de Geneeskunde, 1997).

11. Boudewijn Chabot, quoted by Patrick Arink, "Veel discussie over versterving," (Much discussion of mortification), *Tijdschrift voor Verpleegkundigen* no. 15/16 (1997): 448.

12. J. Mesman, "Dwingende feiten en hun

verborgen moraal: Over doen en laten in de neonatologiepraktijk" (Compelling facts and their hidden moral: On what is done and left undone in neonatal practice), *Kennis & Methode, Tijdschrift voor empirische filosofie* 20, no. 4 (1996): 393.

13. "U gaat moeder toch niet uitdrogen?" *Trouw,* 27 September 1997; "Rusdie en 't Blauwbörgje," *Het Parool,* 14 August 1997.

14. There are two ways to show the complexities and subtleties of concepts and dichotomies. One is analytical philosophy, the other is *empirical philosophy,* an approach that uses empirical description to generate and/or answer philosophical questions. In this article I choose the latter mode for two reasons: (1) it better suits the attentiveness of care ethics to particulars and context; (2) in attempting to overcome dichotomies—beyond refining them—the complexities of practice often turn out to be rich resources. For arguments on using ethnography in a moral study of mortification, see H. Harbers, A. Mol, and A. Stollmeyer, "Food Matters: Arguments for an Ethnography of Daily Care," in *Sociality/Materiality: The Status of the Object in Social Science,* ed. D. Pels, K. Hetherinton, and F. Vandenberghe, in a special issue of *Theory, Culture & Society* 19, no. 5/6 (2002): 207-26. For the broader argument that ethnography can be a valuable approach to studying moral problems in healthcare, see B. Hoffmaster, "Can Ethnography Save the Life of Medical Ethics?" *Social Sciences of Medicine* 35, no. 12 (1992): 1421-31.

15. At the time (1998) I was a graduate student in philosophy, supervised by Hans Harbers and Annemarie Mol. I used the ethnographical field work for my master's thesis. For the publication that followed the thesis, see: A. Stollmeyer, "Voedsel in het verpleeghuis: lichaam, geest of meer?" (Food in the nursing home: body, mind or more?), in *De bindkracht der dingen* (The cohesive power of things), ed. H. Harbers and S. Koenis, in a special issue of *Kennis & Methode: Tijdschrift voor empirische filosofie* 23, no. 1 (1999): 102-28.

16. "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." World Health Organization definition, *http://www.who.int/cancer/palliative/definition/en/.*

17. In families where one of the children has bulimia nervosa (an eating disorder), many conflicts arise from this kind of caring food. Bulimia may be seen as resistance to this care in the form of food: it is "the passive rebellion of a person who cannot rebel more directly against overprotective, intrusive parents, in a family where eating has special significance." R. Schwartz, M.J. Barrett, and G. Sabe, "Family Therapy for Bulimia," in *Handbook of Psychotherapy for Anorexia and Bulimia,* ed. D.M. Garner and P.E. Garfinkel (New York: Guilford Press, 1985), 280.

18. J. Tronto, *Moral Boundaries; A Political Argument for an Ethic of Care* (New York/London: Routledge, 1993): 103.

19. "The Board on Decision-Making with Dementia Patients is of the opinion that a refusal of a dementia patient, even though this only takes the form of physical defense or resistance, should weigh heavily at all times." Commissie Besluitvorming bij Dementerende Patiënten, *Medische zorg met beleid,* see note 8 above, p. 16.

20. Seducing a patient into eating by offering chocolate is another example; for the argument that with different modes of care come different modes of dying—and of living—see Harbers, Mol, and Stollmeyer, "Food Matters: Arguments for an Ethnography of Daily Care," in note 14 above.

21. Even for healthy people, the model of rational autonomy may not be the most appropriate. For feminist critiques of the classical, individualistic notion of autonomy within moral and political philosophy and for the development of the notion of relational autonomy, see C. Mackenzie and N. Stoljar, ed., *Relational Autonomy; Feminist Perspectives on Autonomy, Agency, and the Social Self* (Oxford, U.K.: Oxford University Press, 2000). See also B. Barnes, *Understanding Agency: Social Theory and Responsible Action* (London: Sage, 2002) for the argument that it is the inherent sociability of

human beings that calls for another conception of agency: "social," "collective," and "responsible" agency are the notions the author uses. However, in my use of the notion of relational autonomy, I move beyond the humanist conception of interactions of both feminist philosophy and Barnes (above), by including also interactions with nonhuman actors.

22. The symmetrical study of the human and nonhuman actors in science, technology, and medicine is what distinguishes the Actor Network Theory, a relatively recent approach within science and technology studies that blurs the distinctions between the social and the natural, between humans and things. See for example B. Latour, *We Have Never Been Modern* (Cambridge, Mass.: Harvard University Press, 1993); Law and Hassard, *Actor Network Theory and After,* see note 5 above; M. Berg and A. Mol, ed., *Differences in Medicine: Unraveling Practices, Techniques and Bodies* (Durham, N.C.: Duke University Press, 1998).

23. See note 8 above for the moral counterpart to this empirical observation.

24. I do not refer to a humanism that supposes an autonomous subject: like "autonomy," "humanity" is not given *a priori,* but something that is given shape differently in different sociomaterial practices. Some of the questions I would like to tackle in the near future are about what "humanity," "human" dignity, and (relational) "autonomy" are. Or, more precisely, about how they are *done:* whether and how they are constructed, promoted, sustained, and prolonged—or shortened—in different caring practices.

25. M. Verkerk, "A Care Perspective on Coercion and Autonomy," *Bioethics* 13, no. 3/4 (1999): 358-68. Pellegrino and Thomasma argue for the restoration of beneficence as the fundamental principle of medical ethics in E.D. Pellegrino and D.C. Thomasma, *For the Patient's Good: The Restoration of Beneficence in Health Care* (New York: Oxford University Press, 1988).

26. M. Schermer, *The Different Faces of Autonomy: A Study on Patient Autonomy in Ethical Theory and Hospital Practice* (University of Amsterdam, PhD thesis, 2001).

27. Two classics on care ethics are N. Noddings, *Caring: A Feminine Approach to Ethics & Moral Education* (Berkeley, Calif.: University of California Press, 1984), and S. Ruddick, *Maternal Thinking: Towards a Politics of Peace* (London: Women's Press, 1989). For more recent elaborations of an ethics of care, see, for example, Tronto, *Moral Boundaries; A Political Argument for an Ethic of Care,* in note 18 above, and S. Sevenhuijsen, *Citizenship and the Ethics of Care: Feminist Considerations on Justice, Morality and Politics* (London: Routledge, 1998).

28. Verkerk, "A Care Perspective on Coercion and Autonomy," see note 25 above.

Deciding for Others at the End of Life: Storytelling and Moral Agency

Mark Yarborough

PROLOGUE

Countless times every day, in hospitals across the United States, people must decide about how aggressively to treat others who are approaching the end of life. The routine occurrence of these life-and-death decisions ought not desensitize us to the awesome responsibility that falls upon those who are faced with making them. Nor should we lose sight of how vexing these decisions can be for family, friends, and healthcare providers. While these deaths no doubt occur when lives are judged to be waning and are accompanied by a host of signs of death's approach, they are also accompanied by deliberate decisions by family and friends, acting in concert with healthcare professionals, to decide the timing, manner, place, and other details of another's dying.

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How are friends and family, namely, surrogate decision makers, to understand their part in this setting and in the decision-making process? I want to focus on how to go about making these decisions in many instances, as well as on the importance of fully acknowledging and embracing the substantive role that surrogates and others play in the process. Besides surrogate decision makers, the other parties include clinicians, such as physicians and nurses; ethicists; hospital chaplains; and many others. Try as hard as we collectively might to divorce or minimize the impact of our presence and participation in these moments of choosing more or less life and living for someone else, we unavoidably leave a moral residue. I want to describe and illustrate a narrative method that can help assure that this residue, our moral fingerprint if you will, reveals that we have done right by, and good for, those for whom we have chosen.

INTRODUCTION

Consensus emerged long ago regarding various aspects of decision making at the end of life: surrogates, rather than healthcare pro-

fessionals, should make such decisions.[1] In addition, there is consensus that it is equally valid to proceed from the moral position of the sanctity of life, wherein one believes and acts upon a duty to save all life that can be saved; or the moral position of quality of life, wherein one believes and acts upon a duty to save only some lives that can be saved. Consequently, we generally accept surrogates' decisions that follow from either of these positions. By and large, surrogates tend to be at liberty to choose among all available medical treatment options.

These areas of broad consensus notwithstanding, it does not necessarily follow that all surrogates' decisions that fall within the range of viable treatment options are ethically sound. There are independent standards by which to judge the appropriateness of specific surrogates' decisions for medical treatment at the end of life. Consequently, clinical practices regarding surrogates' consent for adult patients should follow these standards, standards that have been established largely through case law.[2] These standards establish that surrogates' decisions should reflect the explicitly stated wishes of patients, when possible. This is known as the *subjective standard.* When surrogates do not have this knowledge, they should seek to have their judgments reflect and comport with the beliefs, values, and goals of the patient. This is known as the *substituted-judgment standard.* It is probably the most widely used standard, and will be the focus of this essay. Only when surrogates are not in a position to let judgments be guided in this manner either should they rely on the *best-interest standard,* and make clinical decisions that are seen as promoting the well-being of the patient. In the very broadest terms, the subjective and substituted-judgment standards derive their moral authority from the principle of respect for persons, but the best-interest standard is derived principally from those of beneficence and nonmaleficence.[3] I want to explore a method that can assure that surrogates' decisions that utilize the substituted-judgment standard do so in a way that affords patients the full measure of dignity and respect that is their due. (What constitutes this full measure will be apparent in the pages to follow.) This exploration will describe why surrogates, much of the time, will need to be "responsibly creative" in their deliberations, and will highlight the central role that surrogates' discretion frequently plays in making ethically responsible substituted judgments.

Embracing surrogates' discretion as a mechanism to promote respectful treatment of patients does not always get as much attention in clinical bioethics as it may deserve. Perhaps this is because it is the principle of respect for persons that has done much to replace the discretion of third parties in clinical settings, primarily the discretion of healthcare professionals, with the discretion of the patient. Respect for persons has led the charge against the old paternalism in healthcare, helped usher in the era of informed consent and shared decision making, and made common the wisdom that people should be allowed to make their own decisions in the healthcare setting. Given the predominance of the patient's voice that respect for persons has established, what is the import of this principle when people lose their voices and cannot make their own decisions? The substituted-judgment standard is an attempt to preserve the guidance of this principle, and it does so by instructing that surrogates be guided by the goals, values, and preferences of patients. In so doing, the standard implicitly recognizes the necessity of, and authorizes the use of, multiple voices taking part in the process of discovering how we treat others with dignity and respect.

The practical clinical ethical question that confronts us is knowing how surrogate decision makers best derive guidance from this principle when they employ the substituted-judgment standard. Answering this question can be problematic, since the substituted-judgment standard is subject to various interpretations, both in case law[4] and in bioethics,[5] making the ethical responsibilities of surrogates who employ this standard of proxy consent a matter of dispute. The disagreement about the standard centers largely on the de-

gree of discretion in decision making that the standard permits surrogates to exercise. Some bioethics commentators eliminate almost all surrogates' discretion by imposing a "pure-autonomy" standard, wherein the "only foundation" for substituted judgments is "the principle of respect for autonomy, which applies if and only if either a prior autonomous judgment itself constitutes an authorization or such a judgment supports a reasonable basis of inference for a surrogate."[6] It is more typical, though, to interpret the standard as granting more discretion to surrogates so that they make decisions that are based not upon the patient's prior judgments, but rather based upon the patient's known values, goals, preferences, and the like. I will argue in favor of the latter "discretionary" view over that of the former "nondiscretionary" view, and justify and illustrate a method for knowing how we can judge whether the scope and intent of a surrogate's discretion is appropriate.

The discretionary view is consistent with laws in all of the states that grant broad discretion to surrogates whom patients have designated in advance to serve as their medical decision makers. It is also consistent with laws in some states that give broad discretion to surrogates who are identified, not by advance directive, but according to statutory processes triggered after the patient has lost decisional capacity. The discretionary view is inconsistent, however, with laws in other states that, in the absence of a surrogate decision maker designated in an advance directive, impose a standard of clear and convincing evidence to support surrogates' decisions regarding treatment. The following discussion will reveal the extent to which a standard of clear and convincing evidence potentially disrespects and misserves those who are subject to them.

THE INTERFACE OF NARRATIVE, DISCRETION, AND SHOWING RESPECT FOR PARTICULAR PEOPLE

Using a life narrative, which is an authentic account of a person's life, can help illuminate substituted judgments by helping surrogates to think clearly about exactly how they can most respectfully treat those for whom they will make decisions. Thus, my central point will be that discretion is most responsibly exercised by grounding substituted judgments in the life narratives of patients. This method of application, much more so than nondiscretionary explications of substituted judgment, assures that patients are treated with the full degree of respect that is their due.

We show particular people who have lived particular lives that are reflected in particular narratives dignity and respect by making decisions for them that reflect their particularity, not just their humanity. The best-interest standard, along with nondiscretionary interpretations of the substituted-judgment standard, ground decisions out of respect for the humanity of the patient, thus treating the patient in a generic, rather than a particular, way. For instance, according to the best-interest standard, we want to do what is best with respect to the welfare of the patient, and we emphasize generic attributes of all persons, such as the need for comfort, warmth, and the like. While these considerations are certainly important, by no means does their satisfaction exhaust the duty to treat people with respect.[7]

The nondiscretionary interpretations of substituted judgments emphasize one's humanity, rather than one's particularity, by equating respectful treatment of previously competent persons with enforcement of prior autonomous decisions. If this cannot be done, then, as persons, patients are recognized as vulnerable, and thus needing to be protected in their time of vulnerability.[8] This "default setting," in essence, charges surrogates with making decisions with what amounts to little more than a best-interest standard. By creating this dichotomy, wherein people are either fully autonomous or vulnerable, we fail to recognize that there is a morally rich middle ground, manifest in people's life narratives, between these two points on the spectrum. Robin Dillon, in recognition of this middle

ground, has argued forcefully that when we wish to treat persons with respect, "What matters about each of us is not (only) some abstract capacity but the fact that we are the specific concrete individuals that we are."[9] Our life narratives can reveal and illuminate the specific concrete people that we are, and thus inspire surrogates' judgments. For this to occur, however, surrogates must be granted sufficient discretion.

Contrasting the substituted-judgment standard with the subjective standard is instructive to our efforts to appreciate the significance of surrogates' discretion. The subjective standard, wherein the surrogate is literally the mouthpiece of the incapacitated patient and says what the patient would say if able to speak, reflects the patient in his or her full particularity, because his or her actual decisions are being spoken, heard, and deferred to by others. The surrogate is completely transparent in this decision-making process, exercising no discretion, but serving instead as a repository and reporter of the patient's prior decisions and instructions. Such transparency, out of deference to the principle of respect for persons, is a good thing. Precise acting upon the patient's prior decisions grants assurance that surrogates have acted according to the responsibilities stipulated by the subjective standard.

Although it may be our fervent desire that *all* surrogates should never be much more than the voices *of* patients, merely serving to report and replicate their prior decisions, the reality, as the empirical data that are reviewed below illustrate, usually is otherwise. The data indicate that surrogates most often must be the voices *for* patients. Consequently, precision is really the wrong benchmark by which to measure substituted judgments. What is needed in its place is a benchmark that recognizes that surrogates are rightly the voices *for* rather than the voices *of* patients. Speaking *for,* rather than as, another introduces a greater degree of authority, and thus responsibility and accountability, into the surrogates' decision-maker role.

BACKGROUND CONSIDERATIONS

The rich moral agency that surrogates at times embody is apparent when we examine some telling empirical evidence regarding advance care planning, evidence that renders nondiscretionary interpretations of substituted judgment essentially inapplicable. First we ought to note that surrogate decision makers can be relied upon to accurately predict the treatment preferences of patients who lack decisional capacity, that is, surrogates are "invisible," as they should be under nondiscretionary interpretations of the substituted-judgment standard, only 66 percent of the time.[10] This reliability is a function of patients having conversed with their surrogate about clinical situations that they later find themselves in, but this reliability quickly erodes once the seriousness of the medical condition or the invasiveness of the procedure lessens. (Of interest here is one study that indicates that patients value such conversations much less than their surrogates do.)[11] In the absence of explicit conversations about directly analogous clinical situations, surrogates are only slightly more accurate than a coin toss at correctly anticipating the decisions that patients would make for themselves regarding medical treatment preferences.[12] In other words, surrogates' decisions match those of patients only when the surrogates are in a position to correctly employ the subjective standard of surrogate consent, showing that surrogates' invisibility, or even limited transparency, truly is confined to this other standard of surrogate consent.

Evidence further indicates that less than 25 percent of the adult population have advance directives,[13] suggesting that not as many explicit advance discussions about treatment preferences occur as we would ideally desire if our picture of a "good" substituted-judgment surrogate decision maker is one who mimics patients' decisions. Also complicating matters, though, is the following. Even if such conversations were routine and widespread, it is not clear to what extent such advance decisions would comport with the actual de-

cisions people might make should they be able to make them while in a state of decisional capacity. It is difficult for most of us to anticipate in more than a general way the decisions that we would make in future, changed situations. Chances are we would later change our minds about our treatment preferences anyway, once we had experienced a situation, rather than merely speculated about it.[14]

The guidance that surrogates who must make substituted-judgment decisions often receive from clinicians, ethicists, and others does not always comport with this empirical record. Surrogates are often prompted in ways that mask, rather than acknowledge, their discretion and visibility. For instance, it is not uncommon for the instructions that surrogates receive to be limited to asking them to decide as they *presume* the patient would decide if she or he were only able to understand the pending choices and decide among them. Such guidance encourages surrogates to speculate about what the patient would say and/or what decisions she or he would make. While these are correct questions to ponder to see whether a surrogate can make a subjective-standard decision, as the empirical evidence indicates, the honest answers to such questions most of the time will be "I don't know." Rather than helping surrogates to move beyond this impasse by instructing them how to find something besides a patients' prior decision upon which to ground decisions, clinicians often allow surrogates to continue to engage in speculation about what the patient might say or do.

I call this the *presumptive-judgment* method of substituted judgment. Surrogates are expected to be able to presume to know what patients likely never considered and thus never knew. Here we see the inappropriate benchmark of precision, and the desire for an "only slightly adulterated" informed consent sneaking its way into the implementation of the substituted-judgment standard, and muddying the waters as a result. The surrogates' task ought not be to anticipate what the patient might decide if she or he were miraculously capable of deciding for herself or himself. That approach seeks the impossible from surrogates: knowing how another would decide a question she or he never decided, an exercise in little more than guesswork. The data indicate the problematic nature of this approach, and simultaneously reveal that surrogates play, by necessity, a substantive role in the life-and-death decisions they are called upon to make. Clinicians should be cognizant of this substantive role, and understand how they can best guide surrogates to make ethically responsible decisions.

The data indicate that, on a routine basis, surrogates must exercise discretion in the decision-making process. This reliance on discretion is not an intrinsically good or bad thing. Rather, it is merely a fact of the decision-making process, one that highlights the importance of having the correct benchmarks and methodology to assess and employ substituted judgment. That is why the benchmark of precision, so appropriate to surrogate decisions based upon a subjective standard, is so ill-suited to typical substituted judgments.

In place of precise (or, as the empirical data suggest, imprecise) judgments by surrogates, I want to argue for *characteristic* judgments from surrogates. The use of what I call the *constructed judgment* method can lead to characteristic judgments, judgments inspired by life narratives. Such judgments can help assure that surrogates' choices comport with the responsibilities, set forth in the substituted-judgment standard, to have choices that are informed by patients' values and goals. In what follows, I hope to illustrate this method, indicate the benchmarks of good decisions embedded within it, and show how it preserves the appropriate weighing of the principle of respect for persons with those of beneficence and nonmaleficence.

Before turning to this method, however, two additional related and important aspects of surrogate decision making in the clinical setting need to be noted. First among these is the most obvious. As already noted in passing, surrogates' decisions affect the time, man-

ner, place, and other aspects of another person's dying. So the stakes for both patients and decision makers could not be higher. Surrogates' decisions that opt for aggressive treatment may result in the patient living for many years in a physically and cognitively impaired state. Conversely, their decisions may result in an earlier death for the patient.

However, it is not just another's survival that is at stake, but his or her legacy. Aristotle's considerations about happiness illustrate this. Happiness "turns out to be activity of soul in accordance with virtue. . . . But we must add 'in a complete life'."[15] In this view, happiness is a lifelong achievement that includes, to some extent, the circumstances of one's death and legacy. "For there is required [for happiness], as we said, not only complete virtue but also a complete life, since many changes occur in life, and all manner of chances, and the most prosperous may fall into great misfortunes in old age, as is told of Priam in the Trojan Cycle; and one who has experienced such chances and has ended wretchedly no one calls happy."[16] Aristotle further mentions that, in the pursuit of happiness, there is a death that is "worthy of [one's] life."[17]

These passages from the *Nicomachean Ethics* remind us not to underestimate the importance of surrogates' decisions about life-sustaining treatment with respect to both the denouement of one's living and dying, as well as one's legacy and thus ultimate happiness. They also remind us of the extent of our interconnectedness with others, that is, the inescapable ties of family and friendship-based relationships. This brings us to the second important feature of surrogates' decision making that we should note, namely, the new status of the patient's moral agency. Previously autonomous adults are not the same as fully autonomous adults. Their independence that previously characterized them has now been replaced by dependency. Above all else, dependent patients lack their voices, their ability to make independent judgments, and therefore the power enjoyed by their fully autonomous counterparts. "[F]amilies gradually (and eventually completely) take on both the decision-making and care-giving needs of their [demented] relatives. . . ."[18] To view, then, incapacitated persons as akin to someone for whom precise judgments exist and can be made or as someone who is (just) helpless and in need of protection is to misunderstand the nature of their current personhood. *Dependency* is now a central characteristic of theirs, meaning they are dependent on others not just for their physical care and well-being, but the subsequent unfolding of their lives, as well as their role and place in their larger community. What they do, what happens to them, the social role they fill, all of this and more *depends* on the judgments others make on their behalf. This dependence is a *brute fact* that cannot be wished away. Consequently, discretion is an unavoidable hallmark of many, if not most, surrogates' decisions about treatment near the end of life. All of these considerations show how crucial it is that we, especially those of us who have a clinical role with surrogates, recognize the central role of surrogates' discretion, and that we have a method by which to understand how that discretion is responsibly exercised.

THE CONSTRUCTED-JUDGMENT METHOD

The constructed-judgment method can responsibly guide surrogates' discretionary judgments. For those times when we must decide for those we know and there is no prior decision to replicate, yet we know enough about them that it would be wrong to view them as some generic person to whom our duty to treat with respect is fully captured by our duty to promote their welfare while avoiding undue harm—we know them well enough that there is a substantive difference between the duties that flow from respect for persons compared with beneficence and nonmaleficence—a constructed judgment is ethically preferable. Based on joining our knowledge of them—their past, their desires, their values, and their character—with our knowledge of their medical situation, knowledge that the

patients are not privy to, we can construct *characteristic* judgments, that is, respectful decisions that comport with their life narratives. Employing this method of the substituted-judgment standard, being able to determine the extent to which a surrogates' decision is "in" or "out" of character for a patient, becomes the proper benchmark, rather than precise comportment with a prior decision, by which to measure surrogates' decisions.

Recalling the earlier point about the need to treat people as the concrete individuals they are, the value of using a narrative method is apparent. It is our life narratives that reveal our concrete characters. Narratives pertain to lives lived in relationship with family, friends, and others,[19] and thus are constructed largely in public view. Our concrete subjectivity is manifest in our conversations, behaviors, dispositions, and attitudes, meaning there is a transparency to our subjectivity. It is our life narratives that also can "uncover" the concrete individuals we remain, even in times of dependency. The task of surrogate decision makers who use a constructed-judgment method is to do this uncovering.

In practice, the constructed-judgment method would establish the following. Surrogates would be obliged to recall the narrative unity of the patient's life revealed through the public dimensions of that life, since they are not privy to the purely private aspects of the other's life; learn what the various treatment options are; and then *judge,* that is, exercise discretion, regarding what type of treatment decision complements and helps complete the narrative or avoids creating dissonance within the narrative. Blustein has suggested that such a narrative surrogate decision-making process can be approached as an effort to write the last chapter of someone's life.[20]

In effect, in writing the last chapter, surrogates would be called upon to reconstruct and employ the *authoritative voice* of the patient's narrative. What is the authoritative voice and where is it to be found? All narratives are constructed from a time and place. Within a narrative, one can look forward and backward, that is, read the narrative, from a *constructive vantage point* that gives the life contained in the narrative continuity and meaning. The existence of a constructive vantage point reflects the fact that a life is constructed by its author(s) in relation to its unfolding. Thus, there is embedded within any life narrative an authoritative voice, the voice that speaks from a constructive vantage point. The more that a surrogate's decisions "ring true"[21] with the authoritative voice of the patient's narrative, the more respectful those decisions are. Surrogates' decisions "ring true" to the extent that they not just complete, but also *continue,* the patient's life narrative in a way that *compliments* the portions of it that have gone before. Complimentary portions of the narrative are those that are characteristic of the subject of the narrative. So the benchmark by which to judge that last chapter is the extent to which it is characteristic. Employing the authoritative voice to speak from a constructive vantage point can help assure that this benchmark is attained.

Given the brute fact of dependency, we must acknowledge that there are times when the authoritative voice is spoken not by the subject of the life, but rather by those who choose on behalf of the subject. Dependency produces multiple authors for a narrative.[22] Taking this inescapable consequence of dependency into account reminds us of the immense power to decide the course of life for others that is naturally inherent in the surrogates' decision-making role. Tempering this power with the responsibility to treat patients with dignity and respect is the purpose of surrogate consent, regardless of which standard of surrogate consent is employed. Joining power with the moral responsibility of authorship is what sets the constructed-judgment method of the substituted-judgment standard apart from the other standards. Recalling the empirical data discussed in a previous section, responsible authorship is a reasonable constraint to place on the discretion that surrogates inevitably enjoy. Accordingly, clinicians must not just grant surrogates power;

they must hold them accountable for the manner in which they exercise their power. The constructed-judgment method is a responsible, and, as I hope to show, an intuitive and thus feasible manner by which to exercise power.

CHALLENGES TO CONSTRUCTED JUDGMENT

The criterion of my proposed constructed-judgment method of surrogate consent, characteristic completion of a life narrative, that is, an episode that complements rather than creates dissonance with the preceding episodes, is not as precise as some may desire. Recalling Aristotle, however, precision is not always possible in our reasoning about moral courses of action.[23] What is possible and appropriate with respect to the criteria is that they are ethically sound and achievable in practice, not that they are precise. And I think the criterion for the constructed-judgment method is both sound and achievable.

Perhaps a criterion's suitability is best appreciated by turning to some obvious criticisms of the constructed-judgment method. For instance, will surrogates know patients' life narratives well enough, and if so, will those narratives adequately portend the judgments that ought to be constructed? In many instances, narratives will contain very explicit prods to surrogates, such that their decisions will come close to comporting with the subjective, as opposed to the substituted-judgment method. As the empirical evidence noted earlier suggests, however, this will be the unusual rather than the normal circumstance. So most narratives will contain suggestions rather than explicit prods to surrogates.

Does it follow from this that respectful judgments therefore cannot be constructed in these instances? It is true that constructed judgments require an element of responsible "play" and interpretation, since the decisions that surrogates must make are constitutive, that is, determinative, of how the individual's life subsequently unfolds. But prior chapters of the patient's life narrative can serve as useful prompts, that is, constraints, on surrogates. As Dillon notes, surrogates must seek to "promote what the other person regards as important; or where that is not possible or where we cannot bring ourselves to do that, then we at least have to take account of her conception of her own good. And that, too, requires informed understanding."[24] Presumptive judgments, which attempt instead to anticipate patients' hypothetical, that is, nonexistent, decisions, obfuscate the need for constitutive decisions, as they hide behind these hypothetical presumptions and act as if they were other than hypothetical.

Acknowledging the need for these constitutive exercises of discretion, while recognizing their moral legitimacy, should be acceptable, first, because the judgments are grounded in the patient's particularity and individuality. Second, being dependent forecasts that the unfolding of our lives during times of full dependency are constituted largely by the decisions of others. There is nothing disrespectful about this recognition, unless those who have the power over that unfolding fail to take inspiration and direction from the dependent person's life. This direction, limited though it is, is better than the "direction" afforded by presumptive judgments. As noted previously, the surrogates' task is not to guess what the patient might decide if he or she were miraculously capable of deciding. Surrogates cannot possibly *know* how another would decide a question she or he never decided.

Taking the full import of dependency into consideration, we should recognize that surrogates' decisions are not a search for knowledge, of having surrogates' decisions correspond with patients' decisions. Such correspondence is an elusive dream; there are no prior decisions with which surrogates' decisions can possibly correspond. Rather, surrogates need to seek information to inform and inspire their judgments; life narratives are the richest source for both. Thus, reliance upon life narratives can best assure that surrogates' discretion is exercised responsibly. Surrogates

who know the patient well have a broad understanding of both the patient and his or her current lived context. They are in a position to decide the action consistent with the patient's narrative, that is, the *characteristic* course of action. Thus, constructed judgments do not emerge from guesswork, but emerge from the understandings and within the trust that are the hallmarks of close relationships. Therefore, these judgments, more than others, are characterized by responsivity and responsibility. They are *responsive to,* that is, informed and inspired by, the subject's life narrative, and they are *responsible for* the continuation and completion of that narrative in a manner worthy of the prior chapters in the narrative.

Consider a hypothetical example of an adult brother and sister who are faced with the decision to discontinue life-preserving medical treatments for their father, who has at least temporarily lost his decisional capacity because he has suffered a serious stroke. The neurologist is very guarded about their father's prospect for a full recovery, but she states that there is a chance that their father can be discharged home, and that, with appropriate rehabilitation, can recover what many people would consider a meaningful quality of life. There is also a strong chance that he will experience little or no further recovery. This inability to be sufficiently confident in the extent of recovery is what creates the need to decide about continuing life-preserving medical treatments.

As is frequently the case, let's also assume that their father has not completed an advance directive, but he has talked with his children about "his wishes." He has stated on numerous occasions, "I don't want to be a vegetable. I'd rather die than be a burden to others." This is not an unusual situation, in that there is no advance directive and no ability for either child to follow the subjective standard, that is, no one knows with any certainty what the patient would decide were he able to make his own decision. However, since they know their father well, they are able to employ the substituted-judgment standard rather than the best-interest standard. One can imagine that the children are conflicted. The patient's daughter might say, "Dad would never want to live like this because he always said he didn't want to be a vegetable. I know that if he could only see himself in the hospital bed, hooked up to so many tubes and needles and machines, that he would want us to just let him die." It is not difficult to imagine the son countering, "I had those same conversations with Dad. But don't you think if he could talk with the doctor and hear that there is a chance that he'll get better, that he would take that chance? I think it's too early to give up."

Such a case illustrates that frequently, even when surrogates have had conversations with patients about their treatment wishes, these conversations lack specificity to dictate certain decisions. In this case, neither the son's nor the daughter's view is directly at odds with the words spoken by their father. Rather, given that the father is not privy to his current situation and given that his comments were made without specific reference to what he would want were he to suffer a stroke and have an uncertain prognosis, both surrogates' views are plausible. No one can dictate that, based upon Dad's previous statements, the daughter is right and the son is wrong, or vice versa.

I think this brief hypothetical case is illustrative of the situation of many surrogates' decisions that must be made. Even in the presence of prior conversations, there frequently is no obviously *right answer* to the exclusion of all others. This means we are left with finding the *right method* that, when used, will produce a respectful answer. I am proposing the constructed-judgment method as the method for surrogate decision makers to use as they struggle to make ethically appropriate decisions that will determine, to a large extent, both the content and duration of their father's life narrative.

All the children can do in this instance is decide the denouement of their father's life, in light of the facts as they are known, their understanding of his values and preferences,

how he has lived his life, and what kind of future for him is most characteristic of him. Their task is a challenging one, insofar as Dad never fully thought through and/or communicated anything to unambiguously decide the question to be decided. Thus, Dad's narrative, like those of all living people, is in continuous process and play, and is in "need of completion." It falls to his children to do that in a respectful manner. This is done by them, as they become his authoritative voice and find that constructive vantage point that lets them see more clearly than other vantage points, such as what they want for their father or what they think is best for their father: what constitutes respectful treatment of him.

I recognize that it can prove very difficult for surrogates to adopt the constructive vantage point, but it need be no more difficult than asking them to adopt the presumptive vantage point. The more they are asked by clinicians what they think *their father* would decide as they struggle to make *their* decision, the more likely they are to guess about what their father never decided. I am suggesting instead that they be instructed by clinicians to make "characteristic decisions" rather than say what they think "Dad would do." This will afford surrogates the opportunity to think back on the other's life and living, and construct a remaining "living while dying" that is consonant with the patient's prior living.

In considering this recommended method of making substituted judgments, I think the field of bioethics needs to acknowledge the indeterminacy that is a hallmark of substituted judgments. If my reading of the empirical data is correct, most people never decide end-of-life matters, at least not beyond who they want their surrogate decision maker to be, or, if they do arrive at clear and specific decisions, they do not communicate their decisions accurately. As a result, others *must* decide for them, and the decision will be the surrogate's, not the patient's, decision. Try as we might to declare the decision to be the patient's—because "this is what we think Dad would say"—does not negate that the decision is a work of fiction. I think what the bioethics literature, and clinical ethics practices as well, have failed to fully appreciate is that all substituted judgments are fictions at some level. The challenge is to know how to discern the responsible fictions from the irresponsible ones. I have offered the constructed-judgment method as a way to make that determination. If a surrogate's responsibility is to make a decision that treats the patient with dignity and respect, surely a judgment that is explicitly inspired by the patient's life narrative is preferable to one based on speculation about an unmade decision.

Terms such as fiction, play, responsivity, inspiration, and the like will no doubt be troublesome to many, prompting worries that the constructed-judgment method gives too much discretion to surrogates.[25] Perhaps it gives them license to selectively read a narrative and, rather than responsibly interpret it from the constructive vantage point, co-opt it according to the surrogate's desires on behalf of the subject. In other words, how can we trust that the surrogate's interpretation is correct?

There is no doubt that surrogates can make poor decisions. What makes for a poor decision, though? At one level, surrogates' decisions can be flat-out wrong because they fail to use an ethically and legally prescribed standard. For instance, a surrogate who is in a position to make a subjective-standard decision but who fails to do so would make a wrong decision. What we most need to concern ourselves with, however, are those instances in which the correct standard is misapplied. Thus, one could misapply the best-interest standard by making decisions that are contrary to others' assessment of the patient's well-being; one could misapply the presumptive method of the substituted-judgment standard by making decisions that do not match presumed hypothetical judgments; or misapply the constructed-judgment method by making decisions that would be out of character for the patient. The task of surrogates and clinicians, then, is first to make sure that the correct standard is used, and second to strive to assure that it is applied correctly. If we assume

that respect for persons is to be the primary guide for surrogates' decisions, then we should use the best-interest standard only as a last resort. If my prior assessment of the faults of the presumptive method of substituted judgment stands, then the constructed-judgment method prevails.

No doubt, some readers will still be troubled by possible misapplication of this method, since one has to rely on the surrogate's interpretation of another's life narrative. After all, we cannot, nor should we, set aside all of our disquiet when one person makes life-and-death decisions about another. Some may experience more disquiet with the constructed-judgment method than other methods, since it sanctions more discretion on the part of the surrogates. If my defense of the need for more rather than less discretion is sound, then such readers are really questioning whether the principle of respect for persons should be the preferable ethical justification for surrogates' decision making in this setting. Other readers may accept the primacy of this principle, yet nevertheless question the wisdom of letting one person interpret, and thus dictate, how another person's life narrative should unfold. I would remind these readers to consider the true moral import of dependency. There is simply no escaping the fact that one person will determine the unfolding of another's life. Further, there is no escaping the fact that all life narratives, autobiographical ones as well as biographical ones, always merely suggest, and never decree, their own unfolding. So the play and indeterminateness of a narrative method like the one I am arguing for is inescapable. For those who remain unconvinced of the virtues of the constructed-judgment method, I ask to know what the alternative method is that is grounded, on the one hand, in respect for persons, but that, on the other hand, does not require interpretation and other kinds of discretion by the surrogate.

The foregoing considerations notwithstanding, I do not mean to suggest that we do not need to worry that surrogates will never make poor judgments. What I do mean to suggest is that worries about the frequency of poor judgments can be mitigated when we remember that the method will likely be very familiar, rather than foreign, to surrogates, because the decisions produced by the method frequently will be similar to the kinds of decisions surrogates are already making for those who are dependent on them. We are called upon to judge for others all of the time, and we do not typically require that when we judge *for* another that we judge *as* another would, as required by the presumptive standard of consent. So this proposed method, even though it lacks the illusory "precision" of the presumptive method, is consistent with prevalent social practices in both family life and friendship, wherein we act on behalf of those close to us, especially when their ability to act on their own behalf is compromised.

There are other considerations that support confidence in this narrative method's ability to promote responsible surrogate decision making. First, the value of the narrative method in bioethics is well-established.[26] Second, the constructed-judgment method comports well with a bioethics theme that has been sounded elsewhere, which is that people's moral status, and thus the key to knowing how to assure their respectful treatment, is fully understood only if we account for their familial and other social status as persons.[27] We cannot presume to know how to treat another who is previously well-known to us with respect in our interactions, consensual or nonconsensual, if these interactions are not informed by our understanding of who that individual is, based upon how that individual lived his or her life. This level of understanding, and hence respect, cannot be achieved if the social nature and features of subjects that are contained in and revealed by their narratives are ignored.

Even in light of the preceding discussion, some readers may still ask whether use of the constructed-judgment method would make any substantive difference to the decision making of surrogates when compared with use of the presumptive-judgment method. I think the answer is both yes and no. At one level,

since both methods involve speculation, application of either will provide for a range of possible decisions. Thus, it is reasonable to assume that there may be a broad overlap of decisions arrived at by thinking about "What would Dad do?" versus "What decision would be most characteristic of Dad?"

What, then, is the principal value of the constructed-judgment method? Its value resides in the fact that this method is firmly, rather than merely peripherally, grounded in the principle of respect for persons. While I would not go so far as to say that thinking about "What would Dad do?" could be "wild speculation," it is not *necessary* that it be very disciplined speculation either. Surrogates who speculate about what Dad would do might draw upon his values, past behaviors, and the like, but they also might just engage in guesswork. In contrast, one cannot answer the question about the most *characteristic* course of action without formulating an answer that is grounded in Dad's *character*. Thus, surrogates' decisions that are made with the constructed-judgment method *necessarily* are *disciplined by* and *focused in* the particular life narrative of the person whose fate is at stake. Surely this discipline and focus guarantees respectful treatment of the patient in a way that presumptive judgments do not. And if respect for persons is the ethical principle that provides justification for substituted judgments, then surely the method of applying that principle should be one that assures, rather than merely permits, that surrogates' decisions are in fact grounded in the principle. Thus, the greater ethical soundness that emerges from use of the constructed-judgment method lends greater moral authority to surrogates' decisions than do presumptive judgments.

However, these important benefits cannot be realized unless clinicians and others correctly guide surrogates throughout their decision making, highlighting the need for clinicians to correctly understand the responsibilities of surrogates. I stated earlier that clinicians sometimes guide surrogates in ways that mask rather than acknowledge the need for discretion, when they ask surrogates to decide as they presume the patient would decide. This too-common tendency of clinicians poorly reflects and frames the extensive responsibilities of surrogates. Equally problematic in this regard is the tendency for some clinicians to only get surrogates to answer questions about procedures. They want to know whether to continue a therapy, institute a new one, or the like, and thus ask, "If your father's heart were to stop, do you want us to try to resuscitate him?" or "Should we begin dialysis to treat your father's kidney failure?" Surrogates are asked "What to do?" when in reality, if we want assurance that the morally responsible thing will occur, clinicians need to engage surrogates about "How to be clear about how to decide what to do."

In other words, one cannot appropriately determine what to do if one is not clear about how to decide what to do. It is not ethically adequate to just get an answer to the question, "What should we do?" Surrogates can answer that question in any number of ways, but they have both an ethical and legal responsibility to answer it in the correct, that is, ethically and legally justified, way. It is the role of the various standards of surrogate consent to arrive at justified answers. Only when clinicians are clear with surrogates about *how they should decide* can we have any assurance that answers about what should be done are morally justified. I think I have made clear why people should decide using constructed judgments, rather than presumptive ones, when their responsibility is to make substituted judgments. Even though both methods of applying this standard may produce identical outcomes in many instances, constructed judgments will possess a moral authority and reflect a degree of dignity and respect that presumptive judgments may lack.

CONSTRUCTED-JUDGMENT CONSENT AND RESEARCH

Constructed judgments need not be limited to clinical decision making. They can be just as useful in the research setting, when

surrogates are called upon to decide whether to enroll a dependent person in a research protocol. To show the value of constructed judgments in this setting, I will limit the discussion to considerations of nontherapeutic research, since surrogates' decisions to enroll participants in nontherapeutic research contrasts most from surrogates' clinical treatment decisions. In this context, what constitutes respectful and dignified treatment of these subjects? The constructed-judgment method can shed light on two matters: one is practical and the other more theoretical. I will begin by addressing the practical matter.

It has been documented that surrogates make decisions to enroll persons in research even when the surrogates believe the research participants themselves would not agree to be in the research.[28] Such findings, along with additional findings that report that researchers themselves believe that surrogates require more preparation for their role of proxy decision maker,[29] demonstrate that a practical way to instruct surrogates on how to make surrogate decisions is needed. The regulations that govern research involving human subjects in the U.S. that is federally funded, the "Common Rule,"[30] stipulate only that surrogate consent be obtained in research that involves minimal risk, but they do not stipulate what standard of consent should be used. Some defend the use of the best-interest standard,[31] even though, as I have argued here and elsewhere,[32] the use of that standard permits less than fully respectful care and participation in research, even when the research poses no or minimal risk.

Many recommendations exist, most notably from the National Bioethics Advisory Commission, that call for the use of the substituted-judgment standard by surrogates.[33] If we opt for nondiscretionary interpretations of substituted judgments, we have to recognize that very few surrogates can ethically grant consent to participate in research. People are much less likely to discuss in advance whether they would want to participate in nontherapeutic research once they lose their decision-making ability than they are to discuss which clinical treatment decision they would want in the same circumstances. So few, if any, surrogates would be aware of prior autonomous agreements to enroll in such types of research. Since constructed judgments do permit more discretion to surrogates, it allows the opportunity to enroll more participants, provided that such enrollment constitutes respectful care for and participation by the research participants.

Deciding whether enrollment in research characteristically or uncharacteristically compliments and helps conclude a life narrative can be an accessible and intuitive way for surrogates to exercise their discretion. Surrogates can judge, for instance, that participation in a purely observational study related to palliative care would be uncharacteristic, even though it would pose no risk or inconvenience to the research participant. On the other hand, some surrogates would also recognize that participation in nontherapeutic research that poses significantly more than minimal risk would be characteristic with the participant's life narrative, suggesting that enrollment is the more respectful decision. This brings us to the more theoretical matter.

Should Institutional Review Boards (IRBs) and regulatory bodies permit surrogates to use the constructed-judgment method to consent to research that presents greater-than-minimal risk? Answering this question requires us to determine how best to strike a balance between protecting dependent people from unnecessary harm and permitting them to make appropriate sacrifices in the name of progress, when their surrogates are persuaded that is what respectful treatment condones, at least—if not requires. Knowing how best to strike that balance is contentious; for example, commentators disagree whether adults with dementia—and presumably, by extension, many other adults as well, who are thought to have irretrievably lost their decisional capacity—can be enrolled in nontherapeutic research

that presents more-than-minimal risk, even in the presence of explicit advance consent, such as a research advance directive.[34]

The thrust of my argument thus far would require, out of respect for subjects, that we permit the use of advance explicit consent to enroll in research that presents more-than-minimal risk. The loss of decisional capacity ought not deprive one of the opportunity to engage in altruistic actions when one assumes risk, albeit only with general knowledge, in advance. For example, if we consider a case study that required a bronchoscopy for research, rather than for diagnostic or treatment purposes, I see no good reason why people could not consent to such a procedure in advance, even though, as others have noted,[35] the consent might be granted in the absence of detailed knowledge about the investigative procedures and the kinds of risk they pose. Others disagree because of the vulnerability of the population, and to respect the directive of *The Belmont Report* that we treat vulnerable people with respect by offering them protection.[36] I would argue that advance consent essentially negates their current vulnerability and justifies their enrollment.

If one grants this point for the sake of argument, could a surrogates' decision based upon a constructed judgment, rather than an advance directive, also suffice? On one hand, I see no good reason why it could not. After all, the source of the justification for surrogate enrollment is the degree of comportment with one's life narrative, not the degree of risk. But herein lies a problem, because this manner of justification is at odds with how IRBs assess such questions. Regulations of research categorize research by risks, with different levels of risk triggering different considerations by IRBs and other regulatory bodies. Thus, despite the merits of the criterion of narrative comportment for determining what constitutes respectful participation and treatment of adult research subjects, adoption of such an approach across the categories of research risk does not seem possible, given the regulatory constraints to which IRBs are currently subject.

Consequently, from a practical standpoint, we are left at the point where respect for persons sways us to require non-enrollment in minimal risk research when enrollment does not constitute respectful treatment, even though current regulations would permit enrollment. At the same time, the regulations require non-enrollment in research that presents more-than-minimal risk, even though we know there are times when surrogates are persuaded that such enrollment would, in fact, constitute respectful treatment. We can tolerate this inconsistency when we consider that IRBs and the institutional research they sanction must satisfy obligations to more than just individual research subjects. They must be accountable to their communities, as well as those who sponsor and regulate research. Thus, until such time as the regulations permit more flexibility, it seems that constructed judgments permitting enrollment in nontherapeutic research will have to be limited to research that poses minimal risk.

We need not abide this inconsistency permanently, however. The scope of nontherapeutic research involving adults who lack decisional capacity, to which surrogates can consent, is a topic worth reconsideration for a host of reasons, not least of which are prudent, given demographic trends. If we are satisfied that we know what respect for persons means for this population of research participants, and if we are satisfied we know how surrogates best provide this respect in the research setting, then we will know how best to weigh respect for persons with the principles of beneficence and justice in the research setting.

MISCELLANEOUS MATTERS

There are two remaining substantive matters related to constructed judgments, whose full exploration remain beyond the scope of this essay. First, there surely will be specific

times when we ought not give full decisional authority to a patient's life narrative. For instance, characteristic completion of some narratives may be unjust, because this may require an inappropriate use of resources, while characteristic completion of others may be callous or uncaring, because this may continue hurtful family dynamics. It is not clear that surrogates or healthcare professionals are duty-bound to implicate themselves in such injustice or malfeasance. So we must be clear to recognize the limits of narratives; they do not constitute or replace, in and of themselves, normative deliberation.[37] While reliance on narrative can surely enhance surrogate decision making, and thus clinical decision making,[38] it will not settle substantive debates in bioethics.

The second remaining issue is more anthropological than it is bioethical, as it has to do with whether surrogates can be motivated to use constructed judgment or any other method of substituted judgment. Surrogates may wish to eschew constructing life-and-death judgments for others. Instead, they may feel duty-bound to instruct clinicians to continue treatment to preserve life until and unless they become persuaded that a patient is unavoidably dying. These surrogates would not accept that they are responsible for or complicit in the living and dying of another, clinical realities notwithstanding.

CONCLUSION

I have explored how we show an appropriate degree of respect for persons when their dying is at stake and there is no prior informed-consent or other explicit decisions to guide surrogates in their decision making. I have suggested that the way we treat patients with the degree of respect that is their due is to have surrogates ground and constrain their discretionary judgments by delving deeply into patients' life narratives, so that they do all they can to assure that patients' narratives are completed in a characteristic fashion. Although there is always the risk that this method of surrogate consent, like any, can be misused, the risk is less for constructed judgments than it is for other prevalent approaches. The method seeks to produce surrogates' judgments that grant patients dignity and respect, and that its manner of application is consistent with widely accepted social practices that permit friends and loved ones to exercise discretion and respectfully judge for those who can no longer judge for themselves.

EPILOGUE

We must be careful that the routine occurrence of decisions to withhold and withdraw life-sustaining medications and technologies does not numb us to their moral significance. Not only do such decisions orchestrate[39] the dying of people, but they can also have a lasting impact on those who have the awesome responsibility to make such choices. In the absence of clear directives or statements that give us instructions we know we must follow, how do we know, in a given situation—whether it is a decision to withhold medication for a life-threatening infection or to withdraw mechanical ventilation—if this is an instance when we should try to save a particular life in a particular time? The family and friends who are responsible for making these most intimate of decisions must ground their decisions in something. That something can be, indeed ought to be, the patient's life narrative. Such grounding can generate good—that is, characteristic—decisions for patients and grant assurance to surrogates that they have made right decisions—that is, that they have appropriately acquitted themselves of their responsibilities. We should not expect, nor can we achieve, a more fitting moral residue when we make decisions for others who are near the end of their lives.

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NOTES

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22. A. MacIntyre, *After Virtue* (Notre Dame, Ind.: Notre Dame University Press, 1984), 213-4. MacIntrye describes how life narratives always exist in relation to and are embedded within multiple narratives; see also note 3 above, p. 148, wherein the author states that "our characters come attached to others."

23. See note 15 above, p. 1094b.

24. See note 9 above, p. 125.

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Case and Commentary

Emancipation, Capacity, and the Difference Between Law and Ethics

Evan G. DeRenzo, Philip Panzarella, Steve Selinger, and Jack Schwartz

THE CASE

TE was 16 years old and 29 weeks pregnant when she was admitted to an urban Maryland hospital for fever and back pain. She was admitted to labor and delivery (L&D), where she was diagnosed with pyelonephritis, inflammation of the kidney due to bacterial infection. Within one day of admission, TE's condition worsened, and she developed systemic inflammatory response syndrome (SIRS). She was transferred to the intensive care unit (ICU).

Shortly after transfer, the patient began insisting that she had to leave the hospital because her room was too small and she wanted to take a bath in her mother's hot tub. TE's course in the ICU was characterized by recurrent high fevers (up to 103°F), and at times she was agitated, angry, and incoherent. She received antipyretics and a cooling blanket, along with other treatments. After 72 hours she continued to run a high fever. Because it was suspected that she also had a renal abscess, a sonogram was scheduled.

TE's attending physician and consultants, along with the nursing staff, informed her of the potential risks to herself and to her fetus if she were to leave the hospital in her current state. When she was asked if she cared about her pregnancy, she said she wanted to have a healthy baby, but moments later she would again act as though she would leave, complaining that her room was too small.

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TE had registered late for her obstetrics care and had had only two prenatal visits prior to her hospitalization. The obstetrician (OB) attending her met her for the first time on this admission. TE was not speaking to the father of the baby, who was not involved with her during the pregnancy. She lived with her mother and four siblings. Her mother was with TE during much of the hospitalization and tried unsuccessfully to convince her daughter to stay. The nurses caring for TE related that she was verbally abusive to her mother, and that her mother seemed unable to influence her daughter's behavior. TE's cousin was close to her, and, when present, was able to convince TE to stay. Invariably, however, TE would repeat her intention to leave, and, when agitated, would act in furtherance of her stated intention—for example, she would try to pull out her lines and climb out of her bed.

Late in the evening of TE's third day in the ICU, the risk manager for the hospital was consulted. Because TE was pregnant, the risk manager said that TE was an emancipated minor under Maryland law, and, as such, she had the legal right to make her own decisions, which included leaving the hospital against medical advice (AMA). The risk manager and the hospital attorney advised the treatment team to document that they had explained the risks of leaving the hospital AMA to TE, and then to let her walk out. The treatment team felt moral distress on receiving this advice. They sensed it was unsound, but believed they must follow legal counsel.

ON ROUNDS

The next morning during ICU rounds, which the hospital bioethicist joined weekly, the attending physician and treatment team reported on the advice they received from risk management. The attending made it clear that the consensus on the team was that the advice went against their better judgment and was antithetical to their understanding of their clinical obligations. They admitted, however, to being unsure about how to reconcile their ethical assessment of the case with legal advice.

The bioethicist, the attending, and the treatment team began a lengthy discussion. They first reviewed the basic matter of standards for assessing capacity to make medical decisions, which are the same whether a patient is an emancipated minor or an adult. The bioethicist underscored that upholding the principle of respect for persons included protecting those whose ability to be self-determining is limited. The group discussed the ancient deontological principles of nonmaleficence and beneficence, which obligate caregivers to avoid and prevent harm, and to act in the patient's best interest, respectively. They also covered an abbreviated listing of possible consequences, good and bad, short and long-term, of following this legal advice. They reviewed the various possible mechanisms that were available to hold a patient who is acting in ways that pose imminent harm to herself and/or others, and briefly reviewed the ethical issues related to maternal/fetal conflict. They considered the differences between law and ethics, and agreed that when legal advice is counter to sound ethical analysis, it is appropriate to challenge the legal advice.

THE CONSULT

To that end, they consulted with the hospital ethics committee (called a patient care advisory committee in the State of Maryland). The consultation involved the ICU attending and members of the ICU treatment team, a social worker and a nurse on the ethics committee's consultation subcommittee, the ethics committee chairman, the bioethicist, and the hospital obstetrician/gynecologist who transferred TE to the ICU. It also included representatives from Child Protective Services (CPS), who did not consider TE to be an emancipated minor.

During the ethics consultation meeting, the patient's nurse reported that she had documented that there was a correlation between

the patient's behavior and her temperature. That is, when the patient did not have a fever, she verbalized her intention to leave, but did not make any attempt to act on her intent. It was when TE's temperature exceeded 101°F that she began to pull out her lines and attempted to climb out of bed. This information confirmed the ICU attending's clinical judgment that the patient's decision-making capacity was severely impaired, and all agreed.

TE did not seem to appreciate the potential consequences of her actions in leaving the hospital AMA, nor was she able to reason in a consistent manner about what was in her—or her fetus's—best interest. That there was a pattern that connected the changes in TE's clinical symptoms to fluctuations in her impaired mental function added confidence to the appropriateness of assessing her capacity. The criteria for determining a patient's capacity, which are well-established clinically and ethically, are explicitly incorporated into Maryland law on healthcare decision making.

The group then agreed that simply documenting that they explained the risks of leaving the hospital AMA to TE was not sufficient to meet their ethical obligations for her care. Instead, and only as a last resort, it was agreed that if TE could not be managed so that she stayed willingly through a diagnostic workup and a course of treatment, which would be the standard-of-practice care for any patient in her condition, pregnant or otherwise, then the attending and the consultants would resort to initiating involuntary commitment procedures, and sign certification papers for a 72-hour temporary stay, pending a court hearing.

It was central to the plan of care, however, that this step would be avoided if at all possible. Therefore, the group developed a plan to transfer TE back to L&D, where the rooms are larger and TE would be able to take a bath. The only way to do this safely, however, would be to attach an ICU nurse to TE on a one-to-one basis, with continued care by the consulting intensivist. This unusual utilization of an ICU nurse was considered by all to be a fair use of hospital resources, because there were times (albeit rare) when the OB department provided the ICU with a nurse to assist in monitoring a pregnant patient who was transferred to the ICU. The plan also included marshalling other resources, including asking the cousin with whom TE was most comfortable to spend additional time with her in the hospital. Also, the patient's OB changed her order for PRN [as-needed] acetaminophen to acetaminophen around the clock, to attempt to better manage TE's fever and to maximize her mental status.

TE was transferred to L&D. Her sonogram was negative for an abscess and, over the next two days, she responded to the treatment for infection. Approximately 72 hours after TE's transfer back to L&D, her treatment was successfully concluded and TE was discharged to out-patient follow-up with her obstetrician.

POST-CONSULT FOLLOW-UP

The discrepant interpretations that TE was an emancipated minor by hospital counsel and risk management, and that she was not by Child Protective Services, confused the treatment team and those who participated in the ethics committee consultation. During the consultation, this issue was put aside because it quickly became apparent that TE did not meet reasonable criteria to be deemed a capacitated decision maker, which rendered her legal status as an emancipated minor moot. To sort it out, however, several days after the case concluded, advice was sought from the Maryland State Attorney General's Office. This advice is summarized as follows.

> A minor's legal authority to decide about healthcare issues may be based on either the status of the minor or the nature of the healthcare decision. As to status, a minor is deemed to have the same capacity as an adult to make healthcare decisions if he or she is married or the parent of a child. It is important to note that a minor who gains legal authority on

> this basis is subject to the same exception as an adult; that is, if the attending and a consulting physician determine that the minor is incapable of making an informed decision, decision-making authority passes to a proxy (usually the next of kin).

The Maryland Attorney General's advice also included a consideration of whether TE might have other legal authority to reject treatment for her acute condition. A minor is authorized to consent to treatment (and so, by implication, to decline consent) for a variety of specific health matters, including "treatment for or advice about pregnancy."

This provision, like its counterparts that allow minors to consent to treatment for substance abuse and sexually transmitted diseases, deals with medical conditions that a minor might not wish to be revealed to a parent. A pregnant young woman is thus enabled to seek treatment that is related to the pregnancy without the need for parental consent.

The provision, however, does not emancipate a minor for all healthcare decisions simply because she is pregnant. To be sure, many aspects of the health of a pregnant woman might have an indirect effect on the pregnancy, but the grant of legal authority here is limited to treatment for the pregnancy itself.

Because TE was neither married nor a parent, she was not emancipated for general healthcare decision making, in the view of the Maryland State Attorney General's Office. Moreover, because the treatment initiated in the ICU was for an acute infection that was unrelated to the pregnancy itself, TE did not have legal authority to refuse the treatment under the "treatment for pregnancy" provision of the law.

ANALYSIS

CAPACITY

This case raises important issues about how paying attention to patients' legal rights and law-driven risk assessment can affect morally coherent actions in the clinical care setting. On the surface, this can be read simply as an interesting clinical ethics case in which capacity assessment is the central issue. From this vantage point, whether or not TE was an emancipated minor and the fact that she was pregnant are irrelevant to a determination of what was ethically and clinically optimal care. What comes through most clearly at this first level of analysis is how complicated capacity assessment can be. Although TE showed fluctuations in her mental functioning that were connected to rises and drops in her fever, it took skill and attention on the part of her nurse to connect the two. TE was never overtly delirious. And although TE's fever curves were charted in a way that allowed physicians and nurses to track them hour by hour, the subtleties in her levels of agitation, which swung back and forth from merely verbal to more active, would not necessarily have been charted in a way that would make the connection between her fevers and agitation obvious, across changes of clinical staff over only a few days in an ICU.

Performance of a thorough and refined capacity assessment requires skills that many house staff have not learned. Especially in the ICU, where so many patients are unable to communicate verbally or at all, a physician who is inexperienced in performing refined capacity assessments is likely to make the common error of equating lucidity with capacity. In this case, wanting to leave because the room is too small and because one wants a bath is certainly odd, and, at the very least, a demonstration of immaturity and poor judgment, but it is not the kind of nonsensical talk a physician is able to immediately define as disordered thinking.

Because TE was not floridly psychotic, the house staff did not think that they needed to call psychiatry to have her declared so. Even if psychiatry had been called, a psychiatric evaluation may or may not have assisted, and perhaps could have made matters worse. Although a highly skilled psychiatrist would most probably have determined that, although she was lucid, TE was impaired because she

was suffering from a disassociative disorder, it is just as likely that this degree of diagnostic skill would have been absent. Instead, a psychiatrist, most likely a psychiatric resident, would have determined that TE was not suicidal, psychotic, or depressed, and, therefore, was capable of making her own decisions about leaving AMA. Once that psychiatric consult report form was on the chart, the ability to challenge the consultant's assessment would be greatly diminished.

Medical consults carry substantial weight—as they should. ICU care is markedly enhanced through consultation by infectious disease specialists, cardiologists, and the many other subspecialty experts who are regularly called to assist in the care of ICU patients. The value of a psychiatric consultation for the purpose of assessing a patient's capacity to refuse treatment is more debatable. In this case, it is possible that TE would have met the criteria for a disassociative disorder. If a psychiatrist had evaluated TE when her fever was down and she was functioning at her highest cognitive level, however, she might not have. Also, the standards one applies for determining the ethical validity of a patient's decision making are different from the criteria that a patient must meet to be diagnosed with a psychiatric disorder. *Instituting mechanisms to protect patients from the bad consequences of impaired mental function does not always require that patients be psychiatrically diagnosable.* That point moves this analysis to a key ethical issue.

The assertion just made—that ethical care may require taking actions that protect patients from self-harming decisions, in the absence of frank psychiatric disease—is open to debate. Because the contemporary ordering of the principles of respect for persons and beneficence places such emphasis on the autonomy of patients, clinicians have internalized this notion to mean that whatever patients or surrogates want is what they should get. Throughout medicine today there is a disinclination to probe or to challenge patients' or surrogates' expressions of preference. Although a discussion of the implications of this phenomenon is well beyond the scope of our current analysis, relevant to TE's care, it reduced the level of suspicion among the house staff that what they were interpreting as valid expressions of preference on the part of a decisionally capable patient were, instead, evidence of mental impairment sufficient to require instituting additional patient protections. In fact, during discussion on rounds about what might be done, the residents indicated that the only alternative to letting TE walk out AMA was to keep talking to her to try and persuade her to stay. Equating an expression of a patient's preference with ethically meaningful autonomy is so ingrained in young physicians that temporary involuntary commitment never crossed the residents' minds. This bias towards making ethically valid self-determination synonymous with acceding to whatever patients say is seen, also, in the results of capacity assessments that physicians other than psychiatrists make.

Evaluation of data that one obtains from a thorough capacity assessment is, no matter how well conducted, subjective. The now generally accepted criteria for capacity are the ability to:

1. Express a choice,
2. Understand the information being provided,
3. Appreciate the implications of one's situation and the potential consequences of one's decisions, and
4. Reason in a way that is consistent with one's beliefs about what is in one's own best interest.

These criteria do not give one a neat list of behavioral manifestations to check off, or laboratory values to measure. Words such as "understand," "appreciate," and "reason" are not easily concretized. Thus, the biases of the clinician performing the assessment will influence how the data obtained from the assessment are marshalled and evaluated. Given the context that expressed patients' preferences usually go unchallenged, one can see

how TE's talk of leaving based on room size and the need for a bath were frustrating, but not seen as manifesting decisional impairment.

PREGNANCY

From problems of interpreting TE's mental status, our analysis next moves to the issue of deciding if, and if so what, moral role TE's pregnancy held in this case. Physicians and nurses in an ICU view an infected patient as a patient who needs treatment. But TE was not merely an infected patient. She was an infected pregnant patient. Clinicians treating a pregnant woman really have two patients, the pregnant woman and the fetus. Putting to one side, as beyond the scope of this article, the debate over the ethically appropriate extent of clinicians' obligations to treat an adult female patient who is also pregnant, it is important to note that the emphasis on patients' preferences influences this aspect of the case analysis. Concerning the fetus, we shall simply make the claim that, at a minimum, some moral consideration is owed. In TE's case, the fetus was estimated at 29 weeks and assumed to be viable, increasing by some margin the moral consideration owed to the fetus.

When called about the case, risk management and hospital counsel focused on the patient's pregnancy as giving her legal control over her own decisions. Although one wonders why they, like house staff, missed the issue of capacity, it is possible that the house staff described the patient in such a way as to reduce the possibility of the risk manager's asking a question about TE's mental status. Taking that as a reasonable working hypothesis, it is not surprising that the legal bias was towards autonomy and liberty rights, contemporary principles in medical ethics that have been imported into modern medicine from the law. These autonomy and liberty rights, as society and the courts have tended to view them, privilege the rights of decision making of the woman over any rights that might be owed to a fetus. Again, this issue brings our analysis to a point of heated social debate that far exceeds the boundaries of this case discussion. Nonetheless, given that the position of the treating team is that they had two patients, and the view of the rest of those involved in the consult that the fetus is owed at least some moral consideration, in the face of TE's decisions that seemed beyond what a reasonable person might make, the legal recommendations produced dismay and moral distress. Although some might view the legal recommendations as reasonable legal practice, they were inconsistent with sound medical practice.

LIABILITY

Herein we arrive at the final point of the case analysis, the paralyzing influence the legal recommendation had on the moral imagination of the treating team. Physicians, risk managers, and hospital attorneys are exquisitely aware of the risks of being sued. Whether an action that is brought goes to trial or not, simply being named in a legal action is a terrifying prospect to a physician, and an event that clinicians, risk managers, and hospital attorneys want to avoid at all costs. These costs, however, may be the most serious and important lessons this case has to teach.

Not wanting to get sued is understandable, and there is a sense within medicine today that if one disagrees with a patient or surrogate, the patient or surrogate will become angry and sue. What risk managers, hospital attorneys, and clinicians need to remember is that simply doing what someone asks is not necessarily the path to avoiding lawsuits. *Instead, the best hope for avoiding lawsuits is to practice good medicine.*

Clinicians can be sued for doing something or for not doing something. In the case of TE, forestalling her from acting on a preference that was not ethically or legally valid was the correct path to pursue. In medicine and law alike, an ethically and legally valid autonomous decision must be informed, comprehending, and voluntary. Common sense, as represented by the notion of the reasonable person, regardless of whether one is an eman-

cipated minor or not, dictates that a mentally intact person with a life-threatening infection will want to have it properly treated. When that patient is also a pregnant woman, the reasonable person would be expected to be especially eager to get the infection properly and quickly treated. These common sense responses, which seem to easily meet the law's reasonable person standard, are consistent with clinical intuition and ancient ethical norms of medical conduct.

That the treating team reacted with despondence, rather than indignation, incredulousness, and a willingness to challenge the legal and risk management advice, was deeply disturbing. It indicates a learned helplessness within the medical community and a conceptual confusion on the part of risk managers and hospital attorneys over the fundamental goals of medicine and how to achieve them. This is particularly sad in light of the legal advice given by the Maryland State Attorney General's Office, which allied good legal practice with good medical practice. The advice demonstrates how well-crafted laws, interpreted wisely, support excellence in medicine. Somehow, clinicians, risk managers, and hospital attorneys need to find ways to educate each other about what the goals of medicine are, and to challenge each other when one or another comes to conclusions or makes recommendations that are obviously inconsistent with ethically and clinically optimal patient care.

Practice

Proactive Bioethics Screening: A Prelude to Bioethics Consultation

Leon Morgenstern

The scenario is all too familiar. A fragile octogenarian with advanced dementia and a host of co-morbid conditions is now unresponsive, ventilator dependent, in renal failure, and suffering grade-four decubitus ulcers. Death is expected in the near but undeterminable future. There is no advance directive. Of her remaining kin, her daughter insists that "everything be done"; the time has come to consider tracheostomy and feeding gastrostomy.

The hapless doctor knows that further treatment is futile, but feels he has no choice but to accede to the wishes of the daughter, however much he disagrees. The nurses, immersed in the total care and treatment of the patient, suffer moral distress, not related to the care, but to the futile treatment and diagnostic interventions to which the patient is being subjected. The frustrated social worker shuttles between the usual parade of multiple consultants[1] and the family, whose hopes rise and fall as each organ rallies or falters. The variations on this theme are infinite.

Is there a need for bioethics intervention or screening? Arguably so. Out of recognition of this need grew the proposal for proactive bioethics screening. Our concern was not with the consultation requests that were forthcoming, but with those that were never requested, or were requested too late.

Our premise is that many patients in end-of-life situations are "ethically vulnerable." By "ethically vulnerable," we mean that they are subjected to a surfeit of futile diagnostic and therapeutic measures that very likely would be against the patient's wishes, if choice were possible. Vulnerability imposed by surrogates is often times associated with guilt, fear, religious belief, belief in "miracles," denial, uncertainty, and other miscellaneous motives. At the very least, a full and open discussion of the goals, values, and expressed wishes of the patient is strongly indicated.

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THE SETTING

The Cedars-Sinai Medical Center is an 876-bed tertiary care facility in a large metropolitan area. It is a teaching hospital with more than 245 interns, residents, and fellows; and more than 1,700 physicians. It has a large geriatric population who have diverse ethnic and religious affiliations. Among the most active services are general medicine and surgery, oncology, trauma, organ transplantation, neurosurgery, obstetrics, and neonatal pediatrics. There are 127 critical care unit beds, in medicine, surgery, coronary care, cardio-thoracic surgery, respiratory care, pediatrics, and neonatal intensive care, all providing ample instances of end-of-life situations.

There is an active structured bioethics program, part of which is a 45-member bioethics committee. It was a task force of the latter that drew up the criteria denoting "ethical vulnerability" and the steps to be taken to initiate a proactive screening process.

The following proposal was made to be added to the rules and regulations of the administrative manual of the hospital.

THE SCREENING PROCESS

1. The ethically vulnerable patient is defined as one who fits the following profile and who is being subjected to a number of futile treatments and/or diagnostic procedures without evidence of a discussion about the patient's goals or preferences, and about the burdens and benefits of the plan of care and treatment.
2. Typically, the patient is of advanced age, suffering severe organic dementia, accompanied by one or more of the following conditions:
   - Intensive care unit stay > 15 days
   - Ventilator dependent > 10 days
   - Profound neurologic deficit, for example, Glascow Coma Score < 7 for 7 > days
   - Multiple decubitus ulcers, usually advanced
   - Acute renal failure complicating existing conditions
   - Terminal illness
   - Recurrent aspiration pneumonia
   - Multiple re-admissions to the hospital
   - Intractable pain, typically due to neoplasm
   - Profound paralysis, post-cerebrovascular accident (CVA)
3. Next steps:
   A. In intensive care units (ICUs) and other areas where there are a high incidence of ethically vulnerable patients who meet the listed criteria, nurses, physicians, and social workers will provide a list of potential bioethics patients to the Bioethics Office on a periodic basis.
   B. Bioethics consultants will screen lists provided by patient care centers to determine who might benefit from a proactive bioethics consultation conference.
   C. If a proactive bioethics consultation is felt to be warranted, a bioethics note for the attending physician will be attached to the patient's chart suggesting the advisability of a bioethics consultation conference. This form is *not* part of the official medical record. Preferably, the bioethics conference should take place in a timely way, within the next few days.
   D. The purpose of such a consultation conference with the family, surrogates, and caregivers would be to define goals, discuss outcomes, and weigh the burdens versus the benefits of diagnostic and treatment options.
   E. It is to be emphasized that in no way will care and comfort of any patient be compromised. Religious and cultural factors will be respected. When necessary, the involvement and advice of chaplaincy, legal affairs, and risk management will be sought.
   F. Bioethics consultation conferences

should be of assistance and support to attending staff, families and surrogates, caregivers, and, most importantly, to the patient. For the latter, alleviation of suffering and care, in keeping with the highest ideals of medicine and nursing, will always be the prime motivation of the activity.

4. A note will be attached to the patient's chart suggesting consultation (a sample note is provided in figure 1).
   This proposal was unanimously approved by the Medical Executive Committee of the medical center and was implemented in September 2000.
5. The form used to request a proactive bioethics screening is shown in figure 2.
   The notice shown in figure 3 is e-mailed biweekly to nurse managers of all nursing and critical care units as well as to the social service workers of all units.
   Finally, daily rounds on nursing units and critical care areas, made by the director of the bioethics program and his assistant, provide advice and encouragement to the healthcare team in requesting appropriate screening requests.

Figure 1.
Sample Note to the Attending Physician

This patient has a clinical condition for which a bioethical consultation might be helpful. The purpose of such a consultation would be to facilitate a dialogue with the patient or surrogate and the healthcare team regarding the goals of therapy, the burdens and benefits of such therapy, and the guarding of the best interests of the patient.

No decisions will be rendered nor will any issues be forced. The goal of the consultation is consensus, based on ethical, cultural, medical, and humanistic concerns.

Feel free to call the Bioethics Office at: [number] or fax to: [number].

_____

[Signature] Director, Bioethics Program
Approved: Medical Executive Committee

Figure 2.
Bioethics Proactive Screening Data Sheet

Date: _____
Patient's Information
Name: _____
☐ Mr. ☐ Mrs. ☐ Ms
Age: _____
Location/room: _____
Phone: _____
MRN no.: _____
Date entered hospital: _____
Diagnosis: _____
_____
Referral Information
Who requested consultation?
☐ Attending
☐ Family member
☐ Nurse
☐ Resident
☐ Social worker
Name(s) of requestor(s): _____
_____
Phone: _____
Attending: _____
Phone: _____
Other Dr.: _____
Phone: _____
Social worker: _____
Phone: _____
Subject
_____
_____
Description of Bioethical Concerns
(For Bioethics Office use only) _____
_____
File #: _____
Disposition
_____
_____

RESULTS AND DISCUSSIONS

Since the initiation of the program, there have been 160 requests for proactive bioethics screenings. Each request was investigated by a visit to the patient's bedside, a review of the medical record, and, in most cases, a conversation with the nursing and social service staff. After screening, approximately one-third were deemed unsuitable for a formal consultation, one-third elicited no direct response from the attending physician or a consultation request, and, in the remaining one-third, a formal consultation request was made, resulting in a family-physician conference with bioethics consultants. The numbers of proactive screening requests have been increasing steadily, as have the number of cases that eventuate in full consultations.

One occult factor that is not immediately apparent in the above statistics is the influence exerted by the note suggesting a bioethics consultation. This often initiates a more intense and effective communication between physicians and patients' surrogates, obviating the necessity for bioethics involvement. Also, since a bioethics consultation can be requested by any member of the healthcare team (nurses, social workers, house staff), there have been an increasing number of consultation requests by individuals other than the attending physician. Although it is immensely preferable that the attending physician concur in the necessity for the consultation, requests by other team members are honored. No consultations are held, however, without the knowledge of the attending physician, who is fully informed of the reasons given for the consultation request and the unit staff or group that requested the consultation. Identification of the requestor by unit or service, rather than a specific individual, is done to avoid any unnecessary conflict that might be engendered by the request. As the program has developed and the role of bioethical consults has become better known, instances of animosity or ill-feeling displayed by attending physicians have been negligible.

The major objective of the proactive screening process is to transform the process of requesting bioethical consultation from a completely passive process to one in which the bioethics program is *actively* involved. A component of this objective is to encourage more timely bioethics intervention in cases in which the surrogates are unclear about treatment decisions. When physicians feel obligated to provide questionably indicated treatment, when nurses suffer moral distress in providing such treatment, and, above all, when the "ethically vulnerable" patient suffers needlessly from futile interventions, a bioethics consultation is strongly indicated.

The barriers to timely bioethics consultation are legion. They have been well summarized by Davies and Hudson.[2] Fletcher[3] discussed how more-timely interventions might be facilitated, and DuVal[4] suggested practical steps toward earlier consultation. Often it is only the momentum of treatment that has already been initiated, without consideration of goals and values, that relentlessly drives a treatment plan, without proper thought of the ethical implications. On the part of physicians, it can be a mistaken sense of unwanted intrusion, usurpation of responsibility, or even criticism of their professional ability. On the part of the nurses and other healthcare workers, it may be a fear of retribution for suggest-

Figure 3.
Sample E-Mail Notice

Dr. [name] would like to hear from you regarding possible candidates for proactive bioethics screenings. Please forward to Dr. [name] via e-mail [e-mail address] the names and location of any appropriate patient candidates.

Thank you for your cooperation and participation.

Bioethics Office phone number: [number]

[Signature]

ing ethical intervention. On the part of the family or surrogate, it may be unawareness of the availability of a bioethics consultation or a misunderstanding of its purpose. Some families mistakenly feel that a bioethics consultation is tantamount to a verdict for death over life, or, occasionally, vice versa. Education and increasing experience should lower these barriers on the part of all concerned, if bioethics consultation is provided in a timely and effective manner. The consultation standards issued by the American Society for Bioethics and Humanities provide a valuable guide toward this end.[5]

A study by Dowdy and colleagues suggested process-oriented, proactive ethics consultation for critically and terminally ill patients with extended lengths of stay.[6] It involved a small cohort of patients in the setting of an ICU. In commenting on this study, Schroeter and colleagues emphasized the usefulness of such proactive ethics consultations from the point of view of nurses,[7] and Danis recommended the merits of the proactive approach for more general use.[8] Our program extends and defines a process for encouraging timely bioethics consultation, hospital wide, as a valuable adjunct to decision making for critically ill patients. It is a screening process that is designed to lead to consultations that should be requested, but for various reasons are not.

In summary, this process helps to identify patients who might benefit from a bioethical consultation and outlines the steps leading to such consultations. As of the present, it has been modestly successful in increasing the number of consultations leading to an ethical benefit for the patient, family, and healthcare team. As experience of the positive attributes of this method grows, it should provide a new dimension in encouraging bioethics consultations.

NOTES

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4. G. DuVal et al., "What Triggers Requests for Ethics Consultations?" *Journal of Medical Ethics* 27 (2001): 124-9.

5. Society for Health and Human Values—Society for Bioethics Consultation Task Force on Standards for Bioethics Consultation, *Core Competencies for Health Care Ethics Consultation* (Glenview, Ill.: American Society for Bioethics and Humanities, 1998).

6. M.D. Dowdy, C. Robertson, and J.A. Bander, "A Study of Proactive Ethics Consultation for Critically and Terminally Ill Patients with Extended Lengths of Stay," *Critical Care Medicine* 26, no. 2 (February 1998): 252-9.

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Readability Level of HIPAA Notices of Privacy Practices Used by Physical Rehabilitation Centers

Steven Walfish and Sean P. Sharp

Physiatrists (physicians who specialize in physical medicine and rehabilitation) have an ethical obligation to assure that their patients understand the documents that they sign to assent to treatment. Section 8.08 of the American Medical Association (AMA) *Code of Medical Ethics* addresses this issue directly: "The patient's right of self-decision can be effectively exercised only if the patient possesses enough information to enable an intelligent choice."[1] This may present a problem to the developers of informed-consent documents; 50 percent of the adult population read at or below a ninth-grade reading level.[2] In 2003, Paasche-Orlow and colleagues reported in the *New England Journal of Medicine* that most informed-consent documents were written at a grade level higher than would be understandable to the average American adult.[3]

In April 2003, the federal government implemented the Health Insurance Portability and Accountability Act (HIPAA), which mandates the adoption of privacy protections for individuals' health information.[4] Healthcare providers are required to provide patients with a Notice of Privacy Practices (NPP), a form that explains how providers may use their patients' personal medical information and the patients' rights under HIPAA. Patients are asked to sign, initial, or otherwise acknowledge that they receive this notice. It is similar to signing an informed-consent document, acknowledging and agreeing to accept treatment or to participate in research.

As an extension of previous research on readability of informed-consent documents,[5] the current investigation examines the readability of NPPs that were obtained from physical rehabilitation centers around the United States.

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METHOD

PROCEDURE

NPPs were gathered from independent rehabilitation centers or rehabilitation units within hospitals from each of the 50 states and Washington, D.C. All of the forms were acquired via the internet in July 2003. The documents were rated for ease of reading and comprehension using the Flesch formulas,[6] which are included with Microsoft Word (MSWord).[7] The Flesch Reading Ease formula examines the average length of sentences in a text and the average number of syllables per word to assign the text a number from 0 to 100; a higher score indicates easier reading. MSWord suggests that an easy-to-read document should score within the 60 to 70 point range. A score of below 30 falls into the "very difficult" range. The Flesch-Kincaid Grade Level formula converts a document's Flesch Reading Ease score to a grade-school level; that is, a document with a score of 7.0 would indicate that a seventh-grade student should be able to understand the text. MSWord suggests that a document should have a Flesch-Kincaid score between 7.0 and 8.0; the ceiling for this measure is 12.0.

RESULTS

The reading grade levels and reading ease scores of the NPPs surveyed are presented in table 1. Of the 51 NPPs analyzed, the mean grade level was 11.47. The NPPs of only three states (5.9 percent) fell below the tenth grade level; the two lowest scores had a grade level score of 8.6. The highest grade-level score of 12.0 was achieved by 35 (68.6 percent) of the NPPs surveyed.

The average reading ease score was 37.83 (standard deviation, or S.D., = 8.22). The lowest score was an 18.8. None of the samples yielded a score within the optimal 60 to 70 range. NPPs from three of the states (5.9 percent) scored below 30, in the "very difficult" range. The vast majority (94 percent) fell in the "difficult" range of reading ease.

DISCUSSION

Careproviders have an ethical obligation to assure that patients understand the documents that they are asked to sign to participate in medical treatment or research. In addition to the AMA *Code of Medical Ethics* noted above, the issue of readability is also addressed in the ethical codes of rehabilitation counselors and psychologists, two groups of careproviders who are actively involved as members of treatment teams in rehabilitation centers. The *Code of Ethics for Rehabilitation Counselors* states:

> Rehabilitation counselors shall respect the integrity and protect the welfare of people and groups with whom they work. The primary obligation of rehabilitation counselors is to their clients. . . . Rehabilitation counselors shall serve as advocates for their clients and people with disabilities. . . . Rehabilitation counselors will take steps to ensure that clients understand the implications of diagnosis, the intended use of tests and reports. . . . Clients have the right to expect confidentiality and will be provided with an explanation of its limitations, including disclosures to supervisors and/or treatment team professionals. . . . Rehabilitation counselors will explain the nature and purposes of assessment and the specific use of results in language the client can understand.[8]

Section 3.10 of *The Ethical Principles of Psychologists and Code of Conduct of Psychologists* reads as follows: "When psychologists conduct research or provide assessment, therapy, counseling, or consulting services in person or via electronic transmission or other forms of communication, they obtain the informed consent of the individual or individuals using language that is reasonably understandable to that person."[9] Since 50 percent of the adult population reads below a ninth grade level,[10] the results of the present investigation suggest that each time a patient at a

rehabilitation center is provided with an NPP (which occurs on a daily basis) there is a significant risk of a violation of one (or more) of the ethical codes cited above.

The majority of the NPPs surveyed in this study reached the Flesch-Kincaid Grade Level ceiling of 12.0, which indicates that these informed-consent documents are written at the college level. The mean readability grade level is a low estimate, because this readability measure has a twelfth grade ceiling. The mean grade level for the NPPs surveyed would probably have scored higher using a readability scale that had a higher ceiling.[11] Further, all of the NPPs surveyed fell into the "very difficult" or "difficult" range of reading ease.

It has been suggested that a good informed-consent process leads to better outcomes and avoids potential risks.[12] What is clear is that NPPs do not have to be written at a difficult reading level. In an investigation of informed consent to participate in medical research, it was found that these documents could be written at an eighth grade level or below.[13] In a consultation to a specialty medical clinic, the senior author of this article was able to reduce

Table 1
Readability Levels of NPPs of Rehabilitation Centers

State	Flesch-Kincaid Grade Level Score	Flesch Reading Ease Score	State	Flesch-Kincaid Grade Level Score	Flesch Reading Ease Score
Alabama	12.0	40.0	Nebraska	12.0	42.1
Alaska	12.0	30.5	Nevada	12.0	40.2
Arizona	12.0	36.9	New Hampshire	12.0	33.7
Arkansas	12.0	37.4	New Jersey	12.0	34.9
California	8.6	46.7	New Mexico	11.6	41.6
Colorado	12.0	38.4	New York	11.7	44.0
Connecticut	12.0	38.2	North Carolina	12.0	41.2
Delaware	11.6	43.1	North Dakota	11.6	41.9
Florida	12.0	39.1	Ohio	12.0	42.1
Georgia	11.4	48.0	Oklahoma	12.0	40.1
Hawaii	9.6	42.7	Oregon	11.8	43.7
Idaho	12.0	40.1	Pennsylvania	12.0	37.8
Illinois	12.0	35.2	Rhode Island	12.0	39.0
Indiana	12.0	34.6	South Carolina	8.6	50.0
Iowa	12.0	27.3	South Dakota	11.5	42.0
Kansas	12.0	28.9	Tennessee	11.5	41.9
Kentucky	12.0	32.8	Texas	12.0	18.8
Louisiana	12.0	39.8	Utah	12.0	34.7
Maine	12.0	33.9	Vermont	11.6	34.9
Maryland	12.0	39.8	Virginia	12.0	31.2
Massachusetts	12.0	39.9	Washington	11.0	49.3
Michigan	11.3	45.8	Washington, D.C.	12.0	42.7
Minnesota	10.6	48.4	West Virginia	12.0	38.6
Mississippi	12.0	39.6	Wisconsin	10.6	48.4
Missouri	12.0	42.7	Wyoming	12.0	31.6
Montana	12.0	33.6			

the reading level and increase the reading ease of an NPP without changing its content. Before the consultation with the author, the NPP had a Flesch-Kincaid Grade Level score of 12.0; after the consultation, the grade level score was reduced to 7.2. Similarly, the Flesch Reading Ease score of the original document was 40.7 (in the "difficult" range); after the consultation, this was increased to a score of 66.8 (in the "optimal" range). With an understanding of what makes a document readable, rehabilitation centers may rework their NPPs. In this way, they do not have to risk making repetitive ethical violations, can reduce their liability, and can improve their informed-consent process, which Handelsman suggests could lead to better treatment outcomes.[14]

It is unclear how the NPPs examined in the current investigation were developed. Some may have been written by the rehabilitation centers themselves. More likely they were purchased from a professional organization or private company that emerged to assist facilities to comply with HIPAA requirements. However, it should be pointed out that the burden of ethical practice falls on rehabilitation centers that utilize these documents in their work with patients. For this reason, all rehabilitation centers should consider revising their NPPs to a level that is readable by the majority of their patients.

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NOTES

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4. U.S. Department of Health and Human Services, *Fact sheet: Protecting the Privacy of Patients' Health Information, www.hhs.gov/news/facts/privacy.html,* accessed 26 July 2003.

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8. Commission on Rehabilitation Counselor Certification, Code *of Professional Ethics for Rehabilitation Counselors (2003), http://www.crccertification.com/pdf/code_ethics_2002.pdf,* accessed 26 July 2003.

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10. See note 2 above.

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12. M. Handelsman, "Accurate and Effective Informed Consent," in *The Mental Health Desk Reference,* ed. E.R. Welfel and R.E. Ingersoll (New York: Wiley, 2001), 453-8.

13. See note 3 above.

14. See note 12 above.

Physicians, Medical Ethics, and Capital Punishment

Timothy F. Murphy

In the 1986 decision *Ford v. Wainwright,* the United States Supreme Court held that executions of the mentally disordered violate the Eighth Amendment prohibition against cruel and unusual punishment.[1] In that case, Justice Lewis Powell articulated a standard that prisoners should, at minimum, be able to understand that they are about to die and why. What was not resolved in that case was whether the government could medicate condemned prisoners who became mentally disordered after trial but before their execution. Since receiving a death sentence for a 1979 murder, Charles Laverne Singleton has become delusional and paranoid. In early 2003, the U.S. Court of Appeals for the eighth District ruled that Arkansas can try to bring Singleton out of his disordered state by medications given against his will.[2] In October 2003, the Supreme Court declined to hear an appeal of this ruling. The decision opened the way to the forcible medication of Singleton. At state behest, physicians did exactly that, and, after Singleton's mental state was successfully restored, he was executed in the summer of 2004.[3]

The state's expectation of physicians' assistance in readying psychiatrically disordered convicts for execution is at profound odds with the moral standards that physicians have set for themselves. As a matter of professional ethics, major medical organizations have concluded that physicians should not participate in executions, in general, and should not ready prisoners with mental illnesses for execution, in particular. As matters stand, there is an unnerving dissonance between what many states expect from physicians at criminal executions and what professional codes describe as ethically acceptable conduct.

A moral standard that is routinely ignored invites contempt for both the standard and its author. To avoid this effect, there are several options open to the medical profession. Medicine could ignore the conflict as something eclipsed in importance by other pressing goals. It could also work to bring state statutes into line with the moral standards of the

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profession. Physicians could also simply boycott executions and leave states empty-handed when it comes to carrying out death sentences. Or, in the name of respecting the choice of individual physicians, it could alter its advisories against involvement in criminal executions. Despite the *laissez faire* approach advocated by some commentators, there are morally convincing reasons why physicians should withdraw from executions even if states ask for their help in putting people to death, even if the law continues to define a role for them.

A QUESTION OF MEDICAL ETHICS

Physicians do not hold uniform views about capital punishment. The influential American Medical Association (AMA) *Code of Medical Ethics* concedes, "An individual's opinion on capital punishment is the personal moral decision of the individual."[4] That said, the AMA *Code of Medical Ethics* then goes on to prohibit direct participation by physicians in criminal execution, namely actions that directly contribute to the death of the prisoner or that otherwise assist, supervise, or enable another person to cause the death, as well as actions that "automatically cause" executions to be carried out. Among other things, the AMA *Code of Medical Ethics* specifically excludes prescribing or administering drugs that are part of the execution procedure, monitoring vital signs, rendering technical advice regarding the execution, or otherwise attending or observing the execution as a physician.

By contrast, the AMA *Code of Medical Ethics* does allow *indirect i*nvolvement in criminal execution, such as medical testimony from a physician regarding competence to stand trial, forensic testimony, testimony regarding medical matters relevant to sentencing, and testimony related to legal assessments of competence to be executed. It also permits physicians to certify death, provided someone else has made a prior declaration of death. Physicians may witness executions so long as they do so in a nonprofessional capacity. Physicians may even administer drugs to relieve suffering so long as they do so at the prisoner's specific request and not, for example, at the request of the state to make the prisoner more pliant for execution. The *Code of Medical Ethics* also specifically forbids readying psychiatrically disordered prisoners for execution.

While the AMA has the most fully developed advisory on these matters, it does not stand alone in its opposition to the direct involvement of physicians in execution or readying psychiatrically disordered prisoners for execution. The American Psychiatric Association takes a very similar stand,[5] as do the American College of Physicians,[6] the World Medical Association,[7] and Physicians for Human Rights.[8] Many state medical societies are of the same opinion. In Texas, which carries out more executions than any other state, the Texas Medical Association advises physicians, "A physician may be present at an execution by lethal injection *for the sole purpose of pronouncing death*."[9] (Emphasis added.) In its formally defined standards, medicine has drawn up a uniform and invariant standard against the direct participation of physicians in execution that is neither unclear nor ambiguous. It does not appear that any professional medical group that has considered the matter has ever come to a different conclusion.

PHYSICIANS AND CRIMINAL EXECUTIONS

Despite the monolithic counsel of medical organizations, physicians do participate in executions. Indeed, physicians hold a central role in the history of capital punishment. In the eighteenth century, the French physician Joseph Guillotine devised the decapitation device named after him.[10] Another physician, Antoine Louis, contributed the angled blade that made that iconic device more effective. Physicians oversaw the first electrocutions in the U.S. in 1890.[11] It was a U.S. anesthesiologist who in 1977 formulated the method of lethal injection now in wide use.[12] Regardless of the method involved, physicians are ordinarily not far from executions. Jurisdictions that allow capital punishment some-

times require physicians at the execution. In some states, execution guidelines do not appear to preclude physicians from themselves administering lethal injections.[13]

States that allow capital punishment are not unaware that professional ethics condemn physicians' participation in executions. Some states address this discrepancy not by withdrawing physicians from execution, but by protecting physicians who do participate from any legal or licensing repercussions. For example, some states have adopted statutes that define the administration of lethal substances at executions as behavior that falls outside the realm of medicine. What this means is that the administration of lethal substances is specifically excluded from the medical practices that fall under the review of state medical licensing agencies that are entitled to investigate physicians for violations of professional ethics.[14] Under such statutes, physicians do not have to answer to licensing agencies because of their involvement in executions. Legislatures have put other statutory protections in place as well. In the summer of 2003, Illinois withdrew physicians entirely from execution.[15] Prior to that, however, the state used statutes to keep the names of physicians who were involved in execution confidential and allowed cash payments for their services, to protect their identities. In most jurisdictions, therefore, physicians may participate in execution—even to the point of administering lethal substances—without fear of interference from the state agencies that have been charged to oversee physicians' ethics.

Statutory requirements for physicians' involvement in executions have survived legal challenge. In 1998, a group of California physicians sought to enjoin the state from requiring physicians' participation; they pointed to professional licensing standards that forbid unethical conduct. The penal code in California at the time required three "alienists" to examine inmates who were scheduled for execution and to investigate their mental state. The physicians who brought the suit claimed that examinations of this kind were forbidden as a matter of medical ethics. In *Thorburn v. Department of Corrections*, the California Court of Appeal held that the state legislature did not intend this involvement to open physicians to charges of professional misconduct.[16]

The profound conflict between formally stated medical ideals and the reality of criminal execution is not simply a state of affairs imposed by state legislators on unwitting physicians. Although the matter is not well studied, ethical advisories against physicians' involvement run up against the actual beliefs of physicians who believe there is a place for medicine at executions. After an imposed moratorium on executions, the Supreme Court eventually upheld the legitimacy of capital punishment,[17] and most Americans favor the practice, as do many physicians.[18] It appears that most physicians are unaware of professional advisories against participation in executions.[19] Two companion studies of physicians from all fields showed that only 3 percent of the respondents knew that professional organizations offered any ethical guidelines on the matter.[20] Moreover, a majority of those surveyed actively supported physicians' involvement in capital punishment, and substantial numbers of physicians believe it would be appropriate for a physician to carry out some of the procedures that ethics codes specifically describe as morally objectionable, including the administration of lethal injection.[21]

In short, when it comes to capital punishment in the U.S., physicians help design the means of death, evaluate fitness, sometimes inject lethal substances, and otherwise act as agents of the state in putting prisoners to death. They do so against the wishes of their professional bodies, and their actions are protected as a matter of law. This conflict is too important to leave in a state of permanent contradiction. Moving to resolve this conflict will help promote the values that are important to medicine and to throw light on executions themselves. There is a strong case to be made that a resolution will require physicians to withdraw from any direct role in execution as a matter of professional morality.

THE ETHICS OF PHYSICIANS' INVOLVEMENT IN CRIMINAL EXECUTIONS

Medical ethicist Edmund Pellegrino has said that medical ethics is almost entirely the elaboration of one precept in the Hippocratic Oath: "I will follow that system or regimen which, according to my ability and judgment, I consider for the benefit of my patient and abstain from whatever is deleterious and mischievous."[22] Many of the theological and historical components of the Oath have no place in contemporary moral analysis. No one worships, for example, at the temples of the gods in whose name the oath is sworn, gods such as Apollo, Hygiea, and Panacea. Furthermore, the Oath's categorical prohibition of surgery lacks credibility. Nevertheless, could the Oath be useful in providing guidance about medicine and criminal executions? As philosopher Robert Veatch has observed, there is nothing in the Oath that explicitly rules out physicians' involvement that way.[23] On the one hand, one could say that readying a prisoner for execution and taking part in that execution offer no benefit to the prisoner, insofar as those actions ordain the prisoner to death. On the other hand, it might be plausible to say that physicians' involvement protects prisoners from undue harm and cruelty. As in other matters, the Hippocratic Oath fails as a practical guide on this question, and physicians must look elsewhere when trying to decide the morality of physicians' involvement in execution.

THE CASE AGAINST PHYSICIANS' INVOLVEMENT

Since 1980, the AMA has justified its opposition to physicians' involvement as a matter of preserving life when there was hope of doing so.[24] Critics have not failed to note that physicians are frequently involved in decisions to limit or forgo treatment when patients or their surrogates conclude that additional treatment is without meaningful benefit. In other words, physicians do not act to prolong life under all circumstances. That being the case, shouldn't physicians be free to participate in execution? One commentator put the matter this way: "What is important is not that physicians stave off death, but that they tailor their actions, as much as possible, to the interests of their patients and the realities and necessities of the circumstances."[25] The AMA justification is rightly open to criticism because it is overbroad and idiosyncratic. It is overbroad because prolongation of life is not the goal of all medical interventions, and it is idiosyncratic because this rationale is not used anywhere else in the AMA *Code of Medical Ethics* as a guide to physicians' conduct. If this is all there were to the matter, it would have to be ceded to the critics that the rationale against physicians' participation in criminal executions is unconvincing.

In fact, there are other moral considerations that make a much more convincing case against physicians' involvement. For example, the AMA expresses its position on the responsibilities of physicians to their individual patients this way: "A physician shall, while caring for a patient, regard responsibility to the patient, as paramount."[26] This kind of moral vision—centered on advocacy within a therapeutic relationship—offers a better rationale against physicians' involvement in execution than prolongation of life. Asking a physician to design, supervise, and carry out executions undercuts the therapeutic goal of caring for the well-being of a person. In other words, an essential component of the relationship is abrogated.

Participation in criminal execution also opens up several important questions about whose interests physicians are serving, and at what cost to their own intellectual and moral independence. The matter can be raised as a case of divided loyalty. To whom does the physician ultimately answer, the prisoner or the state? In some cases, there is also reason to worry that physicians are not participating entirely of their own free will. Many physicians who participate in execution do so as employees of departments of corrections. A 1994 report by Human Rights Watch described the job pressure felt by several physi-

cians who played a role in their state's executions.[27] Concerns along these lines raise worries that both prisoners' and physicians' interests both are directed by the state. It is hard to see that a patient's interests can be protected as paramount under these circumstances.

THE CASE FOR PHYSICIANS' INVOLVEMENT

Despite medicine's professional advisories, some commentators believe that criminal execution is more humane when physicians are involved; when they use their skills and expertise to ensure that executions go smoothly.[28] For example, physician and attorney Kenneth Baum argues that physicians should be at executions for the psychological good of the prisoner, specifically because of their medical expertise in dealing with terminally ill patients. In fact, Baum goes so far as to say, "Condemned death row inmates are, for all practical purposes, terminally ill patients, albeit under a nontraditional definition of the term, and deserve to be treated as such."[29]

Physicians' involvement could protect against some of the botched executions that have been reported.[30] What remains unsettled, though, is why a physician's presence is necessary, rather than the involvement of other skilled parties. Surely, executions are not botched because there is imperfect knowledge about what it takes to kill a human being by way of lethal injection, hanging, or electrocution, for that matter? Perhaps the solution to botched executions is not the involvement of physicians, but a greater sharing of knowledge and techniques among state agencies that carry out executions? It should also be noted that prisoners are not terminally ill patients in the sense of having underlying pathological processes that will eventuate in their death. Condemned prisoners face death in consequence of intentional actions undertaken for the explicit purpose of killing them. A physician's actions in the execution process do not diagnose, prognosticate, or treat a prisoner for an underlying pathological disorder. The psychological state of condemned prisoners is important to physicians, but these concerns are fully addressed in medical ethics: physicians may aid and even medicate condemned prisoners so long as they do so at the prisoner's request. Doing so does not require taking on additional roles assigned by the state.

Some critics of existing codes of medical ethics reject the distinction between direct and indirect involvement that defines the boundaries of legitimate medical involvement.[31] These commentators are skeptical that there is a meaningful way to draw this line, and believe it is morally spurious to say that physicians may testify at trials involving the death penalty, but not declare a prisoner dead after a lethal injection. Commentators in this camp note that the participation of physicians at various points in legal proceedings are integral parts of the process that leads to condemnation and execution. Isn't it simply arbitrary to say that physicians may do certain things in this process but not others?

By way of response to this line of criticism, it should be noted that few distinctions fully cleave a subject into wholly separate parts. Nonetheless, it is reasonable to distinguish physicians' involvement in the justice system *prior to* conviction and sentencing from physician involvement *afterward.* During the course of criminal proceedings, physicians aid the state as they diagnose, prognosticate, and testify about medical aspects of a case. However, these activities are part of a process designed to evaluate allegations of wrongdoing, as well as fitness relative to a proposed sentence. The physician's participation with the legal system prior to conviction is not inherently ordained toward conviction or a specific punishment: this participation is part of a *truth-finding process.* Participation in execution has no parallel function: its purpose is enforcement. This difference between truth-finding and enforcement is enough to sustain a meaningful moral distinction between direct and indirect participation in execution. While it is true that some condemned prisoners are spared by unexpected, last-minute reprieves or for other reasons,

physicians who take direct roles in criminal execution are no longer acting as advisors to the court.

When it comes to the views of individual physicians, some commentators note that medical organizations allow physicians to support capital punishment as a matter of individual conscience, but then go on to forbid their actual involvement.[32] What justifies, they wonder, closing off freedom to act on that belief? These commentators want the matter left to individual choice, as is done some with other controversial medical practices.[33] Yet, as a matter of logic, there is no contradiction here: it is one thing to say that individuals are free to believe as they choose about whether states ought to use capital punishment. It is another thing altogether to say that physicians' involvement in this practice betrays certain values important to the profession and—for that reason—no physician should play anything but an indirect direct role.

What about physicians' involvement in other socially controversial practices, such as abortion? Isn't that a precedent that opens the door to physicians acting in accordance with their own consciences, without the need for a uniform standard for all physicians? Despite its nineteenth-century history as a prime mover behind the criminalization of abortion in the U.S.,[34] the AMA *Code of Medical Ethics* now advises that its principles of ethics do not prohibit a physician from performing an abortion under appropriate medical and legal circumstances.[35] Why not treat participation in execution the same way? One key difference between abortion and criminal execution is the question of agency. In abortion, physicians act on behalf of a patient whose deliberated choice is the ultimate justification for the procedure. In criminal execution, by contrast, the physician is acting on behalf of the state, whose judgments do not coincide with the interests of the prisoner. In criminal execution, the physician is enlisted by the state for the purpose of killing a party, about whom the physician may otherwise know nothing—except that he or she will be put to death. These prisoners are not free to terminate this relationship or agree to the physician's involvement, something they are free to do in other healthcare relationships. In execution, the physician must perform to the satisfaction of the state, not to the satisfaction of a patient. This difference in agency is enough to distinguish physicians' involvement in abortion as materially different from involvement in criminal execution; it is enough to call the participation of any physician in these circumstances into moral question.

TREATING PSYCHIATRIC DISORDERS IN ACCUSED AND CONDEMNED PARTIES

The state asks for physicians' help not only at executions proper, but also to ready psychiatrically disordered prisoners for execution. The courts have generally accepted involuntary medical treatment for prisoners and accused parties when important legal considerations are at stake. In 1990, the Supreme Court held that prisons could medicate prisoners against their will in order to protect their well-being and that of others; prison guards, for example.[36] What about treating prisoners so that they may stand trial and undergo execution? In 1992, the Supreme Court held in *Riggins v. Nevada* that the state could not medicate a particular prisoner to make him competent to stand trial.[37] That ruling turned on particular facts of the case, and did not mean that states could never medicate to make accused parties competent to stand trial. In the summer of 2003, the Supreme Court decided a case involving a mentally disordered dentist accused of fraud and money laundering; he believed involuntary medication was part of a conspiracy to kill him.[38] The court held that involuntary treatment is acceptable when that treatment is necessary to achieve an important government goal, when there is reasonable likelihood of its success, and when there is little risk of significant side-effects.[39] This ruling affects not only the accused dentist, but all other similarly situated accused parties. It is a reasonable approach, because medical treatment for psychosis is presumably

in the dentist's best interest, to the extent it enables him to participate in the truth-finding purposes of the court. The case of the accused dentist is, therefore, materially different from the case of Charles Singleton in Arkansas. The question at stake in Singleton's case is whether he ought to be medicated, brought out of mental disorder if possible, only to be walked down the hall and injected with lethal substances. In this case, it is the state that is the primary beneficiary of Singleton's treatment.

The AMA advisory against readying psychiatrically disordered patients for execution does not mean that physicians should never treat death row prisoners. That approach would orphan people who suffer from medical disorders. The AMA is sensitive to the dilemma that may confront some physicians: if a physician treats a prisoner at the state's request, that treatment may in fact hasten the execution of the prisoner, opening the physician to a charge of violation of fiduciary responsibility toward the prisoner as patient. On the other hand, if all physicians decline to treat condemned prisoners, these prisoners may be left in extreme suffering. An internal AMA report described medical responsibility in these cases this way: "If [death row] prisoners lack competence to provide informed consent to treatment, therapeutic interventions, including the use of psychotropic medications, can be provided in accordance with ethical principles and state law. . . . In such instances in which there is extreme suffering, medical intervention, which is intended to mitigate the level of suffering is ethically permissible."[40] In drawing the distinction between the alleviation of suffering and preparing for execution, the report noted, "it will not always be easy to distinguish between these situations, perhaps even to determine when treatment initiated to reduce extreme suffering should be stopped. While even brief treatment of a severe psychotic disorder may have the unintended effect of restoring the prisoner's competence for execution, there is no alternative at this time than to rely upon the treating physician to exercise judgment in deciding when and to what extent treatment is necessary to reduce suffering."[41]

It will certainly be difficult to negotiate this finely drawn line—between treatment to reduce suffering and treatment to prepare for execution—in all cases. To protect physicians from crossing this line, however, the AMA and other professional groups recommend that states commute the sentences of condemned prisoners who have disabling psychiatric disorders. In this way, physicians would be able to treat prisoners without worrying that they are—through that very treatment—readying their imprisoned patients for execution. Medical organizations have concluded that commutation is desirable because it serves a balancing function between conflicting interests: the government's interest in enforcing the law and medicine's interest in avoiding any direct role in causing death. The State of Maryland has, in fact, chosen this approach: it requires the commutation of capital sentences when prisoners are not competent—despite treatment—to understand that they are to be executed and understand why.[42]

COMPLICITY IN INJUSTICE AND ERROR

In early 2003, Illinois brought capital punishment in the U.S. under international scrutiny when its former governor, George Ryan, pardoned four inmates on death row and commuted the death sentences of 164 others to life imprisonment. Ryan said the justice system was "broken," both in the way capital sentences were levied and prosecuted. This assessment was not original, but the governor's sweeping actions were without precedent in U.S. history. Whether owing to prosecutorial bias or malfeasance, substandard legal representation, or misjudgments by juries and judges, the justice system is vulnerable to the conviction and execution of innocent parties. According to one prisoner advocacy organization, more than 100 people have been sentenced to death in the U.S. but cleared afterward.[43]

As matters stand, physicians' involvement in executions occurs without any independent

evaluation by the medical profession that individual capital sentences are justified. Withdrawing from roles in execution spares medicine from any complicity in misjudgments and malfeasance that take innocent human life. Many Americans—physicians among them—seem to accept the assumption that the state's prosecutions and executions adequately express a consistent and equitably applied standard of justice. Attorney and author Scott Turow, who served on a 2002 Illinois commission charged to review capital punishment, has rightly questioned this assumption. He points out that several factors lead to wrongful convictions: extreme and repellent crimes, social pressure to execute, the jury selection process, expansive standards of eligibility for death, and a general shift of the burden of proof from the state in proving guilt to the defendants to prove their innocence.[44]

A number of variables affect how prosecutions go forward and how sentences are imposed, and this includes the race and gender of the victim (some crimes are punished more vehemently than others) as well as the location of the murder (some jurisdictions are more prone to use capital punishment than others). As Turow notes, these variables call into question the notion that capital punishment expresses a uniform or broadly shared morality, as opposed to a system that is open to prejudices and preconceptions.[45] Even people who are tried for the same crime can meet with different outcomes. In 1999, Illinois freed Anthony Porter after a wrongful conviction for multiple murders; at one point, he was just two days away from execution. The man who was eventually convicted for these murders was sentenced only to 37 years of imprisonment. The troubling lack of uniformity in sentencing outcomes could hardly be starker than this difference between death and life.

All social systems are imperfect, of course, so it is reasonable to wonder whether mistakes in capital punishment are more grievous than those tolerated elsewhere, such as deaths due to plane or automobile travel, for example. Capital punishment is a social judgment that people's lives—not some portion, not some part, but life itself—ought to be forfeited because no other social reaction is commensurate to their crimes. Making a mistake, taking an innocent party's life, is therefore unlike any other kind of error: participation in this kind of error trivializes our deepest moral expressions. Yet physicians' participation in executions at present goes forward without any independent assessment from medicine that execution is merited as a matter of justice or deserved by the individual prisoner in question.

The question of complicity with a flawed system of criminal executions is not, of course, a question for physicians alone. It is a question for every citizen of states that allow capital punishment. But the importance of the question increases in moral gravity for those who play a significant role in criminal execution: prosecutors, judges, defense attorneys, even wardens and prisoner guards. People in these groups have pressing reasons to consider the integrity of their work in relationship to a system's flaws that end in the execution of the innocent and the collapse of the state's integrity. It is especially incumbent upon physicians to consider their involvement with a flawed criminal execution system, because doing otherwise compromises their own deliberated ideals of professional responsibility to patients and the improvement of society.

For many commentators it is an open question whether error, prejudice, and malfeasance can be rooted out of the system of capital punishment. Doubts about equity in capital punishment have been given eloquent expression by the U.S. Supreme Court Chief Justice Harry Blackmun, who famously wrote in his 1994 dissent to the majority opinion of *Callins v. James,* "From this day forward, I will no longer tinker with the machinery of Death," and, "The basic question—does the system accurately and consistently determine which defendants 'deserve' to die—cannot be answered in the affirmative."[46] The question worth raising is, are individual physicians willing to continue their participation in executions as though they did not know whether an indi-

vidual prisoner was sentenced to death fairly and equitably; as though they did not know whether their participation amounts to moral complicity with a miscarriage of justice?

In calling for physicians at executions, Baum has argued, "Physicians also participate in executions to assist society in ensuring that individuals are treated fairly and that some degree of humaneness may potentially be added to the process."[47] In his view, the presence of physicians sends a signal to the public that people are not subjected to barbaric treatment as they are put to death. However, this argument fails to note that the presence of physicians also extends to execution some degree of integrity that the public attaches to medicine. The presence of physicians at execution could wrongly signal to the public that all is well with a system that is, in fact, open to mistakes and malfeasance. If the state wants to kill people, the state should take the responsibility for execution and not ask physicians to loan the halo effect of medicine—such as it is—to a process that is not only flawed, but apparently willing to hide its own mistakes.

TOWARD A MORE CONSISTENT MEDICAL ETHICS

The ethical advisories of major medical organizations present a unified front against physicians' direct involvement in criminal execution. This consensus is undercut by states that require physicians in key roles at execution and offer them cash, confidentiality, and professional immunity in return. Physicians themselves also undercut this consensus when they prepare, assist, monitor, and carry out execution.

Some critics have said that medical organizations should not use their advisories to advance a political agenda against the death penalty.[48] But resistance to the involvement of physicians in execution is primarily an ethical consideration, one rooted in a moral vision of what is important to the ethics of healthcare. Medical organizations have concluded that it is inconsistent to involve physicians in criminal execution, and, at the same time, expect them to act with compassion, respect, and in the best interests of their patients. As it is, some physicians behave as if medical groups had concluded nothing about capital punishment. If professional organizations genuinely believe that physicians' involvement is unethical, it certainly falls to them to communicate that message across their membership. It also falls to them to make the case plainly and persuasively to all physicians, not just to those who object to capital punishment in general.

There is a stark choice at hand for U.S. physicians: whether to participate in executions or whether to work to undo laws that give them a role in the death penalty. Even if changes in the law are not forthcoming, physicians should withdraw from criminal execution to protect their ability to serve as advocates for people under their care, to protect the independence of their judgments, and to avoid complicity with misjudgment and error. There is, otherwise, a glaring contradiction between the lofty ideals of the profession and the gritty reality that physicians are not far from most executions in the U.S. Given misjudgments made in the course of prosecution, trial, and sentencing, it is hard to avoid the conclusion that the community would be better served if medicine threw its critical intellect to questions of equity in the death penalty rather than fine-tuning individual executions. In any case, reinvigorating debates about medicine's role in execution would go a long way toward shoring up professional standards and helping rethink how prisoners are put to death in this country—and with whose help.

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Organizational Ethics

Saying "Good-Bye": Ethical Issues in the Stewardship of Bed Spaces

Katrina A. Bramstedt and Paul L. Schneider

INTRODUCTION

The phrase "scarce medical resources" applies to personnel (for example, nurses), as well as healthcare funding, certain types of medical services (for example, organ transplantation), and even hospital bed space. While there are approximately 980,000 hospital beds in the United States,[1] hospitals can be at or near full capacity even in times lacking war, epidemic, or natural disaster. With the yearly total of hospital admissions rising[2] and hospital bed space capacity falling,[3] the dilemma of stable patients who refuse to be discharged must be addressed. While the national incidence of patients who refuse to be discharged is likely small, we have found that their effect on hospital medical staff and administration is large.

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CASE REPORT

Both authors worked jointly on an ethics consultation request that was solicited by the Geriatrics Service of the Veterans Administration (VA) Greater Los Angeles Healthcare System (West Los Angeles VA Medical Center), with regard to a 79-year-old female patient who refused to be discharged from the hospital. She had been admitted to the hospital due to chronic, severe hip pain. The patient had been experiencing gradually increasing bilateral hip pain, to the point that it prevented her from ambulating and caused her to have to leave her own apartment and move in with her brother for assistance with activities of daily living. She was seen in our Rheumatology Clinic five days prior to admission and was given bilateral trochanteric bursae injections to relieve hip inflammation and pain. On the day of admission, she was seen in the Geriatrics Clinic, where she complained that she had received no relief from the injections and demanded that she be admitted to the hos-

pital. There was some question about stress she was causing her caregiver as well. Even though the patient appeared clinically stable, she was admitted to the Geriatrics Unit to address her hip pain and to provide rehabilitation, aiming toward future placement in a suitable assisted-living facility.

The patient had a long history of psychiatric disease that included severe depression since the 1950s (requiring electroconvulsive therapy in 1996); mixed personality disorder with borderline, dependent, and passive-aggressive features; and memory problems. The patient was widowed and had three grown children from whom she was estranged; however, she had remained close to her brother. Her past medical history was significant for lumbar degenerative disk disease with spinal stenosis, lumbar radiculopathy, gout, hypertension, osteoporosis, coronary artery disease, diverticulosis, colonic polyps, history of hysterectomy, and history of splenectomy.

During her hospital stay, the patient had extensive consultation with psychiatry for evaluation and treatment of depression. Her hip pain was evaluated with MRI (magnetic resonance imaging), demonstrating mild degenerative joint disease of the lumbar spine and hips. The patient refused treatment with NSAIDs (nonsteroidal anti-inflammatory drugs) because she had experienced gastritis when taking them in the past. Physicians tried to convince her to accept other medications, such as H2-blockers and/or proton-pump inhibitors, which would protect her stomach lining from NSAID-induced damage, but she refused to try them. She also refused to try tramadol, which had been recommended by the consulting rheumatologist. Extensive efforts were made by various individuals to convince her to try physical therapy, but she consistently refused this, saying she was in too much pain to participate. Psychiatry felt she possessed decision-making capacity to refuse these treatments. She got repeat injections into her trochanteric bursae, as well as neurontin, which provided some eventual relief. The patient also had a gouty flare in her left wrist during the hospitalization which was treated with colchicine effectively. Memory loss was noted at different times during the hospitalization, although her formal memory testing was normal. Vitamin B12 and TSH (thyrotropin) levels were checked, and both returned as normal. She was placed on vitamin E.

A date for discharge was set at hospital day #22, but the patient refused. A meeting was held with the patient and her brother, at which both refused any options for discharge and out-patient treatment. Both insisted on continued in-patient treatment until the painful condition was "completely gone," even though it was explained to them that this might take many weeks more. Specifically, she refused to go to her own home because of steps in the entry way, and her brother refused to have her return to his home because of his ill health. She also refused placement in a community nursing home or board and care facility because she did not want to share any of the cost.

Bioethics was consulted on hospital day #32 regarding the patient's refusal to accept treatment and to be discharged. She was lucid and possessed decision-making capacity regarding her own placement. We recommended that she be discharged from the hospital without further delay. On hospital day #44, after consultation with hospital officials, she was finally discharged to a community nursing home and, immediately upon arriving there, took a cab to her own home, where she remained.

DISCUSSION

Ethical stewardship of resources requires that there be prudent exercises of evaluation, application, and withdrawal of medical resources.[4] In general, the bioethics literature has focused on stewardship from the standpoint of rare technologies (for example, organ transplantation) and costly technologies (for example, expensive medications, expensive medical devices). While hospital bed spaces are not rare in North America (and some other

continents), bed space capacity can be considered as finite within each facility, and bed space occupancy can often be at or near 100 percent. Bed spaces can also be considered expensive, with daily, semiprivate, per diem charges in the acute care hospitals in the U.S. ranging from $700 to $1,000.[5]

We argue that stewardship of bed space precludes the premature discharge of patients; that is, the discharge of patients who are neither mentally nor physically stable, but also it precludes permitting patients to stay beyond their clinically appropriate discharge date (unless an appropriate discharge destination is unavailable). Two cases from legal literature exemplify this, namely, *Muse v. Charter Hospital*[6] and *Wickline v. California*.[7] In the first case, a teenager who had been hospitalized for 32 days (two days in excess of his insurance coverage) for treatment of depression and suicidal tendencies committed suicide two weeks after home discharge. The jury found that while the hospital had no written policy requiring doctors to discharge patients when funds expire, the hospital did have practices that encouraged doctors to do so. The jury awarded the patient's parents $7 million.

In *Wickline v. California,* a patient with Medi-Cal insurance (also known as California Medicaid, a federal and state tax-supported program for children and adults with low income and resources) was hospitalized for an obstruction of the terminal aorta in her leg. Medi-Cal authorized surgery and 14 days of hospitalization, but the doctor had requested 18 days. The patient was discharged on day 14, suffered complications, and eventually had to have her leg partially amputated. The court indicated that if it was in the patient's best interest to be hospitalized for 18 days, the doctor should have made some effort to keep her there. Further, the court indicated that Medi-Cal was not a party to the medical decision to discharge the patient, and thus could not be held liable for harm resulting from a negligently made medical decision. Both cases evidence that physicians retain ultimate responsibility for care, *even in the face of a lack of reimbursement.* Further support of this notion comes from the American Medical Association (AMA) which argues that physicians may not discontinue treatment of a patient, as long as further treatment is medically necessary, without giving the patient "reasonable assistance and sufficient opportunity" to make alternative arrangements for care.[8] Also, once having undertaken a case, a physician should not neglect the patient.[9]

In the case we presented, our patient was mentally and physically stable for discharge; however, she refused to leave the hospital. Her adamant refusal to vacate the hospital was frustrating for the medical staff as well as for hospital administration. The case consumed a considerable amount of personnel time and wasted medical resources, in that the care provided to this patient was done so in a setting that was not appropriate, based on her needs. This diverted resources from patients whose needs were a better match with our facilities. The Veterans Administration, as well as other healthcare systems, does recognize the fact that specialty geriatric in-patient programs may actually operate as a hybrid of acute and subacute care. That is to say, because of the complexity of caring for the elderly, a somewhat slower pace, as well as a multidisciplinary approach with some aspects of rehabilitative care, are justified to improve patients' quality of life, at the expense of prolonging length of stay.[10] Needless to say, even when these principles are accepted, stewardship of bed space and medical resources remains an important driving factor in the hospital environment.

In addition to our case, we identified two cases in the legal literature regarding stable patients who refused discharge. In the first case, *Jersey City Medical Center v. Lillian and Richard Halstead,*[11] the patient (Lillian Halstead) was hospitalized for five months for treatment of a "cardiovascular condition," after which time the hospital determined that the patient could be adequately cared for in a nursing home. Six more months elapsed, and the patient was still at the hospital, with nei-

ther the patient nor her son (durable power of attorney for healthcare) having done anything to effectuate a transition out of the hospital. The hospital petitioned the court and was granted an injunction requiring the patient's removal on the grounds that she was trespassing.

In the second case, *Wyckoff Heights Medical Center v. Luis Rodriguez*,[12] a diabetic, quadriplegic (Luis Rodriguez) was deemed stable following 10 days of hospitalization. A discharge plan was created that denoted transfer to a nursing home because the patient was not eligible for home nursing care, due to his past history of physical abuse of nurses. In fact, only one nursing home agreed to accept the patient for transfer; however, the patient refused transfer, indicating he did not approve of the facility. The hospital petitioned the court and was granted an injunction ordering the patient to leave the hospital on the grounds that his continued presence was an "abuse." Further, the court indicated that the fact that the patient did not approve of the nursing home was "immaterial."

The University of California, Los Angeles (UCLA) Medical Center has reported five cases of "involuntary discharge."[13] In their experience of dealing with difficult patients, they have created a Patient Care Management Issues (PCMI) team who deals with 19 categories of patients, including those who disobey hospital rules (for example, smoking on the ward) and those who refuse discharge. All hospital staff receives training on how the PCMI team can help them deal with difficult patients. As with most institutions, involuntary discharge is seen as a last resort and is preceded by a warning letter to the patient. UCLA reports no adverse (litigious) consequences of these forced discharges.

Table 1
Discharge Planning Guidance

1. The patient *must* be stable for discharge.
2. The decision for discharge *must* be based on medical, not financial considerations.
3. Encourage the patient (or surrogate) to participate in discharge planning.
4. Give the patient (or surrogate) written notice of the intent to discharge.
5. Allow for an appeal of the discharge determination.
6. Involve Social Work, Pastoral Care, Legal Counsel, Ombudsman, and the Ethics Committee/hospital ethicist as necessary.

Hospitals have a moral duty to reserve bed spaces for persons who actually need medical care in a hospital setting. Failure to appropriately discharge patients causes the potential for serious prejudice to patients who actually require hospital care. That said, hospitals have a duty to the public to remove patients who no longer need treatment. Table 1 presents guidelines for discharge planning. Some hospitals have even incorporated bed space stewardship into their corporate Code of Ethics.[14] If surrogate decision makers are confounding the discharge process and their decision-making capacity is suspect, it is appropriate to consider appointment of a new decision maker so as to effectuate a discharge plan. Guidance for this process is discussed elsewhere.[15]

We acknowledge that removing patients who refuse to be discharged can be potentially problematic for hospitals, from the standpoint of media relations. Patients who are "unhappy" for a variety of reasons sometimes use the media (for example, newspapers, television) to intimidate hospitals into catering to their demands. Additionally, court orders and litigation do have a "yuck factor." Thus, in an effort to avoid "bad press," hospitals often succumb to these patients' demands, or they transfer them to other facilities that can meet their "needs." No hospital wants to be viewed as kicking a 79-year-old female patient "to the curb," yet, for the reasons discussed, in these situations, there should be a balance between hospitals as "medical Marriotts" and as treatment centers. We agree with the American

College of Emergency Physicians' stewardship perspective, that ". . . physicians must keep the patient's interest as a primary concern while recognizing that inappropriate, marginally beneficial and futile care is not morally required."[16]

In the case of patients who are unruly or noncompliant, yet are in need of medical care, there is effectively no treatment alliance between the medical team and the patient, thus attempts to optimally treat the patient are confounded.[17] In these situations, the best option often is to transfer such patients to other hospitals where a treatment alliance can be established, since the creation of a treatment alliance can be a first step toward ethical stewardship of medical resources.

CONCLUSION

Hospitals have a duty not to permit their facilities to be diverted to uses for which they are not intended (for example, hotels, nursing homes). Likewise, physicians and hospitals should not be held captive by patients. Whether the need is to discharge hospital patients or to move them to lower intensity of care settings within the hospital, medical staff must not allow patients to abuse the system that takes care of them, as this diverts material and human resources from patients who need it most. While evicting patients from the hospital may be emotionally taxing for staff and administrators, failure to do so results in poor stewardship of resources and is a disservice to the community the hospital serves.

ACKNOWLEDGMENT

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Comment

A Response to Shalowitz and Emanuel

Gerrit Kimsma, Keith L. Obstein, and Tod Chambers

As the authors of "Practicing Euthanasia: The Perspective of Physicians" in the Fall 2004 issue of *The Journal of Clinical Ethics*,[1] we would like to respond to some of the criticisms raised by David Shalowitz and Ezekiel Emanuel in "Euthanasia and Physician-Assisted Suicide: Implications for Physicians," published in the same issue of *JCE*.[2] We must respond to prevent misunderstandings and incorrect interpretations of our data.

1. Shalowitz and Emanuel write, "The limited available data indicate that physicians are deeply ambivalent about participating in euthanasia and PAS" (p. 233). This implies that ambivalence is, in itself, not a positive trait, a self-evident indication of the immoral nature of euthanasia or physician-assisted suicide (PAS). While we do not think that ambivalence is always desirable, we do believe, in this case, that one may conclude that it is a positive attribute. Without this ambivalence, it could be argued, there really would be cause to worry; it would be an indication of emotional callousness. Even for physicians who believe that euthanasia or PAS can be a morally appropriate action, such ambivalence may indicate that they recognize the emotional complexity of carrying out such an action.

2. "This absence of regret may reveal either of two things: (1) the physicians carefully considered their actions . . . or (2) they had and still have doubts about their actions, but try to avoid facing those doubts by affirming that their actions were right. Despite expressing confidence in their decisions, a large proportion of physicians report that participation

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in euthanasia or PAS significantly affects their personal and professional lives" (p. 233). In this statement, Shalowitz and Emanuel suggest that there may be some sort of mass cognitive dissonance. It again appears that admitting ambivalence and having such actions affect their lives seems philosophically problematic for Shalowitz and Emanuel. While we have a range of opinions on euthanasia and PAS, we do not think that the fact that such actions may have an emotional impact on these physicians necessarily means that their actions cannot be justified.

3. "Other Dutch physicians have stated that their attention to cases of euthanasia results in less time and energy for their family and friends. American physicians additionally cite effects of performing euthanasia and PAS on their professional practices" (p. 233). In this statement, Shalowitz and Emanuel make a serious error in comparing the practice of euthanasia and PAS in the Netherlands with the United States, for it is only in the Netherlands and in the state of Oregon that euthanasia and PAS can be practiced openly.

4. "Many physicians are also concerned by the possibility of euthanasia becoming more common in medical practice. . . . Data collected in both the United States and the Netherlands have highlighted a troubling failure of physicians to adhere to proposed safeguards regarding the practices of PAS and euthanasia. . . . patients did not confirm their requests for the intervention . . . did not participate in the decision at all. . . . Increased requests . . . or a greater willingness to act . . . could, therefore, potentially increase the frequency with which patients' autonomy in end-of-life decisions is violated" (p. 233). Shalowitz and Emanuel's statements suggest that they are not clear as to their own objections. First, physicians who feel ambivalent about euthanasia and PAS fear an increase in requests and have reservations. Second, they insinuate that such reservations are unfounded, for, apparently, according to Shalowitz and Emanuel, patients' lives are usually ended without confirmed requests or without a request at all, violating their autonomy. Third, increased requests, with a greater willingness to act, would increase violation of patients' autonomy.

Shalowitz and Emanuel should take a stand. Either the reservations of physicians are authentic, giving rise to prudential practice, or their reservations are untrue because of the increased cases without confirmed requests or requests at all—a serious claim without substantiation—which, in turn, leads to increases in violations of the law. This may be the case in all but one of the states in the U.S., where no case of euthanasia and PAS can be officially reported, but, in the Netherlands, there has been a steady increase in the reporting of these interventions. Furthermore, even though concerns in the possibility of an increase in future requests may exist, it does not necessarily lead one to conclude that this leads to more violations of autonomy.

5. Shalowitz and Emanuel suggest ". . . the standard for euthanasia is effectively that of the most permissive physician—this visibility of this effect will increase as requests for PAS or euthanasia do" (p. 234). To substantiate this statement, Shalowitz and Emanuel cite a recent book by Raphael Cohen-Almagor, in which it is suggested that patients tend to choose their physicians on the basis of a willingness to perform euthanasia and PAS, and that physicians may face economic pressures as a result.[3]

Cohen-Almagor's conclusion was based on a limited number of interviews. As he was one of those that Cohen-Almagor interviewed, Kimsma has followed his study quite closely, from the interviews to the publication of this book. Kimsma's experiences are entirely different than those reported by Cohen-Almagor, and he feels that his experiences are representative of those of his colleagues, Dutch family physicians.

It may be surprising to those in the U.S. how few people in the Netherlands actually

discuss euthanasia and PAS with their physicians. Even fewer hand their physicians a written request prior to an actual terminal disease. Further, the issue is not problematic because 88 percent of Dutch physicians are willing to engage in euthanasia and PAS. In fact, patients in the Netherlands who have long-term relationships with their physicians—an exception in the U.S. rather than the rule—hardly ever change their physician based on a physician's willingness to actively end a life. As a member of a Regional Euthanasia Evaluation Committee, Kimsma sometimes, but rarely, sees a change of physician in a terminal situation where the previous physician has refused euthanasia or PAS. If this rare change does take place, all due respect is given to all participants.

In the final part of their response, Shalowitz and Emanuel admit their opposition to euthanasia and PAS. We feel that their opposition affected their reading of the data of our study. We, the authors of the study, differ significantly in our position toward euthanasia and PAS, but we concur with Shalowitz and Emanuel that euthanasia and PAS are no substitutes for quality end-of-life care. This study is a descriptive study of the practice of euthanasia and PAS, and we do not think that it itself provides justification for or evidence against these practices.

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NOTES

1. J.L. Smith, R.M. Miller, Jr., and W.C. Callahan, "Tracking the Virus in Africa: The Etiology of AIDS," Journal of AIDS Epidemiology 124, no. 6 (June 2003): 1147-59.

2. L. Greene and W.K. Nelson, "The Ethics of Care," in Principles of Nursing Science, vol. 2, ed. W.K. Nelson (Plano, Tex.: Nursing Administration Press, 2002): 122-4; T.M. McCall et al., "Cost-Effectiveness v. Total Patient Care: Who Wins?" Health Care Administration Quarterly 6, no. 2 (Summer 2002): 150-6.

3. See note 1 above, pp. 1147-8.

4. Ibid., 1149.

5. Greene and Nelson, "The Ethics of Care," see note 2 above.