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# At the Bedside

# The Best Place for Bare-Knuckled Ethics

Edmund G. Howe

### **ABSTRACT**

In the documentary *Boston Med*, patients, their family members, and their careproviders agree to be filmed in real medical situations. Why would they do this? The possible answers to this question may help us to make sense of the paradoxical results of a recent study, in which patients with terminal illness ranked their careproviders highly for communication, even though the patients had failed to learn that they had a fatal illness.

Based on this analysis, I offer careproviders a practical approach they can use to improve communication with patients, particularly to help patients to feel less alone. This same approach can also be applied in bioethics consultation.

In this issue of *The Journal of Clinical Ethics* (*JCE*), several authors discuss the ethics of filming patients and careproviders in real-life medical situations for a TV documentary, *Boston Med*.<sup>1</sup> The documentary filmed patients who

**Edmund G. Howe, MD, JD,** is Professor of Psychiatry and Director of Programs in Medical Ethics at the Uniformed Services University of the Health Sciences in Bethesda, Maryland; and Editor in Chief of *The Journal of Clinical Ethics*. ©2013 by *The Journal of Clinical Ethics*. All rights reserved.

were dying. Should the privacy of these patients have been especially protected? For example, hospitals could paternalistically prohibit such filming, even when patients, family members, and careproviders had agreed to participate.<sup>2</sup> On the other hand, such filming may have been warranted, not only for the reasons these authors give—such as providing additional information to the public—but for other reasons.

The recording and sharing of such deeply moving and private events is something new. A similar situation is that of a woman who lived with people who are the worst-off in India, so she could later publish her experiences, some of which are shocking. For example, she saw a 15-year-old boy who was working, stuffing plastic into a shredder, whose hand was "cut clean off." She writes, "The boy's eyes . . . filled with tears but he didn't scream. . . . Instead he stood there with his blood-spouting stump . . . apologizing to the owner of the plant. "'Sa'ab, I'm sorry,' he'd said to the man . . . 'I won't cause you any problems by reporting this. You will have no trouble from me.' "3

Such accounts raise a far deeper question than whether such events should be recorded and shared. Depicting events of this power speaks to the question of who, at our core, we really *are*. If we assume, in the case of *Boston Med*, that we have a great deal in common with the patients and careproviders who agreed to be filmed, we might wonder: Why did they agree to participate? Are they missing some sensibility regarding privacy that most of us have, or are they in touch with something that most of us don't experience? (I use the words we and us intentionally, as a way to encourage readers to ask themselves how they would feel about participating in a documentary, and to identify which group—those who would agree to be filmed, or those who would not—they would be in.) As I go on to discuss why these patients and careproviders might have agreed to be filmed—consciously or for reasons unknown to them (unconsciously)—readers may gain some insight into their own values.

There is another reason that I will consider why people may have agreed to be filmed—to better understand a possible implication of new, highly remarkable findings published in the New England Journal of Medicine (NEJM), that even the authors of the study call "paradoxical." They studied 1,193 patients with terminal cancer who were receiving palliative treatments—treatments that were unlikely to cure their cancer. When queried, the majority of the patients said they believed the treatments could cure their cancer.4 But that is not the finding that is astounding and paradoxical. In the study, the patients who least understood that they were probably going to die gave their physicians the highest possible ratings on communication. This raises, of course, the question: Why?

Why agree to be filmed in such a deeply private context? Why were physicians rated highly by patients who didn't understand they were dying? The answers to these two questions may be related, and may have profound implications for how careproviders of all kinds should relate to patients, especially when ethical conflicts are involved.

I will consider why patients and careproviders may have agreed to be filmed for *Boston Med* and why the palliative patients rated their physicians so highly. I will then consider how careproviders may do more to inform patients

and how the same approaches may be applied to ethics consultation.

## WHY MIGHT BOTH PATIENTS AND CAREPROVIDERS AGREE TO BE FILMED?

We all greatly value our privacy, especially when it involves our medical condition and needs. Careproviders usually try to "be the best they can be" with patients and their peers. Why, then, would some patients and some careproviders agree to be filmed?

#### **Patients**

To be altruistic. It is well known that patients generally do better when they feel more in control over what happens to them,<sup>5</sup> and patients who watch Boston Med may feel they know more, and have more control. In this issue of JCE, the producers of Boston Med, Terence Wrong and Erica Baumgart report, "We have been approached many times by patients who tell us that they found the courage to undergo a particular procedure because they had seen it performed on a patient in one of our earlier series." An example of how important feeling in control can be is that some patients report they are relieved to receive test results indicating they have Alzheimer's disease—they know what they are facing.7

Believing that one is helping others is another way to feel more in control. The wife of a patient who was filmed as he waited for an organ donation on *Boston Med* reports that her husband felt that if he could "just help one person, it would be well worth it." Patients may agree to be filmed as a way to feel more in control, and to feel they may be helping others.

For attention. A simple, much less praiseworthy, and perhaps even derogatory reason is that those who agree to be filmed want the attention it brings. This may make sense in some contexts. For example, people volunteer to participate in stage shows that feature hypnosis, and seem to be compelled to go on stage and cluck like a chicken. While it cannot be shown conclusively that one cannot use hypnosis to compel another to do something against his or her will,<sup>9</sup> people who agree to participate in a stage hypnosis show may later feel that they were not in control of their actions while on stage, and may use this to explain why they acted as they did.<sup>10</sup>

To be less alone. A third possibility is that patients wish to feel, at some level, even unknowingly, less alone. Perhaps this possibility is best understood by the German philosopher Martin Heidegger, who focused, maybe more than anyone, on how humans struggle to deny their own death. For example, Heidegger wrote that we tend, overwhelmingly, to tell ourselves that "one of these days we'll die too, but right now this has nothing to do with us."11 Heidegger said that we habitually and constantly seek to try to distract ourselves from the awareness of our impending death by becoming absorbed in everyday trivia, and that by engaging in this almost ever-present denial, we are being untrue to ourselves. Our being aware of our death, and, indeed, the most incredible fact of our existing at all, should, Heidegger proclaimed, instead move us to feel indebted, and we might, as a result, act in ways that are more true to who we really are.

This makes sense; that as we are more aware of our impending death, it may move us to act in different, better ways, for at least ourselves, if not for others. I think of a mother from my own experience who was dying of cancer. She chose to spend every minute she had left with her grade-school-aged son. But I believe that Heidegger was mostly wrong in his assertion and belief that humans, in response to being more aware of their own death, could, and, thus, should do more. I think he based these beliefs on logic, not on how we, as humans, actually are. Death, and any serious illness, changes us. We feel greater fear and, particularly relevant to this discussion, much more alone. Hannah Arendt, who studied with Heidegger, wrote, "the experience of great bodily pain is . . . the most private and least communicable of all" experiences.12

Patients who agree to be filmed in the hospital may be more in touch with their need for connection with others. These patients may

hope, unconsciously or not, to feel less alone, or not *as* alone, and to be more connected with others. This could be similar to how some of us react when we are stressed—we may find ourselves talking with people we don't know well while we share an elevator, for example.

Agreeing to be filmed with the intent of helping others may even be a psychological or emotional defense, something to shelter us from the terrifying fear that we may die, evoked by being in the hospital. What kind of altruism it is, for the purposes of this discussion, doesn't matter. What does matter is the singular importance of feeling alone when in the hospital sick or dying. This kind of pain is what careproviders can address with the approaches I will describe below, to help patients to be able to know, and to hear, the truth—which is what the NEJM piece reveals that patients need, so compellingly.

### **Careproviders**

Why careproviders agree to be filmed may be as much or more of an enigma, particularly because they may be filmed at their worst. Thalia Margalit Krakower, Martha Montello, Christine Mitchell, and Robert Truog report in "The Ethics of Reality Medical Television," in this issue of *ICE*, that some careproviders in Boston Med were filmed chuckling at a patient's "offbeat behavior"; one careprovider is filmed saying that she liked it much better when her patient was unconscious; still another is filmed saying, in regard to a man who was stabbed by his wife, "All I'm sayin', is you better not mess with your woman." Again: Why? An analogous range of highly disparate, representative possibilities might be considered.

To be altruistic. Careproviders who agree to be filmed may want to benefit patients. They may want to do this in spite of the risks to themselves, and thus this choice may be even more courageous. They may want to benefit patients, for instance, by giving them more realistic expectations, as opposed to unrealistically positive expectations. As a hospital administrator put this, participating in a documentary is an opportunity to "educate the public" about the

hospital's "shortcomings." 14 The producers of Boston Med report that the documentary series shows "the good, the bad, and the ugly." 15 We have all heard careproviders state, sometimes almost bitterly, that patients expect more from them than they can give. I should quickly note here that commonly careproviders blame themselves in these situations. Much too often, they say, they fail to admit to patients when they "don't know." Presumably, they do this to avoid feeling shame, even though it may be harmful to patients and self-destructive. Such feelings of shame are wholly unwarranted. Still, if this is true, careproviders who participate in filming to be altruistic do much more than show courage: they do it despite their fear of shame.

For attention. As discussed above regarding patients who choose to be filmed, careproviders could agree to be filmed for a less admirable purpose — they could just want to be on TV. Careproviders are not different than the rest of the general population; it could be they are seeking novelty.16 But such easy, smug assumptions are harmful. As an example, some patients with an addiction repeatedly request additional pain medication, and it may be easy to link the requests with their addiction. But research indicates that addictions can cause higher pain thresholds, so the patients may actually need higher levels of medication to achieve relief from pain.<sup>17</sup> Or sometimes patients "test positive" for alcohol, leading staff to wonder about parties on the ward. But the test results may have been produced by bacteria growing in the small intestine.18

To be less alone. Wrong and Baumgart report that "careproviders need black humor as a coping mechanism." Why would this be the case? Why might they need—or if not need, at least benefit from—using black humor? 19 This need or possible benefit may be a clue that careproviders, like patients, want not to be so alone in their pain. Even though careproviders, relative to their patients, suffer exponentially less, they still feel pain themselves, as they see patients suffer. And some see this all the time. I think of an instance from my own experience. A baby was born with ichthyosis, a skin condition, often genetic, in which very dry human

skin resembles scales on the skin of a fish, hence the name. The mother's pain, relative to that of the careproviders who were present, was exponentially greater. But exposure to this kind of pain, if repeated, takes its toll. For example, a doctor reports how he felt a patient's eyes fixed on his face, longing to find hope and confidence there, as the patient looked for a reason to feel better. The doctor says that the patient might have found what he was looking for in the doctor's face, but inside the doctor felt sad and depressed, thinking about the sickness of this patient.<sup>20</sup> It is not surprising that careproviders are affected by the suffering they witness, and that they often feel alone. As one doctor put it, "physicians . . . who feel very isolated and alienated have increased symptoms of melancholia, guilt, shame, cognitive distortion, and suicidality that lead to suicidal actions."21

This is echoed in the first episode of a new television show, based on a novel written by a doctor. In the first episode an adolescent undergoing surgery suddenly dies. The surgeon is devastated and knows he must tell the boy's mother immediately. Empathizing with her, he decides he should first take the time to change out of his surgical gown because it is stained with blood. He tells the boy's mother what has happened. In her grief, she is able to empathize with him, and says, "I know what happened there must've been so hard for you." Even though this is fiction, it depicts how a family member can understand the pain that careproviders also experience.<sup>22</sup>

What careproviders and patients most need at times like these is to feel less alone. This may be why the patients in the *NEJM* study rated their physicians highly on communication, even though the patients didn't understand that the treatments they were receiving weren't curative; perhaps the communication that these patients were rating highly was the physicians' ability to help them feel less alone. Maybe this is the case; maybe not. But it could be that helping patients to feel less alone when they are sick or dying may be the most helpful thing that careproviders can do. I will now describe some approaches that any careprovider can use to help patients feel less alone.

# PROVIDING ADDITIONAL INFORMATION TO PATIENTS

Patients may idealize their careproviders and be extraordinarily afraid of offending them. An account depicting this comes to mind from a story by Anton Chekhov, a doctor who practiced a century ago. In this story, a character named Vanda leaves the hospital, without a home and without "a farthing in her pocket." She remembers a dentist who was kind to her and goes to him to ask him for a loan. Vanda is seated for treatment in the dentist's "soft armchair." When he comes in, he asks her, "'What can I do for you?" "Vanda doesn't know how to begin to ask for his help and is silent. He repeats the question, "a bit irritably" this time. Nonplussed, Vanda can only think to say, "'I've got toothache,' " as this was the case when she saw him before, although it isn't the case now. "'You must be brave," the dentist says, attempting to help prepare her for having her tooth pulled. "And his tobacco-stained fingers, smeared with blood, held up the tooth to her eyes...."23 This may seem outdated—but maybe it's not. Patients' desire to please and not offend may be implicit in the findings of the *NEJM* study.

This is exemplified in a recent article published in the Washington Post, in which an oncologist relates his reactions and feelings as he watched his mother die in the hospital. She had had chemotherapy for breast cancer, and was emergently admitted to the hospital with neutropenic sepsis—a serious systemic infection complicated by chemo. The son flew 500 miles to be with her after she was admitted. At the hospital, he found that "few if any of the essential and obvious interventions needed to save her life" had been done. He found the staff irresponsive to his concerns and insisted that his mother be moved to the intensive care unit, to push the staff to begin the hospital's sepsis protocol, but as hours pass and the sepsis protocol is not begun, he says that he "felt lost and powerless. . . . What would happen if I made additional demands? Would the ICU nurse start avoiding my mother's room? If I criticized my mother's oncologist, what would happen to

their relationship? I knew there could be a downside to being too demanding in a hospital. I was losing my own confidence as a doctor, becoming instead the helpless son." He then attempted to have his mother transferred to another hospital. In response, the sepsis protocol was finally begun, 23 hours after admission. But the delay proved too much, and his mother died in a few days.<sup>24</sup>

To return to our consideration of Boston *Med*—it is possible that the patients' and family members' fear of offending careproviders played a role in their agreeing to be filmed. They may have felt fearful like Vanda and the physician whose mother died of sepsis. If such a tendency to want to please careproviders or authority is what influenced some patients and careproviders to agree to be filmed, this would be most problematic ethically. This might suggest that those who later said they were glad they chose to participate in the filming didn't know their "real" underlying reason, like those who participated in stage hypnosis and later try to rationalize their actions. Even if only a small percentage of those who agreed to be filmed responded from a desire to please, this might warrant barring the practice.<sup>25</sup>

Depending on the context, we may all feel at some time as fearful and alone as Vanda and the doctor whose mother was dying. This is all the more reason for us do what we can to help patients feel less alone, even when all we can offer patients is *ourselves*, because it may, to some extent, enable them to feel—and actually *be*—less alone.

There are some practical steps that careproviders can take. Sherwin Nuland, himself a surgeon, wrote, "The ideal doctor needs 'skills of the heart' to be able to create 'the aura' that a patient and careprovider are 'both enmeshed in a journey that they're taking together.' "26 Even subliminal cues from a careprovider, outside a patient's conscious awareness, can reduce feelings of being alone, and help a patient recover in a way "something akin to the placebo effect." One strategy is to provide additional information to patients.

Here are some examples of how this might work. (1) When patients feel suicidal, conventionally, understandably, careproviders ask these patients whether they have made plans to carry out their suicidal feelings, and, if they have, whether they have taken any initial steps toward carrying them out. Careproviders may know, though, that insurance companies may, at some later time, ask to see patients' medical records, and may look to see if suicide is mentioned. If it is, some insurance companies may see this as an increased risk and raise rates. As this is the case, careproviders may inform patients of that possibility, and ask patients if they want to discuss how to handle this issue, before they begin the discussion of suicide.

- (2) Some patients may be dangerous, and conventionally, again most understandably, careproviders ask such patients if they own a firearm. Careproviders might say, "Before you answer, you should know that if you say you do own a firearm, I shall have to take action to ensure that you give it up."
- (3) When patients come in "complaining" that recently their memory is much worse, it is conventional for careproviders to test their memory. This makes great sense and is in line with the standard of care: diagnose first, then treat. Still, a careprovider may say, *prior* to doing any testing, "Before I test you—if I do test you—you should know that we all age. We all experience some memory loss. Thus, what you are experiencing may be normal. Yet, at the same time, it may be the first sign of something serious, but, depending on what it is, we may not have much we can do now to treat it. You may, then, want me to not test your memory at all right now. We could discuss the pros and cons of testing, now or later—or not discuss this—if you want." Patients who test at all positively may feel sudden dread that can instantly darken their life. But if there are memory deficits present, they may not progress to dementia, and, even if they do, there is now little treatment for it—current treatments may only slow the disease a short time, at most.

But when careproviders say the things I describe, it gives patients a choice. Such greater sharing between careproviders and patients is what Thaddeus Mason Pope and Melinda Hexum's "Legal Decision Making and Patient

Decision Aids," in this issue of *JCE*, is all about.<sup>28</sup> They state, for example, that using patient decision-support tools may improve individuals' understanding of medical treatment options. They make the point that, in Washington State, careproviders who share more information using patient decision aids have greater legal protection than they usually would if they erroneously disclosed something that was incorrect. Perhaps careproviders who share additional information with patients should have greater legal protection also. Ethically, in any case, careproviders who share additional information may not only increase the degree to which patients can share in making decisions; they may, more importantly, decrease patients' feelings of being alone and isolated by their illness. This is because the only other persons who are likely to "risk" sharing additional information with patients, knowing that this might harm the patients, are people the patients love, like members of their own family. Even if patients go on to disregard the additional information that their careproviders offer, the patients may feel less alone, because their careproviders treated them as equals.

# APPLICATIONS OF THIS APPROACH TO ETHICS CONSULTATION

Edward J. Bergman in his article, "Surmounting Elusive Barriers: The Case for Bioethics Mediation," in this issue of JCE, discusses several strengths of mediation in bioethics consultation.29 As an example of the difficulties traditional bioethics consultants face, Bergman quotes Richard Zaner, who wrote in 2004 that whenever he mentioned that he was "in ethics," others inferred someone might be doing something morally wrong, or that Zaner might be some kind of "moral police." Zaner wrote that this was "a little frustrating" and put "such a damper on conversation." Bergman argues that the "inclusive, respectful, and non-judgmental nature" of mediation does not impede conversation, but instead facilitates the exchange of information and the clarification of "otherwise opaque information." Bergman concludes that the predominant "skill set" needed by bioethics consultants is not so much ethical brilliance, but instead qualities that include "empathy, communication, insight, creativity, [and] trustworthiness."

Nancy Neveloff Dubler, commenting on Bergman, agrees that the issue is whether it would be better to replace professionals who are trained in bioethics with professionals who have more training in mediation, and less training in bioethics.<sup>30</sup> In response, Dubler notes that bioethics mediators must have a specialized knowledge and training beyond what a mediator would usually have. Bioethics mediators, she says, can recognize and address the "despair of providers facing family members, and occasionally patients, who seem not to care about the medical diagnosis and prognosis" nor care about "reasoned decision making." Bioethics mediators can also recognize and address the hopelessness that patients and family members often feel as they are run over by "the juggernaut of care," that their views and wishes not be "heard" or "heeded." Dubler gives several case examples that illustrate what bioethics mediators do best: meet the needs and interests of all parties. For example, she states that a decisionally capable patient's refusal of care "is not the end of the discussion: it is the beginning of the inquiry." She says that if the mediator doesn't help resolve such questions, when the situation becomes emergent, organizational "forces" other than the patient and family will "make the decision."

As I read Bergman and Dubler, I was reminded of a quote from A.J. Ayer: "Another man may disagree with me about the wrongness of stealing," but "he cannot, strictly speaking, contradict me," because "I am merely expressing certain moral sentiments."

Practically, a presupposition such as Ayer's regarding ethical analysis could avoid the dampening of discussion that Zaner lamented. Such an approach could assist careproviders who want to help patients feel less alone. Dubler exemplifies this approach when she suggests that we should always begin conversations with family members by asking, "Tell me about [the patient]."

### CONCLUSION

Ronald Diamond, a psychiatrist, wrote, in regard to helping patients with making decisions, "Our job is not to convince patients to take medications, but to structure the flow of information to help them to make good decisions. . . . People aren't going to take anything if they feel hopeless. We have to engender hope and keep it alive until patients feel they can get better."32 All of us, like the patients, family, and careproviders who agreed to be filmed for Boston Med, when we are ill and/or confronted with dving, may be prone to feeling desperately alone. Careproviders who confront such issues, in any and all contexts, can choose to first help patients feel less alone. Once this is done, we can, as Dubler suggests, do any bare-knuckled ethical analysis later—if and when that becomes necessary.

### **NOTES**

- 1. T.M. Krakower, M. Montello, C. Mitchell, and R.D. Truog, "The Ethics of Reality Medical Television"; T. Wrong and E. Baumgart, "Not a 'Reality' Show"; N. Baer, "First, Do No Harm"; and W.M. Robinson, "Watching *Boston Med*," all in this issue of *ICE*.
- 2. The word *patients* should be understood here, and throughout this discussion, to refer to both patients and their loved ones.
- 3. K. Boo, *Behind Beautiful Forevers: Life, Death, and Hope in a Mumbai Undercity* (New York: Random House, 2012), 15.
- 4. J.C. Weeks et al., "Patient's Expectations about Effects of Chemotherapy for Advanced Cancer," *New England Journal of Medicine* 367 (2012): 1616-25.
  - 5. Wrong and Baumgart, see note 1 above.
- 6. Krakower, Montello, Mitchell, and Truog, see note 1 above.
- 7. "Symptoms of anxiety and depression remain stable or even decline immediately after diagnosis." From, B.O. Carpenter et al., "Reaction to a Dementia Diagnosis in Individuals with Alzheimer's Disease and Mild Cognitive Impairment," *Journal of the American Geriatric Society* 56, no. 3 (2008):405-12, 408. "Gaining knowledge" may also enhance "a sense of self-efficacy where before they might have felt helpless," p. 409.

- 8. Krakower, Montello, Mitchell, and Truog, see note 1 above.
- 9. The "brain-washing" of prisoners or of persons who are kidnapped and subjected to similar techniques by a cult is probably the only means by which one person can control, to a much greater extent, another's behavior.
- 10. Findings suggest that people cannot be hypnotized to carry out acts that they believe are morally wrong. "Certainly, the popular view which holds that hypnosis is able to exert a unique form of control over the hypnotized individual, which can compel him to carry out otherwise repugnant actions, must be rejected. M.T. Orne, "Can a hypnotized subject be compelled to carry out otherwise unacceptable behavior? A Discussion" *International Journal of Clinical and Experimental Hypnosis* 20 (1972): 101-7, 101.
- 11. G. Harmon, *Heidegger Explained* (Chicago: Open Court, 2007), 55.
- 12. H. Arendt, *The Human Condition*, 2nd ed. (Chicago: University of Chicago Press, 1958), 50-1.
- 13. Krakower, Montello, Mitchell, and Truog, see note 1 above.
  - 14. Ibid.
  - 15. Wrong and Baumgart, see note 1 above.
- 16. B.J. Sadock and V.A. Sadock, ed., *Kaplan and Sadock's Comprehensive Textbook of Psychiatry*, 9th ed. (Philadelphia: Lippincott Williams & Wilkins, 2009), 2233.
- 17. K. McCoy, W. Freemouw, and D.W. McNeil, "Thresholds and Tolerance of Physical Pain among Young Adults Who Self-Injure," *Pain Research & Management* 15, no. 6 (December 2010): 371-7.
- 18. J. Bures et al., "Small Intestinal Bacterial Overgrowth Syndrome," *World Journal of Gastroenterology* 16, no. 24 (2010): 2978-90.
- 19. The use of the term *black humor* is ethically problematic, at minimum, due to its associated meanings, whether this ever has been intended or has not.
- 20. S. Frampton, When I am Playing with My Cat, How Do I Know That She is Not Playing with Me? (New York: Vintage Books, 2011), 217.
- 21. N. Osterweil, "Interventions Address Physicians' Mental Health Issues," *Clinical Psychiatry News* 40, no. 12 (December 2012): 20.
- 22. S. Gupta, *Monday Mornings* (New York: Hatchette Book Group, 2012), 38. The TV series has the same name. This show in which this scene appeared aired in January 2013.
- 23. A. Chekhov, "A Gentleman Friend," in *Chekhov's Short Stories Selected*, ed., R.E. Matlaw (New York: W.W. Norton, 1979), 34-7.

- 24. J. Welch, "Doctor Believes Standard Hospital Care Could Have Averted the Death of His Mother," *Washington Post*, 1 January 2013.
  - 25. I am indebted to Norman Quist on this point.
- 26. L.J. Wolfe, "Physician Sees Widening Gap Separating Doctor and Patient," *Psychiatric News* 47, no. 8 (20 April 2012): 27.
- 27. A. Coghlan, "Subconscious Cues Might Help You Heal Faster," *New Scientist* 3215, no. 2882 (2012): 11.
- 28. T.M. Pope and M. Hexum, "Legal Briefing: Patient Decision Aids," in this issue of *JCE*.
- 29. E.J. Bergman, "Surmounting Elusive Barriers: The Case for Bioethics Mediation," in this issue of *ICE*.
- 30. N.N. Dubler, "Commentary on Bergman: "Yes . . . But," in this issue of *JCE*.