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At the Bedside

3 The Best Place for Bare-Knuckled Ethics
Edmund G. Howe

Features

11 Surmounting Elusive Barriers: The Case for Bioethics Mediation
Edward J. Bergman

25 Commentary on Bergman: "Yes . . . But"
Nancy Neveloff Dubler

32 The Chiaroscuro of Accountability in the Second Edition of the *Core Competencies for Healthcare Ethics Consultation*
Lisa Rasmussen

41 Prescribing for Co-Workers: Practices and Attitudes of Faculty and Residents
Carson Strong, Stephanie Connolly, and Laura R. Sprabery

Harvard Ethics Consortium

50 The Ethics of Reality Medical Television
Thalia Margalit Krakower, Martha Montello, Christine Mitchell, and Robert D. Truog

58 Not a "Reality" Show
Terence Wrong and Erica Baumgart

64 First, Do No Harm
Neal Baer

67 Watching *Boston Med*
Walter M. Robinson

Law

70 Legal Briefing: Shared Decision Making and Patient Decision Aids
Thaddeus Mason Pope and Melinda Hexum

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37 East Antietam Street, Hagerstown, Maryland 21740 USA
240-420-8850 • fax: 240-718-7100 jce@clinicalethics.com www.clinicalethics.com

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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*.[1] The documentary filmed patients who 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.[2] 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

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*.

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,[5] 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."[6] 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."[8] 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,[9] 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.[10]

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,"[13] in this issue of *JCE,* 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.[17] 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.[20] 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.[22]

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.[24]

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.[25]

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."[27] One strategy is to provide additional information to patients.

Here are some examples of how this might work. (1) When patients feel suicidal, conven-

tionally, 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.[28] 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 bioeth-

ics 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.[30] 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."[31]

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 dying, 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 *JCE.*

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 *JCE.*

30. N.N. Dubler, "Commentary on Bergman: "Yes . . . But," in this issue of *JCE.*

31. A.J. Ayer, *Language, Truth, and Logic* (New York: Dover, 1952), 107.

32. A. Levin, "Relationship with Patient Can Determine Treatment Success," *Psychiatric News* 47, no. 23 (7 December 2012): 27.

Features

Surmounting Elusive Barriers: The Case for Bioethics Mediation

Edward J. Bergman

ABSTRACT

This article describes, analyzes, and advocates for management of clinical healthcare conflict by a process commonly referred to as *bioethics mediation*. Section I provides a brief introduction to classical mediation outside the realm of clinical healthcare. Section II highlights certain distinguishing characteristics of bioethics mediation. Section III chronicles the history of bioethics mediation and references a number of seminal writings on the subject. Finally, Section IV analyzes barriers that have, thus far, limited the widespread implementation of bioethics mediation.

I. MEDIATION

Mediation is a venerable dispute resolution process. In his authoritative work, *The Mediation Process: Practical Strategies for Resolving Conflict*, Moore notes that "mediation has a long and varied history in almost all cultures of the world."[1] Fundamentally, mediation is a form of assisted negotiation in which a neutral, the mediator, aids disputants in their creation of consensual resolutions to conflict. The integral relationship between mediation and negotiation requires that mediators possess a working knowledge of negotiation theory and practice, with a particular emphasis on integrative, principled, and interest-based negotiation, all of which emphasize the distinction between a party's positions and the party's underlying interests, as a source for the discovery of previously unrecognized common ground or compatibility.[2] The term *consensual* signifies a resolution that all parties can accept as preferable to alternative outcomes in the event consensus cannot be reached. A mediator does not impose an outcome on the parties, but functions as a facilitator and manager of the process. Thus, mediation can be characterized as the least authoritarian mode of dispute resolution, because its outcomes are not determined by third parties, as in arbitration or adjudication, but by the disputants themselves.[3]

There are differing, sometimes contentious, views of the extent to which mediators should perform evaluative as well as facilitative functions. There are also disparate viewpoints regarding a mediator's responsibility for the quality of a mediated outcome. Some argue that, as facilitators, mediators are accountable solely for the quality of the mediation process, including the assurance that each party has made its determinations freely and voluntarily, fully in-

Edward J. Bergman, JD, is Founding Faculty and Principle Mediator of the Penn Clinical Ethics Mediation Program, Perelman School of Medicine of the University of Pennsylvania in Philadelphia, *ejb@gear3.net.*

formed of all relevant information. Others contend that a mediator bears responsibility for the fairness of an outcome, and even for its impact on non-parties to the mediation, including society as a whole.[4] Neither of the above debates is susceptible of definitive resolution, and the continuing dialogue is undoubtedly a sign of the vibrancy of the mediation process.

A third point of contention within the mediation community involves the definition of *neutrality*, and the extent to which it is achievable. Classical mediation is premised on the perceived neutrality of the mediator as a cornerstone for the creation of trust that is prerequisite to an open exchange of information by the parties.[5] In addition, the promise of confidentiality serves as a catalyst for candor. The confidentiality of mediation communications is frequently protected by statute. Many states have adopted the Uniform Mediation Act, which privileges mediation communications, disallowing their use in subsequent court proceedings, with rare exceptions.[6] When a party is reluctant to share information with other parties to the mediation, she or he can confide in the mediator with the assurance that requested confidentiality will be honored, internal to the mediation process.

Mediation is generally viewed as an effective dispute resolution process that incorporates positive attributes of catharsis, party empowerment, potential for continuing relationships (or termination of relationships with a minimum of rancor), and a high likelihood of compliance, stemming from the parties' ownership of consensual outcomes. In the legal world, mediation has been embraced by proponents of efficiency and, simultaneously, by advocates for more humanistic dispute resolution processes.[7]

The mediation process, its stages and techniques, have been exhaustively described in books and articles that are required reading for the prospective bioethics mediator.[8] For purposes of this article, I will note simply that mediators are managers of a process which, utilizing both global sessions and caucuses with individual parties, assists disputants in defining the nature and scope of a conflict; identifying and prioritizing the underlying interests of each participant; understanding the extent to which those interests are identical, compatible, or conflicting; and seeking options for resolution that are optimally responsive to the interests identified.

Mediation is an informal dispute resolution process in which there is no audio record or written transcript of the proceedings. Significantly, there are no externally imposed limitations on the admissibility of statements or other evidence offered by the parties. While the mediator, as a manager, is responsible for the decorum he or she deems necessary to an effective process, constraints should be imposed cautiously to preserve cathartic potential through the expression of emotions that may be requisite to an effective process. Despite its consensual aspect, mediation should not be viewed or practiced as a process that encourages suppression of deeply held feelings.[9] The mediator should be a consummate listener and questioner who clarifies and summarizes the contributions of the parties, acknowledges those contributions, promotes mutual respect, elicits and provides creativity, educates the parties about the process, facilitates access to information that is relevant, and insures that individual decision making is the product of non-coerced, informed deliberation.

The foregoing, in its brevity, constitutes an overview of the classical mediation process to establish a context for those readers unfamiliar with mediation. Readers are urged to examine the sources cited in end notes one through nine for a fuller introduction to the process.

II. BIOETHICS MEDIATION

In 2004, Zaner wrote, "Every time I introduced myself, it seemed someone invariably thought that, since I was 'in ethics,' it was obvious that someone had been *un*ethical; otherwise, why else would someone like me be on the scene? And I, taken to be the local 'ethics cop,' there to catch' em out and put' em away! Curious, and not a little frustrating, how being seen as 'police'—even if merely from 'ethics'—puts such a damper on conversation".[10]

Bioethics mediation encompasses the mediation of conflicts that arise in a clinical healthcare context between or among caregivers, patients, their surrogates, and families. The term *bioethics mediation* is not ordinarily applied to the mediation of healthcare policy issues, or to the mediation of disputes between patients and caregivers that have evolved into malpractice litigation, although these are important categories of healthcare mediation outside the scope of this article.[11] The expertise of classically trained bioethicists is frequently, and appropriately, sought in connection with health policy issues.

In some respects, the term *bioethics mediation* is misleading, as it obscures the fact that most clinical healthcare disputes, like those in other settings, emanate from more mundane sources than moral conflict. Communication, information, culture, and personality-based conflicts are more common than those that are typically characterized as ethical in nature.[12] Such conflicts can be addressed through the application of classical mediation techniques. Thus, a more accurate characterization of a clinical mediator's role might be "mediation of healthcare disputes in a clinical context," embracing the full spectrum of potential conflict.

On a further semantic note, the terms *bioethics* mediation/consultation and *clinical ethics* mediation/consultation are used synonymously. A more confusing semantic concern emanates from the terminologies referenced below, in which *mediation* is described as a "skill set" for, or approach to, "consultation," rather than as a separate and distinct modality. There is nothing inherently wrong with subsuming mediation within the broader category of bioethics consultation, other than the confusion it may engender.

The literature on bioethics mediation primarily addresses conflict that can be characterized as morally *aporetic*. *Moral aporia* indicates a state of perplexity, impasse, deadlock, or stalemate "from which there is seemingly no way out, thus forcing the conflicting parties involved to come to a mutual understanding of their ignorance and helplessness about how to proceed."[13] One party's perspective, informed by his or her own values, and driven by legitimate moral concerns, conflicts with another's principled judgment. For example, Daughter A may advocate for removal of her father's artificial life support, based on an assessment that the associated pain and perceived loss of dignity are not justified by a predictably brief prolongation of life with diminished quality. Daughter B may argue that their father is entitled to any intervention that will extend his life, and may also broaden the window of opportunity for a miraculous recovery. While these morally aporetic positions may be irreconcilable, a decision is required. It should be noted that, in bioethics mediation, it is also possible that one party may persuade another to reconsider, and ultimately revise his or her initially perceived moral calculus, breaking the "stalemate." Thus, resolution can occur via reconsideration of initially espoused principles, or by an acceptance of irreconcilability, along with the need to act, even in the absence of reconciliation.

Proponents of bioethics mediation argue that mediation provides a forum in which moral positions that emanate from disparate value systems can be articulated and challenged, leading to recognition of the legitimacy due each opposing position, and the realization that consensus on outcomes does not necessarily require consensus on principles. Indeed, Clouser and Gert conclude that "principlism" is of little utility in clinical ethics decision making, precisely because bioethics principles (beneficence, nonmalificence, autonomy, and social justice[14]), compete with one another for predominance in ethical conflicts.[15] It is inevitable that, in a morally aporetic situation, there can be no certainty that the correctness of any choice, by consensus or otherwise, enhances the possibility of consensus on outcomes.[16] Returning to the example of Daughters A and B, a decision to either terminate or prolong their father's life support cannot, when made, be assuredly correct or demonstrably superior to, the alternative. In consequence, the likelihood of reaching a consensus whereby, for example, the father's life support is continued for a period of time, after which, if there is no change in prognosis, it will be terminated, becomes more likely when the

parties comprehend the uncertainty associated with either position and the legitimacy of both.

The teaching of ethics through moral dialogue, in which participants experience *catharsis*, defined as "cleansing" or "purification," has its roots in ancient Greek philosophy. In that moral dialogue, the teacher acts, not as the source of superior moral knowledge, but as a *pharmakon,* or medical remedy, through a process of cross-examination known as the *elenchus*. The *elenchus* tests individuals' purported knowledge and stated moral principles. The dialogue itself is the healer. The teacher is not.[17] While an analogy to the ethical education of physicians is not precise, parallels between the described role of a medical ethics professor and a bioethics mediator are striking.

It is those conflicts of a morally aporetic nature that the critics of bioethics mediation target when they assert that mediation takes the ethics out of ethics consultation.[18] In effect, this criticism is premised on an assumption that there are morally "correct" solutions to aporetic conflicts, and that individuals with specialized training and credentials have access to superior moral judgment that enables them to divine the correct solution. The counter-argument can be stated as follows: "in non-ideal everyday situations it is very seldom possible to reach a moral solution that is undoubtedly right and that the real challenge consists rather in reaching an acceptable moral solution, i.e. a solution that all parties involved find they can live with. . . ."[19]

Just as the mediation of healthcare disputes in a clinical context is consistent with the concept of moral aporia, the use of mediation also flows from a contemporary view of the physician-patient relationship based on a negotiation model. Lazare and Dubertret both characterize the foundation of the physician-patient relationship as a negotiation,[20] while Groopman and Chen separately describe the clinical diagnostic interview in terms that incorporate negotiation skills such as rapport building, active listening, the use of open-ended questions, and acknowledgment of the patient.[21] If indeed the physician-patient relationship is a product of negotiation, and mediation is a form of assisted negotiation,[22] mediation appears a logical mechanism for the reclamation of a negotiated relationship gone awry.

Bioethics mediation is also wholly consistent with the contemporary view of medicine as practiced through a shared decision-making process and a collaborative physician-patient relationship. The parties are viewed as co-equal participants, each of whom contributes his or her particular competencies to the collaboration, and each of whom assumes responsibility for impasses that develop within the therapeutic relationship. The traditional paradigm of the "physician-as-expert," while maintaining relevance in the case of medical emergencies to which a physician must respond, and in cases when a patient actively seeks to delegate decision making to an expert,[23] has been supplanted by an approach in which self-determination trumps paternalism.

There are times, however, when individuals may need or prefer to rely on the opinion of others for decisions that are simply beyond their capacity to address.[24] With or without the existence of conflict between stakeholders, individuals are always free to elicit the views of others they respect. Such third parties may be bioethicists, but they may well be religious leaders, mental health professionals, medical professionals outside the immediate caregiver team, et cetera.

Referral of a dispute to mediation does not preclude the possibility that before or during mediation a party may consult with such individuals on her or his own, or upon a mediator's inquiry as to its possible utility. Such consultations can occur outside the immediate framework of the mediation, or a party may seek to incorporate third-party dialogue into the mediation process. One anecdotal, though not uncommon, example is the contribution of clergy when a party is manifestly unclear of the extent to which religious doctrine binds him or her to specific courses of action. Dialogue may reveal that perceived religious constraints can be relaxed in the context of crisis, altering the individual's view of his or her range of options.

It is within the mediator's purview to function as a resource for any information that may

be of assistance to the parties in the process of informed decision making. What a mediator does not do, that a traditional bioethics consultant often does, is to personally assess and opine on the accuracy, weight, ultimate credibility, and relevancy of the disparate information to be considered by the stakeholders.

A skilled bioethics mediator will elicit and acknowledge the competencies of all parties, thereby promoting mutual respect, and will assist the parties in formulating a consensual resolution that reflects their respective competencies. If, for example, a physician believes that a specific physical therapy represents the way to a better, faster recovery, yet acknowledges that the recommended therapy will be more painful than the alternatives, a mediator may elicit the patient's own history of overcoming adversity for the opportunity to achieve future-oriented goals. The mediator may also inquire as to the basis for the physician's assessment, and the basis on which the treatment's efficacy is believed superior to less-painful alternatives. Confronted with that history, the patient may identify her or his own previous successes and use them to revisit her or his initial resistance to short-term discomfort. Conversely, the physician may reframe his or her recommendation as a cost-benefit analysis to be engaged in by the patient.

While the existing bioethics mediation literature does not explicitly acknowledge a familial relationship with narrative medical ethics, the values reflected in narrative ethics clearly resonate with many of the operative principles of bioethics mediation. Charon and Montebello, for example, have noted that

> on the juridical model morality is a matter of solitary judges applying codified rules derived from comprehensive theories as criteria for assessing wrongdoing and making rational choices. . . . The more one knows about the foundations of the theories . . . the greater one's claim to ethical expertise. In contrast, *the narrative approach . . . is collaborative in that it posits, not a solitary judge, but a community of inquirers who need to construct ways of living well together*. [Emphasis added.][25]

Thus mediation can, but need not be, conducted on a narrative model. Winslade and Monk posit just such a model in *Narrative Mediation: A New Approach to Conflict Resolution.*[26] A prospective dialogue between narrative ethicists and bioethics mediators might prove beneficial to both fields and to the individuals touched by each discipline.

Bioethics mediation should be implemented in a manner that reflects the unique confluence of characteristics associated with conflict in a clinical healthcare setting. Those characteristics have been comprehensively delineated elsewhere.[27]

Here, we focus on four distinguishing characteristics of bioethics mediation.

1. *Power imbalances* between patient, family, surrogates, and caregivers are extremely common and frequently profound. Technical complexity, unfamiliar terminology, isolation, uncertainty, cultural differences, and, often, an extreme socio-economic gap lead to intimidation, anxiety, fear, suspicion, and confusion. While power imbalances are not unique to bioethics mediation, their prominence and magnitude place extraordinary demands on the mediator.

The creation of a previously non-existent forum for the management of clinical conflict that can be triggered by a patient or caregiver request may, itself, tend to ameliorate power imbalances. More significantly, the inclusive, respectful, and non-judgmental nature of the mediation process, along with its facilitation of information exchange and the clarification of otherwise opaque information, can bring lucidity to previously incomprehensible facts and opinions. The mediator's skill in eliciting and acknowledging the respective competencies of the parties can be a powerful tool for diminishing dramatic power imbalances.

2. *Neutrality*, in the context of bioethics mediation, has been an elusive concept. Initially, a question arises as to the impact on neutrality when the mediator is employed and/or paid by a hospital. While such conditions would be viewed as problematic in the traditional mediation of legal or business disputes, there are certainly exceptions outside the healthcare

setting in which a mediator is provided or compensated by one of the parties. For example, the United States Postal Service operates and funds a mediation program using independent mediators trained by the service for the management of grievances filed by employees. The program, called REDRESS, has existed since 1994.[28]

Perhaps the biggest determinant of the perceived partiality of a mediator employed and/or paid by one disputing party is the ability of a mediator to credibly present him- or herself as impartial. If the non-payor party believes that the mediator's mandate is to facilitate consensual outcomes because such outcomes are inherently beneficial to the payor, regardless of the outcome in particular cases, the perception of neutrality may be sustainable. Thus, institutional policy in support of access to, and the fairness of, an effective conflict resolution process may be viewed as a credible initiative predicated on enlightened self-interest. The Bioethics Mediation Program at Montefiore Medical Center has operated on that premise since its inception.[29] Nonetheless, the issue of perceived neutrality will remain sensitive to the extent it cannot be guaranteed.

A more complex aspect of neutrality in bioethics mediation stems from the schism between those who believe that a bioethicist's expertise provides access to superior moral judgment and those who contend that training in the application of bioethical principles is tangential to decision making in morally aporetic situations. Superior access to ethically correct choices would render a bioethics mediator incapable of neutrality as to outcomes and limit the mediator to neutrality regarding the parties. This limited definition of neutrality will offend mediation purists as violative of the premise that advocacy for, or against, outcomes that parties reach consensually, is inherently partial. Outside the arena of clinical healthcare disputes, similar debate has arisen. Some commentators posit the view that mediators are charged with accountability to society for outcomes that are unconscionable or damaging to unrepresented parties, including future generations.[30] Opponents of that view counter that mediators have no standing nor accepted standards by which to judge the quality of outcomes voluntarily reached through consensus.[31] "It is, in its most benign form, an invitation to permit philosopher-kings to participate in the affairs of the citizenry."[32]

An equally skeptical critic opines, "clinical ethicists set up ethics consultation services in hospital wards, offering moral advice the way a consulting neurosurgeon might recommend a lumbar puncture or a dermatologist might suggest biopsy."[33]

3. A presumptive common concern for the patient's best interests distinguishes bioethics mediation from conflicts in which opposing parties have disparate and irreconcilable interests.[34] Unless the mediation dialogue reveals a party's self-interested agenda, for example, insistence on an outcome consistent with a caregiver's or a family member's religious beliefs, as distinct from those of the patient, or one that is motivated by personal financial gain, all parties share an objective—the best interests of the patient—and conflict inheres solely in how to achieve that objective. A skilled bioethics mediator will elicit the parties' recognition and acknowledgment of their common interest in the patient's welfare, which may itself reduce the level of conflict and render it more manageable.

4. *Mediation in the absence of the patient* is extremely common in the clinical healthcare setting, as conflict often arises when a patient lacks competency or consciousness.[35] While mediation outside the clinical context is sometimes conducted through agents, those agents can ordinarily confer with their principals, seek ratification from their principals, or be contemporaneously authorized to act on behalf of their principals. In bioethics mediation, the patient is frequently inaccessible for consultation or ratification, and authorization is achieved by an advance directive—a living will or medical power of attorney—or by a statute designating a succession of family members to serve as a surrogate for the patient. Some statutes also provide criteria for the surrogate's exercise of power: frequently, what the patient would have done as determined by prior statements or by

other evidence.[36] If the legal representative or surrogate does not possess unconditional decision-making power, a bioethics mediator can ensure that the mediation dialogue illuminates legal standards to be employed by the surrogate in the event no consensual resolution is reached.

III. HISTORY OF BIOETHICS MEDIATION

Bioethics mediation has been extensively advocated for as a preferred mechanism for the management of clinical healthcare disputes and as a primary vehicle for the practice of clinical ethics. In part, this support can be attributed to a dismal assessment of the performance of hospital ethics committees (HECs), documented in the well-known report, "Ethics Consultations in U.S. Hospitals: A National Survey," authored by Fox, Myers, and Pearlman.[37]

While HECs were initially developed by Roman Catholic hospitals, primarily in the 1960s and 1970s,[38] they became progressively more common in the wake of *In re Quinlan,* in which the New Jersey Supreme Court opined that medical institutions should develop forums to resolve conflict in end-of-life situations that demand professional, subject-specific knowledge and experience.[39] The development of HECs was facilitated by rapid advances in medical technology related to end-of-life care, and by a new cadre of professionally trained bioethicists.[40]

Unfortunately, HECs, as they ultimately were developed, possess no uniform standards for (1) the training and qualifications of members, (2) processes and decision-making rules, and (3) involvement of patients and families in the dispute resolution process. HECs are also notable for their widespread use of authoritarian, top-down decision making in consultation. This decision-making style embodies the questionable premise that ethical "expertise," coupled with titles and degrees, can provide access to superior moral judgment. This judgement is often rendered in the form of definitive "recommendations," rather than as a range of options, each of which may be ethically defensible. Some HECs vote on their recommendations by majority, raising paradoxical concerns about the ethical status of the minority view.[41] Despite the ubiquity of HECs, Fox and colleagues report that few receive substantial numbers of requests for consultation. This appears anomalous, given the widespread perception that clinical healthcare conflicts abound.[42]

While HECs were proliferating in the absence of consensual approaches to the management of clinical healthcare conflict, Nancy Dubler and her colleagues at Montefiore Medical Center in New York, whose active bioethics consulting service dates to 1978, began to explore the application of alternative dispute resolution approaches to conflicts among patients, families, and caregivers. A mediation program was developed and an internal evaluation concluded that classical mediation approaches had been successful, but that, in some instances, a model specific to the hospital setting was needed. A report entitled *Mediating Bioethical Disputes* was published in 1994, describing the initiatives of, and principles embraced by, the Montefiore Bioethics Mediation Project.[43]

In 1992 an article, "Introducing Mediation to Hospital Ethics," by R.J. Wagener appeared, describing the formation of a center in California specializing in bioethics mediation.[44]

In 1994, articles entitled "Mediating Life and Death Decisions" by D.E. Hoffman[45] and "Mediation for Ethics Committees: A Promising Process" by J.M. Gibson[46] were published. Since 1994, bioethics mediation has been widely discussed. "Patient decision-making: medical ethics and mediation," an article by Y.J. Craig, appeared in the *Journal of Medical Ethics* in 1996.[47]

In 1998, the American Society for Bioethics and the Humanities published the first edition of its *Core Competencies for Health Care Ethics Consultation,* in which two of the three skills required for ethics consultation were designated as "process skills" and "interpersonal skills.[48] " Process skills" are described as inclusive of the following:

- create an atmosphere of trust that respects privacy and confidentiality and that allows parties to feel free to express

their concerns (e.g., . . . skill in addressing intimidation and disruption due to power and/or role differentials). . . .
- help individuals critically analyze the values underlying their assumptions, their decision, and the possible consequences of that decision
- negotiate between competing moral views
- engage in creative problem solving.[49]

Interpersonal skills are described as inclusive of the ability to:
- listen well and to communicate interest, respect, support, and empathy to involved parties[ ]
- elicit the moral views of involved parties
- represent the views of involved parties to others
- enable involved parties to communicate effectively and be heard by other parties
- recognize and attend to various relational barriers to communication.[50] [End note reference number removed.]

All of the aforementioned skills are generally recognized elements of a mediator's craft.

Core Competencies goes on to conclude, "the development of these skills is tied to hands-on experience. *Formal training in specific techniques such as mediation, conflict resolution, or facilitation is one way to obtain advanced interpersonal and process skills.*"[51] (Emphasis added.) *Bioethics: An Introduction to the History, Methods, and Practice* appeared in 1999, and contained an article by West and Gibson, "Facilitating Medical Ethics Case Review: What Ethics Committees Can Learn from Mediation and Facilitation Techniques."[52]

Subsequently, in 2004, Dubler and Liebman published *Bioethics Mediation: A Guide to Shaping Shared Solutions*,[53] written with the hindsight of 10 years of additional experience at Montefiore. That seminal work, now succeeded by a second edition, articulates the case for mediation of conflict in clinical settings, and examines the unique characteristics of clinical healthcare mediation. *Negotiating Health Care: Resolving Conflict to Build Collaboration*, by Marcus, Dorn, and McNulty, appeared in 1995.[54] While Marcus and colleagues do not focus on the mediation of healthcare disputes in a clinical setting, they extol the virtues of mediation across healthcare concerns, inclusive of health policy and management. The winter 2007 issue of *The Journal of Clinical Ethics* featured an article entitled "Beyond *Schiavo*," by Caplan and Bergman,[55] with commentaries by Dubler;[56] by Arnold, Aulisio, Begler, and Seltzer;[57] and related articles by Quist[58] and Fiester ("Mediation and Moral *Aporia*.")[59]

In 2009, Dubler, Webber, Swiderski, and the faculty and the National Working Group for the Clinical Ethics Credentialing Project (of which this author was a member), published "Charting the Future: Credentialing, Privileging, Quality, and Evaluation in Clinical Ethics Consultation," in the *Hastings Center Report*.[60] The "definition of clinical ethics consultation" adopted in that article includes "negotiating decision making in complex medical situations and, *whenever appropriate, mediating conflicts between staff members or among staff patient and family*."[61] (Emphasis added.) The section entitled "Measures for Credentialing CE [clinical ethics] Consultants," reads: "Interpersonal Skills: Consultants should have *training and proficiency in the techniques of facilitation, negotiation or mediation*, in order to gather and communicate information, address issues of uncertainty and help resolve disagreements."[62] (Emphasis added.) In 2009, the Center for Bioethics of the University of Pennsylvania published *The Penn Center Guide to Bioethics,* which includes a chapter devoted to "Mediation and Health Care" by this author and Autumn Fiester.[63] Dubler and Liebman's second edition of *Bioethics Mediation* was published in June 2011, reflecting disappointment by the authors concerning the lack of commitment to bioethics mediation training evidenced since publication of their first edition.[64]

This section is, in no sense, a critical or complete history of the literature. Its limited objective is to create awareness that bioethics mediation has been embraced by a wide spectrum

of credible commentators across the healthcare and bioethics communities.

IV. BARRIERS TO WIDESPREAD IMPLEMENTATION OF BIOETHICS MEDIATION

The criticism that clinical ethics mediation is devoid of a moral compass should be subject to evaluation in light of the following concerns.

In an era during which patient autonomy has become an overriding principle,[65] we do not ordinarily subject patient/surrogate medical decisions to ethical scrutiny unless issues of competency arise. Most healthcare decisions are made by individuals—patients or surrogates—in the absence of objection by other legitimate stakeholders. Such decisions are not outsourced for the imprimatur of "experts."

Some healthcare decisions are made by individuals who are legally empowered to make them, although they are informally challenged by other stakeholders who yield to the decision maker's power without formal protest. Here too, there is no guarantee that a decision maker's access to moral authority is superior to that of a challenger's basis for disagreement.

The lack of certainty referenced in the preceding two paragraphs is manifest because there is no universal clinical ethics canon and, perforce, no uniform system of decision making with appropriate safeguards. Resort, in traditional ethics consultations, to "authority," in the form of opinion voiced in the bioethics literature, and claims that said literature constitutes a consensus, are subject to widely differing interpretation and selectivity of sources.

By contrast, the adjudicatory process at the core of our legal system is premised upon the social contract requisite to a society operating under the rule of law.[66] Fairness inheres in the objective application of external norms embodied in statutes, published case precedents, and constitutional guarantees. Such norms are presumed to be just, since they are the product of democratic processes. They are legislated by duly elected representatives or articulated by judges appointed by elected executives, or themselves elected. Rights of appeal and, ultimately, the right to elect successor executives, judges, or legislators support the promise of fairness.

When clinical conflict occurs, legitimate stakeholders can, and sometimes do, seek access to the courts for resolution. But courts are not in the business of deciding ethical questions, other than those embodied in legal doctrine. In consequence, courts frequently, as in the famous *Terri Schiavo* case,[67] decide the identity of the appropriate decision maker and/or whether that decision maker has properly applied criteria set forth in statutes or case law. These determinations do not speak to the moral quality of the decision, but to its implementation in accordance with legal criteria.

Parenthetically, traditional ethics consultation, on a juridical model, sometimes occurs in decision making by vote,[68] rendering the moral status of the minority view unclear in the absence of a duly constituted reviewing authority. Nonetheless, the majority recommendation may have cataclysmic consequences for stakeholders who are in disagreement with the majority.

The biomedical principles of beneficence, nonmalificence, patient autonomy, and social justice can be confused with an ethical canon. It has been noted by Clouser and Gert that such principles merely function as useful chapter headings for ethical discussion, but do not designate outcomes in specific cases. The principles do not provide a methodology by which their often competing concerns can be balanced to arrive at a decision.[69]

The premise that a clinical ethics mediator should be, first and foremost, a professionally trained bioethicist is dubious, in that the primary skills demanded are in the realms of empathy, communication, insight, creativity, trustworthiness, and process management. This is not to suggest that basic knowledge of bioethics principles should be omitted as a component of clinical ethics mediation training, but that the dominant skill set lies elsewhere. Indeed, bioethics principles may be useful to the practitioner in the creation of chart notes expressed, for the benefit of peers, in a common language.[70]

Clinical ethics mediation is non-coercive in that no stakeholder can be compelled to participate in a consensus. Absent consensus, stakeholders retain all of the rights and options they possessed prior to mediation, although they may, as a result of an attempt at mediation, know significantly more about why consensus was unattainable. In the event mediation is unsuccessful, the conflict will be subject to resolution by a legally empowered decision maker, or by application to the court, for a determination of the appropriate decision maker.

A special attribute of bioethics mediation is the value placed on open dialogue among stakeholders, even when the identity of the decision maker is known. Validation of the moral legitimacy of a position that the holder is not endowed with power to enforce can serve to acknowledge that individual—her or his hopes, fears, beliefs, and good faith—irrespective of power. In some cases, validation may create the possibility of modifying the empowered party's perspective. Many conflict situations can be mitigated or even resolved by the mere fact of such recognition.[71] Meaningful inclusion in a process that affords a voice and encourages the expression of feelings and ideas, cuts against the marginalization of all but the empowered party.

The suggestion that an unacceptable moral relativism is inherent in clinical ethics mediation is, in the author's view, a gross mischaracterization. We have examined the reasons why clinical conflict resolution via the application of purportedly settled doctrine is not viable. Yet recognition of the inevitability of value pluralism among stakeholders is not synonymous with an acceptance of moral relativism. It is, instead, a recognition that my moral calculus may differ from yours and, while both of us may hope for reconciliation via persuasion or epiphany, in the absence of that epiphany, we are compelled to make real world decisions without the benefit of a mutually agreed upon source of moral authority. Philosophers undoubtedly believe in the moral precepts they advocate, their sources, and the arguments that support them, but they also know that their contributions are placed within a world of ideas in which no single idea is likely to gain universal traction. This does not, and ought not, diminish the ardor of their advocacy nor compel their conversion to indifference. After all, we inhabit a world in which individuals routinely part company on sensitive matters that are deemed to be ethical in nature. The pro-life/pro-choice issue is but one instance in which deep differences are likely to persist indefinitely, while society functions, absent anarchy, in a state of moral perplexity.

Lassman notes, "Rawls argues there is a deep division between the dominant tradition that holds there is one true conception of the good and an alternative tradition that recognizes the existence of a plurality of reasonable but opposing doctrines of the good."[72] A somewhat less abstract variant of the foregoing proposition can be seen in Larmore's formulation:

> Pluralism is often associated with an appreciation of the possible conflicts among our values and with the recognition that not all good things can exist together in life and society. . . . Sometimes we can find a solution to such conflicts, not by appealing to a common denominator of value, but rather by the exercise of judgment. For just this reason, however, the pluralist will recognize that discerning the correct solution (where one can indeed be found!) can be inherently difficult and open to controversy.[73]

The consensus aspect of clinical ethics mediation is consistent with the concept of medicine as an enterprise for "healing," with an emphasis on empathy, shared decision making, communication, and patient-centered care.[74] The resolution of clinical conflict by institutional fiat does nothing to enhance the likelihood that the whole patient and his or her constellation of concerns has been treated, leaving the patient, careproviders, and family members in a position to move forward in the absence of recrimination. Just as classical mediation has been appreciated on a humanistic level for its embodiment of a "harmony model" of dispute resolution, antithetical to the alienation engendered by processes focused on winners and los-

ers, or right and wrong,[75] clinical ethics mediation offers the potential for healing in the context of managing clinical conflict.

In the second edition of *Bioethics Mediation*, Dubler and Liebman bemoan that "the landscape has changed and mediation is an accepted part of Clinical Ethics Consultations. Our concern, however, is that this acceptance of . . . mediation has arrived without a robust and powerful commitment to the skills that the discipline demands."[76] The skill sets and knowledge bases of mediation and bioethics that are awkwardly conjoined in the ASBH *Core Competencies* and *Charting the Future* may be causally linked to the paucity of commitment to mediation skills observed by Dubler and Liebman. The rigor necessary for acquisition of effective mediation skills is unlikely to be achieved while those skills are explicitly or implicitly painted as supplemental rather than as primary. While professional bioethicists can certainly become skilled mediators, substantial commitment and training are required. Maintenance of the *status quo* is served by continuing to countenance the primary role of clinical ethicists as providers of traditional bioethics consultation, which may be useful at the margins of clinical conflict, but will not serve the pressing needs of hospitals that have been long underserved by HECs and by clinical ethicists. As the authors of *Malignant: Medical Ethicists Confront Cancer,* opine, "Critics argue that the increased presence of medical ethicists in . . . hospitals hasn't done much to improve how patients are treated. According to the critics, the field has not done enough to promote a more patient-centered approach to medical care."[77]

CONCLUSION

Adoption of bioethics mediation as a primary clinical dispute resolution process, available at the request of patients' families, surrogates, and caregivers, would dramatically enhance the manner in which hospitals address conflict. Reliance on *bioethics consultation* by those who are expert in bioethics principles, for imposition of juridically based decisions on individuals in crisis, premised on questionably superior access to moral judgments, has been nothing short of "scandalous" and an embarrassment to the healthcare system.[78] Patients and their families, in particular, are entitled to a nonthreatening, inclusive forum in which they can be heard and respected for their relevant competencies.

Healthcare professionals from across the United States who participate in the intensive mediation courses offered by the Penn Clinical Ethics Mediation Program report increasing utilization of mediation-based skills and techniques at their institutions. As such, their ethics consultations, while not purely mediative, have moved away from an authoritarian model, while adopting greater emphasis on input from the patient/family side of disputes with caregivers. Their approaches frequently acknowledge the consultant's inability to access definitively correct moral decisions.

A strong argument can be made for mediation training that is directed at a wide range of healthcare professionals who regularly encounter conflict in a clinical setting. While many recipients of such training may never attain the skill level of committed professional mediators, familiarity with mediation theories and techniques, particularly when accompanied by participation in simulated clinical role plays,[79] can provide useful tools for the informal management of clinical conflict which, in some circumstances, may circumvent the need for a more formal mediation process. This distinction was recognized by Marcus as early as 1994 in the Montefiore report, *Mediating Bioethical Disputes*.[80]

The frequency of clinical healthcare conflicts that are not typically characterized as ethical[81] and the marginal relevance of bioethics principles to the management of morally aporetic conflicts, evidence the need for skilled mediators with a complimentary understanding of bioethics principles, or other value-sensitive constructs, for addressing pluralism in the realm of ethical conflict. While discussion of bioethics principles and prior case histories may serve as catalysts for the development of moral dialogue, so may other aspects of humanistic inquiry—psychology, philosophy, sociology,

drama—that implicate and challenge fundamental values forged in the cauldron of life experience.

Resistance to change, the protection of turf, and the vestiges of archaic, authoritarian institutional structures, create substantial (yet surmountable) barriers to the adoption of a clinical dispute resolution model that reflects the egalitarian, collaborative healthcare enterprise of the twenty-first century. The civil rights, consumers' rights, and patients' rights movements, coupled with the democratizing effects of an explosion in information technology, have forever altered the landscape of society and healthcare. The broad spectrum of informed support for bioethics mediation and its synchrony with contemporary values bode well for its future at the foreground of clinical ethics.

NOTES

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3. See note 1 above, p. 7.

4. See, e.g., D.T. Weckstein, "In Praise of Party Empowerment—And of Mediator Activism," *Willamette Law Review* 33 (1997): 502-59; R.A.Baruch Bush and J. Folger, *The Promise of Mediation: Responding to Conflict Through Empowerment and Recognition* (San Francisco: Jossey-Bass, 1994); L.L. Fuller, "Mediation—Its Forms and Functions," *Southern California Law Review* 44 (1971): 305; K.Kovach and L. Love, "Evaluative Mediation is an Oxymoron," *Alternatives to the High Cost of Litigation* 14 (1996): 31.

5. See note 1 above, p. 53.

6. See, e.g., *New Jersey Statutes Annotated,* 2A:23C-1, et. seq.

7. See, e.g., A.W. McThenia and T. Shaffer, "For Reconciliation," *Yale Law Journal* 94 (1985): 1660; L. Riskin, "Mediation and Lawyers," *Ohio State Law Journal* 43 (1982): 29; R.A. Baruch Bush, "Mediation and Adjudication, Dispute Resolution and Ideology: An Imaginary Conversation," *Journal of Contemporary Legal Issues* 3 (1989): 1-24.

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10. R.M. Zaner, *Conversations on the Edge: Narratives of Ethics and Illness* (Washington, D.C.: Georgetown University Press, 2004), 5.

11. E.J. Bergman and A. Fiester, "Mediation and Health Care," *The Penn Guide to Bioethics,* ed. V. Ravitsky, A. Fiester, and A. Caplan (New York: Springer, 2009), 173-4.

12. See, e.g., *Core Competencies for Health Care Ethics Consultation,* 1st ed. (Glenview, Ill.: American Society for Bioethics and the Humanities, 1998).

13. J. Solbakk, "Catharsis and Moral Theory I: A Platonic Account," *Medicine, Health Care and Philosophy* 9 (2006): 63.

14. T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics,* 5th ed. (New York: Oxford University Press, 2001).

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

17. See note 13 above, pp. 57-61.

18. See note 16 above, p. 356.

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27. N.N. Dubler and C.B. Liebman, *Bioethics Mediation: A Guide to Shaping Shared Solution,* 1st ed. (New York: United Hospital Fund of New York, 2004).

28. See, e.g., J.F. Anderson and L. Bingham, "Upstream Effects from Mediation of Workplace Disputes: Some Preliminary Evidence from the USPS," *Labor Law Journal* 48 (1997): 601.

29. See note 27 above, pp. 22-23.

30. L. Susskind, "Environmental Mediation and the Accountability Problem," *Vermont Law Review* 6 (1981): 1-47.

31. See further discussion, below.

32. J. Stulberg, "The Theory and Practice of Mediation: A Reply to Professor Susskind," *Vermont Law Review* 6 (1981): 114.

33. C. Elliott, *White Coat Black Hat: Adventures in the Dark Side of Medicine* (Boston: Beacon Press, 2010), 249.

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35. Ibid., 28-29.

36. See J. Menikoff, *Law and Bioethics* (Washington D.C.: Georgetown University Press, 2001), 269-76.

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42. See, generally, note 37 above.

43. N.N. Dubler and L.J. Marcus, *Mediating Bioethical Disputes* (New York: United Hospital Fund of New York, 1994).

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62. Ibid., 32.

63. See note 11 above.

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

65. J. Halpern, *From Detached Concern to Empathy, Humanizing Medical Practice* (New York: Oxford University Press, 2001), 101-27.

66. See J. Rawls, *A Theory of Justice* (Boston,

Mass.: Belknap Press, 1971), 11-16; 83-90; 235-43; 350-5; 520-9.

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72. P. Lassman, *Pluralism* (Malden, Mass.: Polity Press, 2011), 86.

73. C. Larmore, "The Limits of Aristotelian Ethics," in *Nomos XXXIV: Virtue* (Yearbook of the American Society for Political and Legal Philosophy), ed. J.W. Chapman and W.A. Galston (New York: New York University Press, 1992): 187.

74. See, e.g., J. Halpern; D. Schenck, and R. Churchill, *Healers: Extraordinary Clinicians at Work* (New York: Oxford University Press, 2012); Roter and Hall, see note 24 above; see note 21 above.

75. Fuller, see note 4 above, pp. 307-8; Riskin, see note 7 above, p. 29.

76. See note 64 above.

77. R. Dresser, ed. *Malignant: Medical Ethicists Confront Cancer* (New York: Oxford University Press, 2012), 117.

78. N.N. Dubler and J. Blustein, "Credentialing Ethics Consultants: An Invitation to Collaboration," *American Journal of Bioethics* 7, no. 2 (2007): 35-7.

79. E.J. Bergman and A. Fiester, "The Future of Clinical Ethics Education: Value Pluralism, Communication and Mediation," (publication forthcoming, GABEX book project, Japan, 2014).

80. See note 43 above, pp. 18-9.

81. An argument can be made that all clinical conflict incorporates ethical components. For example, communication-based conflict that is not ordinarily identified as ethical should be reclassified if one views a physician's duty to communicate effectively as an ethical mandate. See Halpern, see note 24 above, p. 122.

Commentary on Bergman: "Yes . . . But"

Nancy Neveloff Dubler

ABSTRACT

In "Surmounting Elusive Barriers: The Case for Bioethics Mediation,"[1] Bergman argues that professionals trained in bioethics, reluctant to acquire the skills of mediation, would better be replaced by a cadre of mediators with some bioethics knowledge, to which I respond, "yes . . . but."

Bergman's article is an important contribution to a vital current conversation. Any discussion highlighting the importance of mediation in clinical ethics consultation (CEC) is heartening. However, among the useful historical and conceptual information imparted, the author has a "pitch," that maximum use of mediation to address conflict in the healthcare setting is being hampered by the notion that mediation should be employed as part of CEC. He sees CEC as the assumption of superior moral skills and the paternal use of those skills to resolve what he notes to be aporetic conflict where "*Moral aporia* indicates a state of perplexity, impasse, deadlock or stalemate 'from which there is seemingly no way out, thus forcing the conflicting parties involved to come to a mutual understanding of their ignorance and helplessness about how to proceed.' "[2]

Bergman argues that professionals trained in bioethics, reluctant to acquire the skills of mediation, would better be replaced by a cadre of mediators with some bioethics knowledge, as freestanding intervention teams growing out of and supported by the sufficiently robust tradition of mediation itself. This is more than interesting. It is *the* issue that must be addressed before mediation can be seen either as a legitimate intervention itself, or as one of, if not *the key* ingredient in CEC when the issue presented is the resolution or management of conflict.

Bergman states:

> The premise that a clinical ethics mediator should be, first and foremost, a professionally trained bioethicist is dubious, in that the primary skills demanded are in the realms of empathy, communication, insight, creativity, trustworthiness, and process management. This is not to suggest that basic knowledge of bioethics principles should be omitted as a component of clinical ethics mediation training, but that the dominant skill set lies elsewhere. Indeed, bioeth-

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

> ics principles may be useful to the practitioner in the creation of chart notes expressed, for the benefit of peers, in a common language.[3]

To that analysis, I would answer, "yes . . . but." First of all, arcane and unfamiliar words such as *aporetic* muddy rather than clarify any argument and tend to shut down discussion as if the philosophical term were dispositive. Most of the instances in which CEC is requested are not self-consciously, or in any way, thought of or described as instances of *moral aporia*. They are conflicts, disagreements over which decision, by whom, based on what facts and what understanding of those facts, will lead to an outcome that is in the best interests of the patient. Yes, the following vignettes could be shoehorned into a box labeled "moral *aporia*," but why do that? The discomfort is real however we label its philosophical underpinnings. The distress generally involves careproviders wondering whether this is really the best course for the patient, and the patient and family pondering whether their values, beliefs, and wishes will determine the decision.

Bioethics mediation does not address only moral discomfort, it addresses the *despair* of providers facing family members, and occasionally patients, who seem not to care about the medical diagnosis and prognosis, the looming risks and absent benefits that have been explained repeatedly, that seem to have no effect on reasoned decision making. Bioethics mediation addresses patients and families who feel they have been run over by the juggernaut of care, provided by the best intentioned physicians and nurses, who sense a hopelessness that they, the family, will be heard and heeded. Families fear that nothing will amplify their voices, belief systems, and values sufficiently so that these are honored and respected.

The following vignettes attempt to present the realities of bioethics mediation in the context of patients, family members, and dedicated providers. They will, moreover, make a point that is addressed in various writings but never, in my mind, made sufficiently clear. CEC is a critical nesting site for mediation skills, as it is an accepted part of healthcare institutions and conversations. Some commentators query whether CE consultants may, therefore, not be sufficiently independent. However, consider, in these stories, how their connectedness led to options that might not have been as easily available. Consider also how the mediation skills and bioethical intuitions functioned as hand maidens in the process.

Bioethics mediation addresses the disbelief of a director of an ICU (intensive care unit), facing a patient with end-stage AIDS, who is obtunded and ventilator-dependent with failing kidneys, whose family says, "Do everything," and wants to make arrangements to take the patient home.

Bioethics mediation combats the incomprehension of a surgical resident whose patient, with a fulminating breast cancer lesion, refuses surgery and will not give a reason for her decision.

Bioethics mediation searches for why a patient who has multiple heart blockages and can no longer walk across the room is refusing CABG (coronary artery bypass surgery), for which he is an excellent candidate and which will likely restore him to a prior level of health.

Or, finally, consider Isaiah, a 15-year-old dying of perinatally acquired HIV infection from his heroin-using Mom. He had lived for many years with the disease and had finally been sent by a judge to get treatment because he looked so ill. But the clinic to which he was sent prescribed pills, and no one had ever taught him to swallow a pill. By the time he arrived at the hospital with end-stage AIDS and kidney failure, he had passed the markers that could be reversed to restore his health, and palliative care was his only option.

Let us take each of these vignettes in turn and ask, in each case, if the knowledge, skills, and approach of a person trained in bioethics and mediation might differ from a professional who is trained primarily in mediation. Also note how familiarity with a healthcare institution plays a role in identifying viable options for that particular institution. This last is different from bioethical knowledge. Let us call it "institutional savvy" or "particularized bioethics sav-

vy." In some cases it may be the most important information.

Vignette 1, a woman dying of AIDS in the ICU. The bioethics mediator first met with the legally appointed healthcare proxy of the patient, a 21-year-old daughter who was working full time while attending college full time. The mediator and the daughter then met with the director of the ICU. The daughter stated that she understood the issues, but that her eight siblings, her grandmother, step-grandfather, and other involved family members would need to be involved in the decision. Their collective goal was to bring the patient home to die. She understood that she had the legal authority to make a decision for her mom. She was clear, however, that the moral authority and responsibility was in a space shared by many others. The bioethics literature states that healthcare agents should try to do what a patient would want—if known—and what is in the best interest of the patient, if they are unaware of the patient's particular preferences. However, equally important is to fashion a solution that permits the family and loved ones to go on comfortably with each other when the patient dies.[4]

The next evening, all of the siblings and other relatives—17 persons, many of whom only spoke Spanish—all met in a large room near the ICU. It emerged that the patient, although unable to stop using heroin, was the moral center of her family. Grandma had raised the children, but Mom, whenever she was able, had been deeply involved in their lives and care. Using STADA (**S**it, "**T**ell me about Mama," **A**dmire, **D**iscuss, **A**sk),[5] the mediator first let everyone talk about MOM. Then she admired the family for their love and devotion. Finally, the ICU director, who was fluent in Spanish, began discussing the patient's status and then moved, slowly, to the statement that she was dying. There were many tears, a growing acceptance of the impending death, but also insistence that Mom be moved home to die. What emerged was that the family wanted to be with her every second, so that there was no possibility that she would die alone. Their "do everything and bring her home" translated into a burning interest to prevent the patient's aloneness.

The bioethics mediator who knew the rules for entrance into hospice and home hospice, as well as the rules for ventilator support in a home, realized how difficult, or impossible, this would be to accomplish. She had asked one of the members of the palliative care team to be at the mediation so that this person might be able to construct some kind of in-hospital solution that might substitute—not really, but in the reality of U.S. healthcare Medicaid financing—for home. This was useful, as the palliative nurse practitioner could promise a private room with 24-hour access, which was, in fact, the most important issue for the family.

This vignette demonstrates the utility of knowledge about the funding for and limitations of home care, and savvy about the palliative care structure of an institution. Would a mediator not familiar with these have been able to have help the parties formulate a solution? Probably not as quickly, as she or he would need to do some fact-finding. But the strictures and structures the family faced would have been evident quickly with the help of a good social worker, who should have been involved before this, and, if logistically possible for an evening meeting, should have been a part of the mediation.

But the bioethics mediator was not only a person resolving conflict between the family who was saying "do everything" and the physician's perception that the patient was in the process of dying. Here the CE consultant knew the members of the relevant teams and the limitations on funding imposed by Medicaid. Both were necessary components of a solution. The mediator also knew the literature, which argues that persons who have been appointed as healthcare agents must try to do what the patient wanted, or what is best for the patient in the context of what the living can accommodate in their future relationships.

Vignette 2, the woman who has a fulminating breast cancer lesion. The patient had refused surgery and would not give a reason for her decision. The surgical fellow called for a CEC. Here knowledge of the literature on refusals of care needed to be central to the approach taken by the mediator. I teach that refusal of care by a presumptively decisionally capable patient is

not the end of the discussion: it is the beginning of the inquiry. One must query, Why is she refusing? This lesion is oozing, painful, malodorous, and disgusting to the residents who must change the dressing twice daily. There is a litany of questions to consider, based on the literature: Is this patient capable of making ethically and legally binding decisions about her care? Even if she seems capacitated, is she delusional or delirious? What definition of capacity could she meet? Is there a psychotic denial[6] at play? Does the fact that she is being seen by residents and fellows mean there is no senior physician who has established a relationship of trust with her? The literature demonstrates that lack of a trusting relationship is often a primary reason for refused care. Is there an economic core, a fear of costs to her husband? Is there a misunderstanding of the purpose of the surgery? Given the advanced state of the cancer, might she be right: that if the disease is metastatic and she is dying, can the surgery be curative? If it is clearly palliative, is it morally superior to morphine? None of these concerns is articulated by the patient, but would need to be in the mind of the consultant.

The fact that a patient looks and sounds "together" may not mean that she is "playing with a full deck," to quote my former colleague John Arras. The bioethics literature makes the mediator super-alert to these issues in patients of any age who might be delirious (a condition extremely difficult to diagnose and address) or in elderly demented patients, who might remain socially appropriate but who have such compromised short-term memory that real capacity (which includes the ability to remember a decision and incorporate it into ongoing planning) cannot exist.

A mediator who is not schooled in bioethics concepts and best practice would not have his or her explorations with the physician and patient grounded in this literature. And it is precisely this literature that alerts one to the issues that need to be explored. It is this fact, and the notion that everything that goes on in the hospital is under the legal and moral umbrella of the attending physician, that makes the bioethics mediator a self-conscious player in the mix of other careproviders: independent, but not alone. It is this fact of focused responsibility that requires a bioethics mediator to write a note in the chart describing the intervention, setting forth the recommendation and explaining her or his role. And it can only be a recommendation, as the legal care of the patient is the responsibility, and under the authority of the attending physician. The mediator, as a CE consultant, must understand the dynamics of the intervention and the "principled solution"[7] that sets the boundaries for the consensus reached. Thus the options and the possibilities for a decisionally capable patient are in stark contrast to a patient who is delirious or in psychotic denial. The mediator does not need to make a call on the differential diagnosis, but needs to be alert to the possibilities, so that she or he can call for the psychiatric consultants who have the skills, in complex cases, to determine the patient's cognitive status and consequently level of moral agency—although for most patients decisional capacity is a straightforward component of the clinical picture and is clearly within the skills of the clinical team. And, as these vignettes illustrate, the CE consultant must know the staff at the institution who might be helpful. In this case, on the day after Thanksgiving, a call on a private line to a valued psychiatric colleague drew on the bioethics mediator's "favor bank" and produced a liaison psychiatry consultation from a senior skilled person.

This leads to the focused question: What is the knowledge base and skill base that a bioethics mediator needs to resolve the moral uncertainly and the practical questions that lie at the vortex of conflict at the bedside? Underscoring, at this point, that if a mediator does not help to resolve these questions, identifying and incorporating the values, beliefs, wants, desires, and preferences of the patient and the family, then other forces within the hierarchy of medicine or the administration of the institution will make the decision. These are not decisions that can be put aside for later. They will be decided at the moment to acquit the legal responsibility of the physician and the institution or to reflect the values of the patient and the family. Medi-

cal decisions have a built-in time trajectory, often along a spectrum leading to the label of "emergency." In emergencies, the usual rules for decision making for individual informed consent are set aside and replaced by abstract notions of medical need and effectiveness. Someone will surely argue that this woman is in danger of sepsis if the breast is not removed. That argument, absent her and her husband's views, will then determine the care.

The mediator needs to know *enough about*[8] the ethical framework of decisions, about the medicine of the intervention, about the empirical and theoretical literature of clinical ethics, about theories of conflict resolution, about skills of mediation, to use these skills in pursuit of a consensus that, while perfect for none, is acceptable to all. Moreover, the mediator must ferret out and amplify the values and voices of the patient and family, as the values and voices of medicine infuse all decisions. Without these interlocking pieces of the skill set, the complexities of the situation will be missed.

Vignette 3, the patient with multiple heart blockages. We assume the patient is a capable adult living in the community who is refusing CABG surgery. This is a complicated intervention that may be successful and return the patient to a prior status of robust health or may leave lasting negative cognitive consequences. Patients do refuse CABG surgery. But this patient was a very debilitated, educated African-American man, who seemed to understand that he was a good candidate and was likely to have an excellent outcome. As a mediator or a CE consultant, you might first look to the framing fallacy, that is, had the risks of the surgery been framed as a chance of dying rather than of living? All mediators would try and understand the prior conversations and how and whether the ideas of the surgeon and the patient were similar. Here is a capable patient and it should be possible to penetrate to the issues, in pursuit of agreement. Two concerns emerge: one regarding finances and one regarding the patient's grandson. The patient is the boy's guardian, and the patient is reluctant to leave the boy for the period of hospitalization. Once brought to the surface, these issues can be addressed, especially if part of the team who is meeting with the patient is a skilled social worker.

In this case, a trained mediator would be very helpful in separating out issues and interests and in generating options that may meet the concerns of the patient. There seem to be no focused bioethics interests. But attention must be paid to the documented disparities in healthcare for persons of color, the epidemic of grandparents who raise children as a result of the crack and AIDS epidemic, the regular exclusion of patients of color from regular medical care, all of which lead to distrust and anger. Is all of this a concern for the mediator? It might be. The literature on disparities of care[9] describe a clear pattern of exclusion from medical care that surrounds persons of color. Echoes of Tuskegee[10] still circulate in the African-American community and regularly are at play in patients who refuse care, thinking that it is some sort of research. This was a critical barrier for persons needing care in the midyears of the AIDS epidemic. These sorts of issues are important for all mediators working in diverse populations, but have particular relevance in medicine, given the need for trust

Vignette 4, young Isaiah. This was not the real name of this African-American young man, who had supported himself and his drug-using mom by running as a drug carrier.[11] Once, when he and his mom were subject to a petition for eviction, he came to the judge with his mom and explained that nothing would be gained by evicting them, as they would then burden the homeless system. By the time he came to the hospital, he was dying. He gave a class to the medical students on dying as an adolescent. He was beloved of the staff. (My job was to bring him red gummy bears, which he loved.) One day, as his health status declined one more notch, the director of pediatric nephrology explained a do-not resuscitate (DNR) order to Isaiah, who indicated it would be his very strong desire. But while Isaiah knew he was dying, Mom refused to face this fact. When she came in, Isaiah's decision was explained to her, and she objected. She said he was just a boy, and she could not see that he would not get better, and she would not agree to a DNR. The adoles-

cent medicine staff had a firm rule of never treating an adolescent patient over his or her objection, and Isaiah was a capable decider. After Mom left, one of the nurse managers, the CE consultant on this case who had managed the discussion between the patient and his mom, wrote a note in the chart and sent a copy round to the CEC team. She sent it to the institutional medical director, who stated that the institution would back the patient. When queried if legal affairs needed to sign off, he stated "No." Two nights later Isaiah coded, and Mom demanded that he be resuscitated. He was not.

Bergman states, "there is no universal clinical ethics canon and, perforce, no uniform system of decision making with appropriate safeguards. Resort, in traditional ethics consultations, to 'authority', in the form of opinion voiced in the bioethics literature, and claims that said literature constitutes a consensus, are subject to widely differing interpretation and selectivity of sources."[12]

So, I will end with the "yes . . . but" with which I began. In my discussions of the "Principled Resolution" I state,

> A principled resolution is a "consensus that identifies a plan that falls within clearly accepted ethical principles, legal stipulations, and moral rules defined by ethical discourse, legislatures, and courts, and that facilitates a clear plan for future intervention." In 2005 Carol Leibman and I were first struggling with the tensions among three competing factors: (1) the stringent limits imposed by law on medical providers and institutions, (2) the powerful decision-making authority permitted to individual patients and families in medical decision making, and (3) the power imbalances that infuse the operations of the modern hospital and medical center. The notion of a principled resolution combines the strengths of a mediative process that levels the playing field with legal norms and ethical conventions, and uses both as support for forging a consensus. A principled resolution reflects the deep and thorough support in the law and in society for decisions of patients and families, especially when these decisions contest the juggernaut of modern, institutionalized medical care.[13]

And, finally: "Bioethics mediation is the progeny of bioethics as a field of scholarship combined with the skills and perspectives of mediation. It uses those skills, however, within the framework of case law and regulation, much as child-custody mediation uses the notion of the child's best interest against which to measure the appropriateness of adult agreements."[14]

I stand by these precepts and argue that this richer and broader sense of bioethics mediation is what is required for the benefit of patients, providers, families, and institutions.

ACKNOWLEDGMENT

Many thanks to Carol B. Liebman, who read an earlier draft of this manuscript and tried her best to prevent my public humiliation.

MASKING OF PATIENTS' IDENTITIES

Details in the vignettes have been changed to protect the identities of the patients and their family members.

NOTES

1. E.J. Bergman, "Surmounting Elusive Barriers: The Case for Bioethics Mediation," in this issue of *JCE.*

2. Ibid., quoting J. Solbakk, "Catharsis and Moral Theory I: A Platonic Account," *Medicine, Health Care and Philosophy* 9 (2006): 63. (A note reference number was deleted.)

3. Bergman, see note 1 above.

4. T. Powell, "Extubating Mrs. K: Psychological Aspects of Surrogate Decision-Making," *Journal of Law, Medicine and Ethics* 27 (1999): 81-6. N.N. Dubler, ed., "In Symposium: The Doctor-Proxy Relationship," *Journal of Law, Medicine and Ethics* 27 (1999): 5-86.

5. N.N. Dubler and C.B. Liebman, *Bioethics Mediation, A Guide to Shaping Shared Solutions,* 2nd ed. (Knoxville, Tenn.: Vanderbilt University Press, 2011), 4, 74, 75.

6. R. Goldbecka, "Denial in physical illness," *Journal of Psychosomatic Research* 43, no. 6 (December 1997): 575-93.

7. The definition of *principled resolution* is from

bioethics mediation, see note 5 above, pp. 14-15, 302; the definition of "legal principles," ibid., pp. 24, 70, 271. See also, *Core Competencies for Healthcare Ethics Consultation*, 2nd ed. (Glenview, Ill.: American Society for Bioethics and Humanities, 2011), 6, fn 13, regarding "principled resolution."

8. *Core Competencies for Healthcare Ethics Consultation,* 2nd ed., see note 7 above, pp. 19-32.

9. Institute of Medicine (IOM), *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, D.C.: National Academy Press, 2002); IOM, *How Far Have We Come in Reducing Health Disparities? Progress Since 2000—Workshop Summary* (Washington, D.C.: National Academy Press, 2012).

10. U.S. Public Health Service, "Syphilis Study at Tuskegee," 2011, *www.cdc.gov/tuskegee/index.html,* accessed 17 February 2013.

11. When draconian drug laws were passed in New York State, drug lords began using teens who were not subject to the same penalties.

12. Bergman, see note 1 above.

13. N.N. Dubler, " 'A Principled Resolution': The Fulcrum for Bioethics Mediation," *Law and Contemporary Problems* 74, no. 3 (Summer 2011): 177-200, p. 179. (Note reference numbers were removed.)

14. Ibid., p. 188. (A note reference number was deleted.)

The Chiaroscuro of Accountability in the Second Edition of the *Core Competencies for Healthcare Ethics Consultation*

Lisa Rasmussen

ABSTRACT

"Chiaroscuro" is a art technique that makes use of light and shade to suggest depth and solidity on a flat surface. I argue that the standards regarding accountability in the second edition of the *Core Competencies for Healthcare Ethics Consultation* (*CC2*),[1] are chiaroscuro, because, despite the offered lists of competencies, it is very difficult to imagine how consultants might be held accountable to such standards. It is not clear to which of the many suggested standards a consultant should be held accountable, and even if one stipulates that only the tabulated competencies are meant as standards, the vague wording makes it hard to know how a consultant might fail to meet the standards or perform excellently. In addition, because terms such as "ethics" and "ethical" are not defined in the document, we are left with no way to determine whether consultants have made appropriate recommendations. The document is useful as a point of discussion, but not yet ready to serve as a tool for holding practitioners accountable.

Lisa Rasmussen, PhD, is an Assistant Professor in the Department of Philosophy at University of North Carolina in Charlotte, *lrasmuss@uncc.edu.*

INTRODUCTION: MOUNTING PRESSURE FOR STANDARDS

In the early days of clinical ethics consultation, academics whose work focused on ethics were invited to reflect on clinical dilemmas. This was usually undertaken by individuals (such as philosophers or theologians) whose employment and research focus lay elsewhere. Over time, and for a variety of reasons, clinical ethics consultation has grown, and for many individuals it now constitutes a significant and increasing proportion of their professional responsibilities. This has contributed to the movement to establish clinical ethics consultation as a distinct profession, with its own code of ethics, training standards, certification, et cetera. This is a significant step, for it implies that clinical ethics consultants have a set of skills to offer, one distinct from sets available in existing professions or academic disciplines.

While a significant step, however, it is also problematic. In the past, those contributing their expertise to cases in clinical medicine were almost invariably employed in distinct disciplin-

ary or professional homes (for example, theology, law, philosophy, and medicine) with established standards of evaluation for competence—for example, through peer assessment of research, teaching success, and service contributions. But the more that an individual's work time was spent on the new task of clinical ethics consultation, the greater the need to construct and make transparent the new standards by which she or he should be evaluated for work in that area.[2] In addition, as the practice of clinical ethics consultation expands, its reception (especially by those who pay for it, but also by those who make use of it) will depend in part on whether others understand what to expect of a competent clinical ethics consultant.

As a result of these factors, clinical ethics consultants began to discuss the establishment of practice standards. These discussions have focused on several fronts—for example, a proposed code of ethics,[3] a working group considering credentialing in the field,[4] and the formation of a task force by the Society for Health and Human Values and the Society for Bioethics Consultation devoted to articulating a set of skills for the field of clinical ethics consultation. The first edition of the *Core Competencies for Health Care Ethics Consultation*,[5] the result of the task force's work, was initially published in 1998 (hereafter, *CC1*) and was revised in 2011 (hereafter, *CC2*). A body within the American Society for Bioethics and Humanities (ASBH), the Clinical Ethics Consultation Affairs (CECA) Committee, was recently appointed "to develop standards for ethics consultants working in clinical settings and to ensure clinical ethics consultants' competency and integrity."[6]

Some of these trends have been motivated by the desire to transform the practice of clinical ethics consultation into a profession. However, it is both possible and important to separate two distinct aspirations for the field. On the one hand is the desire to create a profession; on the other is the desire to clarify standards of accountability in the practice. Although professionalism requires accountability, the reverse is not true: it is clearly possible to establish standards of accountability without establishing a profession.[7] Therefore, establishing accountability standards seems like the appropriate first step in clarifying the role of the clinical ethics consultant, independent of whether or not it is considered to be a profession. Insofar as practitioners of clinical ethics consultation think there are ways in which the activity can be conducted poorly or objectionably, it is necessary to articulate what poor or objectionable practice consists of, and how to avoid it.

The *CC2* continues to be the most comprehensive set of standards yet devised for the field of clinical ethics consultation.[8] Proponents of a certain conception of clinical ethics consultation that was omitted from the document could complain about that omission; alternatively, skeptics of the entire field could complain that the document fails to justify robustly the field's very existence. Such arguments may or may not have merit, but at any rate are not my concern. Instead, I approach the *CC2* as a supporter of the field of clinical ethics consultation, with genuine puzzles in mind about the parameters of appropriate practice. Most immediately, appropriate practice is codified in standards of accountability—what practitioners will be held responsible for doing or failing to do. The *CC2* is presented as including standards of accountability, but several problems compromise the document's usefulness in holding consultants accountable, as I will argue.

THE PURPOSE OF THE *CORE COMPETENCIES*

In order to critique the *CC2* for problems with holding consultants accountable to its standards, it must first be shown that this is a central purpose of the document. The task force for the initial report (*CC1*) was assigned the purpose of exploring standards for healthcare ethics consultation. Specifically, "the work of the Task Force was motivated by the belief that when patients, health care providers, or others seek the assistance of health care ethics consultants, ethics consultants should be *competent to offer that assistance*" (*CC1,* 1, emphasis added). That focus seems to continue in *CC2*:

"The ultimate concern of this Task Force is quality assurance and improvement in ethics consultation. Patients, families, surrogates, and health care providers should be able to trust that when they seek help sorting through the ethical dimensions of health care, ethics consultants are *competent to offer that assistance*" (*CC2*, 19, emphasis added). The problem indirectly identified is that clinical ethics consultation is regularly conducted by individuals and teams with strikingly different training and ability, and the task force recognized a need to address the question of competence.

The report focuses on four main areas that: "(1) define the nature and goals of HCEC; (2) identify the types of skills, knowledge, attributes and emerging process standards that are important for conducting HCEC; (3) discuss the evaluation of HCEC; and (4) examine HCEC as an emerging profession" (*CC2*, 1).[9] ("HCEC" is an acronym for healthcare ethics consultation.) In the end, despite the motivating concern regarding ensuring competence in consultation, the initial report made no binding or even strongly suggested recommendations in that direction.

> The Task Force unanimously recommends that the content of this report be used as voluntary guidelines. . . . The Task Force:
> - does not wish certifying or accrediting bodies to mandate any portion of its report
> - believes that certification of individuals or groups to do ethics consultation is, at best, premature
> - does not intend for its report [to be] used to establish a legal national standard for competence to do ethics consultation . . . [*CC1*, 31].

It is likely that, in part due to this retreat at the end of the report, there has not been much in the way of professional adoption of its recommendations.[10] The stance has changed somewhat in *CC2*, from rejection to "endorsement" of using the proposed standards to hold consultants accountable. The task force recognizes "a growing demand to ensure that individuals performing HCEC are qualified to do so," "supports the ideal of having at least one individual who possesses advanced HCEC competencies among the individuals who perform ethics consultation at each facility," and "endorses holding individuals performing HCEC accountable to the standards outlined in this report" (*CC2,* 51).

I take this last phrase ("endorses holding individuals performing HCEC accountable to the standards outlined in this report") as the basis for my critique of the *CC2* document, for several reasons. First, as the task force's own declaration of its aims, it provides the means for assessing the success of the report on its own terms.[11] Second, the basis of some critiques of clinical ethics consultation is that the field is utterly without standards and a means to hold anyone accountable to them, so an articulation of such standards would provide a strong response to critics of the field. Third, I think it accurately represents what *is* part of the goal of the accountability and professionalizing movements, to establish standards for clinical ethics consultation and hold consultants accountable to them as a matter of integrity and responsibility. Finally, I think it is a reasonable statement of what *ought* to be a goal of the accountability and professionalization movements.

What is accountability? Obviously it means the ability to be called to account for one's actions or decisions, which can be interpreted internally or externally. Internal accountability would be holding oneself accountable to one's own standards (for example, a sense of personal responsibility or integrity), and external accountability means being subject to review by others. The more common understanding of accountability is the external sense rather than the internal sense, because an external standard (such as a code of ethics) provides some transparency for the practice and an important check on power without requiring us to leave standards up to individuals' views of their personal responsibility (although this does not prevent internal standards being employed in addition).[12] Therefore, the kind of accountability needed for clinical ethics consultation is one that could be enforced or monitored externally (by a professional or other organizing body).[13]

One is accountable for X if one is responsible for making X the case. So, because one cannot be responsible without being *able*, establishing accountability requires answering a question of ability. Put more philosophically, "ought implies can": it makes no sense to say that clinical ethics consultants *ought* to do something if they are not *able*. There are at least two senses of ability: ability in the sense of something being within one's capacity, and ability in the sense of empowerment. Someone needs both the competence to do something and the power of permission to do it, for us justifiably to hold her or him accountable. For example, a lawyer who is board-certified in state A may have the legal skill to try a case in state B, but is not empowered to try a case in state B in the absence of bar admission there. The reverse can also be imagined: the head of a federal agency may be empowered to act in an emergency, but lack the competence to do so effectively.

The result of this conceptual parsing is that to be held externally accountable, clinical ethics consultants must possess the competence (ability) and be granted the power to do the things for which they are to be responsible. It is worth first considering the "power" aspect of accountability to the *CC2*—that is, to be held accountable, one must be empowered to perform one's responsibilities. This is a helpful facet of the *CC2* because, to the extent that something like the report is formally adopted, this point would enable consultants to explain to their employers the range of power or permission required to perform the job effectively. That is, consultants can argue that if they are to be held accountable for offering reasonable recommendations in clinical ethics situations, it is vital to understand the facts of the case. Consultants must therefore have access to patients, their charts, and their healthcare providers to "discern and gather relevant data" and "assess the social and interpersonal dynamics of the consultation" (*CC2,* 22). The interference (active or passive) by an institution or employee with this process results in a situation where consultants cannot be held accountable because their pursuit of their task is being obstructed. Several professional work conditions follow—for example, as part of their professional role, consultants should have a reasonable purview to ask relevant questions without censure, or to request meetings even with busy providers in the reasonable expectation that the request will be honored.

The importance of this should not be minimized; consultants simply cannot perform effectively in an environment in which the administration does not make it possible for such steps to be taken. Consultants frequently observe that the initial reason stated for an ethics consult (for example, "refusal to withdraw care") is not what turns out to be the actual issue; consultants must be granted the latitude to probe for further information to ascertain what the problem actually *is*.

On the other hand, for consultants to be able to be held accountable entails that it is actually possible to be held accountable to the standards. The problem with some of the standards articulated in the *CC2* is that consultants may literally not be able to comply with them, because they are vaguely stated or ill-defined, as I argue below.

PROBLEMS WITH ACCOUNTABILITY

To reiterate, the *CC2* "endorses holding individuals performing HCEC accountable to the standards outlined in this report" (*CC2,* 51). The task force thus identifies accountability as an important aim, and endorses holding consultants accountable, but offers no conception of what an accountability process or official body for monitoring this would be. This is a trivial problem, because one document is not necessarily meant to serve every purpose. Whatever body is set up to help govern the profession, the task force might endorse, as one aim of the governing body, taking the competencies articulated in the *CC2* to be the basis of a formal process or structure of accountability. The document need not itself specify how this is to be done. However, other problems render it difficult to envision holding consultants accountable to this set of standards.

Practical Problems

An initial puzzle is, which among the many suggestions in the *CC2* are held to be the accountability standards? For example, one standard of accountability might be whether or not consultants achieve the *CC2's* stated goals for consultation: to "identify and analyze the nature of the value uncertainty or conflict that underlies the consultation" and "facilitate resolution of conflicts in a respectful atmosphere with attention to the interests, rights, and responsibilities of all involved" (*CC2,* 3). Other duties are also outlined: "the consultant should notify the involved parties that . . . they may be obligated to report egregious violations" (*CC2,* 4-5), although what constitutes an "egregious violation" is not defined; consultants should not use either the "authoritarian" (authoritatively telling patients what to do) or "pure consensus" (seeking mere agreement) approaches to consultation (*CC2,* 6-7); consultation services should formulate a "thorough and systematic process" for consultation (*CC2,* 12); et cetera. A more likely (but not certain) conclusion is that the accountability standards the task force had in mind are only the competencies themselves, which are summarized in the three categories of skills, knowledge, and attributes (*CC2,* 19). A further ambiguity there, however, is whether only the competencies listed in tables 2 and 3 (*CC2,* 25, 27) should be used for accountability purposes, or instead the more comprehensive (and very long) lists in section 2.2-2.4 (*CC2,* 22-33)? My intention is not to analyze any of these particular suggestions, merely to illustrate that there are many potential accountability standards, depending on which are taken to be most important. This is not a trivial point, because a minimum condition of holding individuals accountable to a set of standards is that one is able to articulate exactly what those standards *are*. As a result of these ambiguities, I will take a relatively narrow interpretation of "standards" as referring only to the tables 2 and 3 in *CC2*, so that I do not attribute more to the report than was intended.[14]

Even then, there are practical problems. The task force acknowledges that consultations can be performed by individual consultants, teams, or committees, and points out that "This Report thus identifies the competencies of a clinical ethics consultant who may function alone . . . as well as the minimum competencies of the *ethics consultation service* (if being provided by a group of individuals who do not each possess all the minimum required competencies outlined in this Report)." (*CC2,* 19, fn 46). In the individual model, who will be held accountable is straightforward, but if the *service* fails to meet the minimum competencies, who will be held accountable? The chair? The institution? Each member? Presumably something like this can be worked out in the details, but it bespeaks a failure to consider just how accountability to the *CC2* might actually work.

Problem of Definition

One main problem with the *CC2* is that it is difficult to establish standards of accountability when a key term, "ethical," (this also includes the variants "moral" or "value") is both undefined and subject to radical disagreement. The problem is compounded, as I articulate below, because it is not clear which standards we should take as the appropriate accountability standards.

The idea that consensus exists regarding what constitutes an "ethically acceptable" choice in a clinical ethics consultation is patently absurd, and, if it were true, it might mean much less work for clinical ethics consultants than is presently enjoyed.[15] Such a consensus does not exist, and *CC1* directly addressed the worry that credentialing standards in consultation might enforce a single moral view: ". . . certification could lead to the institutionalization of a particular substantive view of morality, a certain view of the relation between ethical theory and practice, or one conception of the relative importance of skills that are important for ethics consultation" (*CC1,* 31). Yet in the *CC2*, the recapitulation of that point reads as follows: "Accrediting graduate programs to train ethics consultants to conform to established standards, it was thought, could promote a myopic view of the theory and practice of ethics consultation" (*CC2,* 51). It is the conclusion of the task force that these barriers are no longer

problematic, yet the point about the danger that certification "could lead to the institutionalization of a particular substantive view of morality" is simply dropped without acknowledgment. There are reasonable arguments that consensus exists on *some* issues in clinical ethics consultation, such as the need to obtain consent to treatment for a competent adult patient, which could form the basis for such a claim. Those arguments have not been offered in the *CC2*, which means it would be very difficult to hold consultants accountable for recommending or sanctioning an "ethically unacceptable" choice that wasn't also (like consent) a legal requirement (in which case, the accountability derives from existing laws, not necessarily from the *CC2* or existing moral consensus). Overall, the *CC2* relies on an implicit notion of what constitutes an ethical solution to a clinical ethics problem, which means that although consultants are held accountable to the standard of offering ethical recommendations, what that means—and therefore how to identify when it has been achieved—is radically open to interpretation.

A further problem involves the point made above regarding which standards—the tables or the longer lists in the report—are meant to be the standards of accountability. Relying solely on the tables is somewhat less problematic, because most of the skills listed there direct consultants to act on relatively straightforward tasks such as "identify the nature of the value uncertainty" (*CC2,* core skill A-1, 25), which may only require establishing what is at issue. On the other hand, if the longer lists are meant to give concrete help in applying the competencies listed in the tables—if they are amplifications and clarifications of the more succinct, tabulated skills—there are more significant problems. For example, in the longer lists, *CC2* recommends that among the appropriate tasks of the ethics consultation service is "apply relevant ethical considerations," and "identify and justify a range of ethically acceptable options" (*CC2,* 23). The glaring question is, what constitutes a "relevant ethical consideration" or an "ethically justifiable option?" According to which standards is something rendered "ethical"? Is the fact that a patient belongs to a religion that requires submission to a recognized authority (husband, minister, church elder) a "relevant ethical consideration" requiring a solution, for example, or is it instead an exercise of autonomy? Must a consultant who opposes abortion consider it to be and present it as an "ethically justifiable option"? The reliance on an unspecified notion of "ethical" means that although consultants might be held accountable for offering only "ethically justifiable" solutions, what counts as "ethically justifiable" is at the discretion of the consultant, a particularly problematic notion if the field is trying to establish practice standards for external accountability. Or, if it is not at the discretion of the consultant, the unstated premise here is that there is enough consensus over what lies within the range of "ethically acceptable" that no more needs to be said. Because the standards of what counts as "ethical" or "moral" are not possible to interpret from the *CC2*, both because the terms are undefined and because of uncertainty regarding what should be taken to be the proper accountability standards, consultants would be responsible for something they cannot identify. We should not endorse holding consultants accountable to such nebulous standards.

OTHER PROBLEMS

I have been arguing that the *CC2* fails to offer tenable standards of accountability, which is one of its stated goals and ought to be the goal of a document such as this. However, it is also worth considering what has been omitted from the *CC2* that perhaps should have been addressed.

One omission is that it does not address impermissible practice or behavior. There are sections on conflicts of interest and obligation, as well as confidentiality (*CC2,* 48-49), but no accountability standards for refraining from such practices.[16] It might have been worthwhile to establish some boundaries of permissible behavior, both because that would provide transparency regarding how others should evaluate consultants' practice, and because it would be relatively straightforward to assess adherence

to a proscription. For consultants concerned with the integrity of their practice, as much as for critics, it is important to be able to articulate standards of inappropriate behavior or action in the conduct of clinical ethics consultation.

Another problem is that the *CC2* verges on equivocating on the notion of "standards." The *CC2*, much like the initial *CC1*, seems to describe current practice in an effort to standardize it. Yet obviously standardizing (making things uniform) isn't the same as setting standards (establishing limits of acceptable behavior). For example, Core Skill I-2 states, "Educate involved parties regarding the ethical dimensions of the consultation" (*CC2,* 25). If all consultants were to follow this standard, then we might see that consultants *uniformly educate involved parties* (the practice of education has therefore become standardized). Yet one consultant may educate an involved party that abortion is impermissible, and another that it is permissible. I think that what critics of the field worry about is the latter point (the lack of consistency of ethical advice in consultations—that is, what ethical standards ought to be met), not whether or not all consultants are educating involved parties. The very general categories of the competencies (for example, "effectively run an HCEC service," "elicit the moral views of the involved parties," and "utilize institutional structures and resources to facilitate the implementation of the chosen option") (*CC2,* 25, table 2), may ensure that all consultants know about and attend to the same general categories of their practice. However, absent a metric of success, these and other *Core Competencies* do not establish a practice *standard*.

This is problematic for two reasons: first, as I have been arguing, it is difficult to hold consultants accountable to vague standards. Second, critics might observe that what the field needs to engender trust is a way to identify when practitioners have not lived up to the standards that should be expected, and a mere description of general categories of practice does not satisfy this need. *Standards* are much more normatively forceful than are standardized categories. For standards of practice to succeed in establishing the field's integrity, it is important both that non-practitioners be able to ascertain whether consultants have acted inappropriately, and that practitioners be able to point to standards to defend an appropriate but unpopular action or recommendation. This will be difficult with the standards recommended in the *CC2*.

CONCLUSION

What becomes clear with an evaluation of the *CC2* is that it is a chiaroscuro: it attempts, through the use of light and shade, to suggest depth and solidity where none obtains. The standards of accountability it proffers are too vague and ill-defined to be of help in ensuring the competence of clinical ethics consultants. This does not mean that the field has no integrity, or that the *CC2* does not move forward the discussion of holding consultants accountable. The *CC2* accommodates a great deal of diversity under one umbrella, and with 14 authors (six less than the *CC1*), there is more than a whiff of compromise. This is understandable at the beginning of a profession, but we should not pretend the results are more robust than they are.

NOTES

1. R.M. Arnold et al., *Core Competencies for Healthcare Ethics Consultation*, 2nd ed. (Glenview, Ill.: American Society for Bioethics and Humanities, 2011). Hereafter, *CC2*.

2. Another significant aspect of this change is the economic pressure that attends the inception of a new, salaried occupation: is it worth the money? Or, if it to be a financially losing proposition, do its corollary benefits make that a worthwhile exchange? Since that evaluation will be made by the employer, and will be based on multiple considerations, investigating this aspect is beyond the scope of this article. However, it is intriguing to think about how this might intersect with the criteria of evaluation. Consider one scenario: a healthcare institution has assessed the usefulness of clinical ethics consultation at its facility, and has established that it is a net cost-saving mechanism. It might willingly employ

clinical ethics consultants regardless of whether there are established standards of behavior, certification, training, et cetera. On the other hand, consultants could be trained and certified appropriately, yet find no one willing to hire them because the economic calculation doesn't recommend hiring consultants. In such a case, what might incline the institution to hire consultants is when it faces external pressure (for example, the Joint Commission requirement to have a mechanism in place for addressing ethical issues; a legal precedent in which the presence of an ethics consultation service mitigates risk; or public pressure of a more amorphous sort), which the presence of a clinical ethics consultation service relieves. Because these kinds of pressure surely exist, the field must consider how to guard against their inappropriate effects. I have considered the implications of data suggesting clinical ethics consultants are net cost saving in L. Rasmussen, "Sinister Innovations: Beward the Cooptation of Clinical Ethics Consultation," *Journal of Values Inquiry* 40 (2006): 235-42.

3. R. Baker, "A Draft Model Aggregated Code of Ethics for Bioethicists," *American Journal of Bioethics* 5, no. 5 (2005): 33-41.

4. N.N. Dubler, M.P. Webber, D.M. Swiderski, and the Faculty and National Working Group for the Clinical Ethics Credentialing Project, "Charting the Future: Credentialing, Privileging, Quality, and Evaluation in Clinical Ethics Consultation," *Hastings Center Report* 36, no. 6 (2009): 23-33.

5. R.M. Arnold et al., *Core Competencies for Healthcare Ethics Consultation* (Glenview, Ill.: American Society for Bioethics and Humanities, 1998). Hereafter, *CC1*.

6. ASBH, "Committee Charter," *http://www.asbh.org/about/content/committees.html*, accessed 16 April 2012.

7. Standards of accountability could serve as the basis for further steps towards professionalization, but need not; a separate argument must be offered for why the field should pursue professionalization.

8. Hereafter, references will be to *CC2*, unless otherwise specified.

9. The relevant text of the *CC1* is nearly identical:

> (1) define the nature and goals of ethics consultation (that is, what ethics consultation ought to be and aim to achieve); (2) identify the types of skills, knowledge, and character traits (core competencies) that are important for conducting ethics consultations; (3) address the emerging area of organizational ethics consultation; (4) discuss the importance of evaluating ethics consultations; and (5) underscore some of the special obligations of consultants and institutions.

(*CC1*, 1). Apart from the terminological change from "ethics consultation" to "healthcare ethics consultation," there are four features of the revised text worth noting:

(a) In point #2, "attributes" has replaced "character traits." A cover letter issued with the initial draft of the *CC2* notes that this was merely a terminological change, better to reflect standard language in the health professions.
(b) Also in point #2, the phrase "emerging process standards" has been added. Section 1.2 (*CC2*, 10) focuses on these, stating that "certain process standards have become widely accepted as necessary for high-quality ethics consultations." (No support for the claim of wide acceptance is offered.)
(c) The former #3 (regarding organizational ethics) has been dropped. The cover letter notes that the report's treatment of clinical ethics and organizational ethics has been merged: "The 2nd edition no longer recognizes 'clinical ethics' and 'organizational ethics' as distinct entities. The decision was made to eliminate this distinction because of both the wide divergence of opinion regarding the meaning of these terms, and recognition of the increasing trend to integrate ethics throughout an organization."
(d) The final point on the list (#5 in *CC1* and #4 in *CC2*) has changed from "underscore some of the special obligations of consultants and institutions" to "examine HCEC as an emerging profession."

The main differences here seem to be that a longer list of concerns is offered in *CC2*, and the special section on "Institutional Obligations to Patients, Providers, and Consultants" seems to have been incorporated into this section.

10. However, at least two graduate programs advertise their use of the *CC2* as part of the curriculum. The Alden March Bioethics Institute, located at the University of Albany, offers this description of its "Master of Science in Bioethics, Concentration in Clinical Ethics Consultation" curriculum: "[this program] is designed to provide advance training and supervision in the American Society for Bioethics and Humanities (ASBH) educational core competencies and skills." *http://www.amc.edu/Academic/bioethics/educational_programs/graduate_programs/degrees_certificates/master_science_bioethics.html,* accessed 7 March 2012.

The Bioethics Program at Union Graduate College at the Mt. Sinai School of Medicine describes its degrees similarly: "Two Master of Science programs—an MS in Bioethics and an MS in Bioethics: Specialization in Research Ethics—are designed to meet the needs of working professionals, comply with the requirements of national accrediting and funding agencies, and impart the skills and knowledge recommended by the American Society of Bioethics and Humanities." *http://www.bioethics.union.edu/p-online_Bioethics_MS_Masters_Program.htm*, accessed 7 March 2012. Of course, the use of the *CC2* by these two graduate programs has no necessary bearing on the field, since no degree is required to practice clinical ethics consultation in the first place.

11. E. Bedford, "The Core Competencies: A roman catholic Critique," *HEC Forum* 23, no. 3 (2011): 147-69

12. Reliance solely on an internal standard would also pose two particular problems for clinical ethics consultation. First, internal standards of accountability border on paternalism (an early bête noir of the field), if by that means a consultant could justify acting on her or his own moral views rather than those of the patient. The momentum in bioethics has resolutely been towards providing stakeholders with information relevant to making their own moral choices. What would be made of clinical ethics consultation if it determined that consultants should rely on their own private notions of accountability when bioethics regularly admonishes physicians and others who might forward such a version of accountability in their own field? Second, precisely because what clinical ethics consultants do is value-laden, and because in most places where it is practiced, moral pluralism is the norm, the field must make the values on which it operates transparent. Internal accountability provides no such transparency, so while individuals should always hold themselves internally accountable, this alone does not suffice for purposes of publicity and transparency.

13. What is true in other fields is also true of clinical ethics consultation: there is always the potential for tension between one's personal moral system ("internal accountability" in this discussion) and one's professional moral obligations ("external accountability"). This is but one species of the genus "moral dilemma," and I do not have a solution for it. But it is worth noting the potential tension between these two systems, and I thank an anonymous reviewer for *JCE* for prompting me to do so.

14. Obviously, then, if "standards" are meant to apply to recommendations besides the competencies in table 2, there may well be other problems with accountability to the *CC2* than those articulated here. In addition, the relationship between the competencies listed in the tables and the longer lists of skills in sections 2.2-2.4 is unclear: when interpreting the competencies in the tables, are we to rely on the longer explanations as mere suggestions, or as amplifications of how the competencies should actually be understood?

15. That is, if one of the main reasons for a clinical ethics consultation is to help resolve ethical disagreement, then presumably the more that people tend to agree on moral values, the less cause there might be for an ethics consultation. (Obviously, there are other reasons for consultations that would remain salient.) As an example of the claim that there is not a universally accepted set of moral values, consider Elliot Bedford's article on the *Core Competencies*: Bedford sets out a robust example of a set of ethical standards—the Roman Catholic faith and its *Ethical and Religious Directives for Catholic Health Care Services*—that are in tension with the claim that there is consensus on ethically acceptable options. Bedford, see note 11 above. And of course, we need not limit the source of dissensus to religious beliefs.

16. I have argued elsewhere for this "side-constraint" or proscriptive approach to standards in clinical ethics consultation. L. Rasmussen, "An Ethics Expertise for Clinical Ethics Consultation," *Journal of Law, Medicine and Ethics* 39, no. 4 (2011): 649-61.

Prescribing for Co-Workers: Practices and Attitudes of Faculty and Residents

Carson Strong, Stephanie Connelly, and Laura R. Sprabery

ABSTRACT

Background

Physicians sometimes are asked by co-workers for prescriptions to deal with their medical problems. These "hallway" requests typically occur outside a formal doctor-patient relationship. There are professional guidelines on serving as physician for family members and friends, but no guidelines address writing prescriptions for co-workers. The frequency of these requests and the factors physicians consider in responding to them have not been examined.

Objectives

To obtain data on the frequency of these requests and physicians' attitudes and practices in responding to them, and to explore the ethical considerations in writing prescriptions for co-workers.

Design

A survey was administered to all physician faculty and residents in an academic department of internal medicine. The questions included whether the respondent had ever been asked for a prescription by a co-worker and how often the respondent had received such requests and written such prescriptions in the previous three months. Respondents also were asked to rate how likely they would be to write such a prescription in 15 hypothetical scenarios.

Results

Of the 113 respondents who completed surveys, 68 percent reported having been asked for a prescription by a co-worker. Among those who had ever been asked, 59 percent had been asked one or more times during the previous three months and 88 percent had ever written such a prescription. Also, 88 percent of all respondents stated they were "very likely" or "likely" to write the prescription in one or more of the hypothetical scenarios.

Conclusions

Most physicians in our sample had been asked for prescriptions by co-workers, and most had written such prescriptions. Many respondents indicated a willingness to write such prescriptions in a variety of scenarios, despite the absence of a formal doctor-patient relationship. Further discussion of the ethical considerations in writing prescriptions for co-workers is needed.

Carson Strong, PhD, is a Professor of Bioethics in the Department of Internal Medicine at the University of Tennessee Health Science Center in Memphis, *cstrong@uthsc.edu.*
Stephanie A. Connelly, MD, MPH, is Director of the Kaplan Center at the University of Tennessee Health Science Center.
Laura R. Sprabery, MD, is Co-Chief of the Division of General Internal Medicine in the Department of Internal Medicine at the University of Tennessee Health Science Center.

INTRODUCTION

Physicians sometimes are asked for prescriptions by co-workers such as nurses, secretaries, and other physicians. These requests typically occur in circumstances that lack certain features of a formal doctor-patient relationship, such as a thorough history and physical examination and planned follow up to assess the effectiveness and side-effects of therapy. Without these normal interactions, there is a risk of prescribing an inappropriate medication or not responding in a timely manner to adverse reactions. These considerations raise the ethical question of whether physicians should write such prescriptions. There are professional guidelines that caution physicians against serving as a doctor for family members and friends.[1] However, because there is an absence of guidelines dealing specifically with requests for prescriptions from co-workers, there is a need for further discussion of such prescription writing.

Previous studies have reported that 49 percent to 83 percent of physicians write prescriptions for themselves or family members.[2] At least two surveys of physicians have included questions on prescribing for co-workers. Clark and colleagues surveyed 565 house officers concerning prescriptions for residents, medical students, hospital or clinic staff members, family members, friends, and themselves during an eight-month period.[3] Among 339 respondents, 23 percent wrote at least one such prescription for a psychoactive medication. A total of 1,229 prescriptions were written for nonpsychoactive medications, but the reported results do not state the percentage of house officers who wrote such prescriptions. Of all of the prescriptions written in this study, 27 percent were for psychoactive prescriptions and 16 percent were for fellow residents. Nurses, technicians, and other allied health workers received 21 percent of all prescriptions and 17 percent of the psychoactive prescriptions. The reported results do not permit a determination of the frequency of requests by co-workers, variation in the frequency of requests among house officers, nor the percentage who had refused such requests. Aboff and colleagues surveyed 92 internal medicine and family practice residents at a Wilmington, Delaware, hospital in 1997 concerning their prescription writing for family members, friends, and co-workers.[4] Among the 74 respondents, 85 percent had written at least one such prescription. The reported results do not distinguish the categories of family member, friend, and co-worker and therefore do not permit a determination of the number or percentage of prescriptions written for co-workers.

These studies leave a number of questions unanswered, including the percentage of physicians who receive requests from co-workers, how frequently they receive such requests, how frequently physicians write such prescriptions, and the factors physicians take into account in deciding whether to write them. We examined these questions in a sample of internal medicine faculty and residents. The purpose of the study was to explore these and other aspects of the issue of prescription writing for co-workers.

METHODS

A survey instrument was designed by the authors to collect data on physicians' practices and attitudes in regard to writing prescriptions for co-workers. The study was approved by the institutional review board of the University of Tennessee Health Science Center in Memphis. A self-administered seven-page questionnaire and a cover letter were placed in the mailboxes of all faculty members and residents in the Department of Internal Medicine during May and June 2011. A second and third distribution of the questionnaire to nonresponders was made using an online survey method. In the questionnaire, "co-worker" was defined as "anyone who works where you work, including physicians, other health professionals, secretaries, etc., *and* is not seeing you by appointment in your office or clinic and is not a hospital patient." The questionnaire was completed anonymously and included the following questions:

1. Whether the respondent has ever been asked for a prescription by a co-worker,
2. How often the respondent has received such requests during the previous three months,

3. Whether the respondent has ever written such a prescription,
4. How often the respondent has written such prescriptions in the previous three months,
5. The types of medications for which the respondent has written such a prescription, and
6. Whether the respondent has ever refused a request by a co-worker.

In addition, the survey included 15 hypothetical scenarios in which physicians were asked for prescriptions by co-workers (see figure 1). In the scenarios, a number of factors were varied that might affect the likelihood of prescribing for a co-worker. Using a four-point Likert scale (very likely, likely, unlikely, very unlikely), respondents were asked to rate how likely it was that they would write a prescription. For each scenario, there was an open-ended question asking respondents to list factors present in the scenario that influenced their decision. Also, questions asking for brief demographic information were included. Associations between demographic variables were analyzed using *chi*-square for categorical data. Comparisons between scenarios were analyzed using the Friedman nonparametric test for ordinal data.

RESULTS

Of 111 faculty physicians, 67 (60 percent), and 46 of 136 residents (34 percent) completed the survey; 68 percent of respondents were male (see table 1). Among all respondents, 77 (68 percent) reported having ever been asked for a prescription by a co-worker; 77 percent of faculty and 52 percent of residents had been asked, and this difference was statistically significant (p=.006). Among those who had ever been asked, 59 percent had been asked one or more times during the previous three months: 51 percent were asked one to two times, 5 percent two to five times, and 3 percent five to 10 times. Among respondents who had ever been asked, 88 percent reported having ever written such a prescription and 61 percent stated they had refused such a request one or more times. In a comparison of gender, 52 percent of males and 79 percent of females reported having ever refused, and this difference was statistically significant (p=.025).

Among respondents who had been asked in the previous three months, 17 percent had written zero times, 72 percent had written one to two times, 9 percent had written two to five times, and 2 percent had written five to 10 times. Among the eight types of medications listed in the survey, respondents who had ever written reported most commonly writing for antibiotics (87 percent of respondents), followed by nonsteroidal anti-inflammatory drugs (21 percent), antihistamines (19 percent), birth control pills (9 percent), muscle relaxants (3 percent), antidepressants (2 percent), narcotics (2 percent), and benzodiazepines (0 percent).

Among the 15 hypothetical scenarios, there was considerable variation in the percentage of physicians likely to write a prescription (see table 2). In three scenarios (Scenario 3, Scenario 5, and Scenario 9), a majority of respondents would "very likely" or "likely" write the prescription. Two of these cases involved a co-worker who complained of cellulitis who was not yet covered by insurance. In one of these scenarios, the co-worker is "a physician recently hired into your group practice"; the other involves "your new medical assistant." In the physician scenario, 67 percent of respondents chose "very likely" or "likely." For those who listed one or more factors, the most frequently listed (30 percent) was that the requester was a physician. A number of these responses elaborated that the requester's medical knowledge would enable her or him to know the risks of antibiotics and to diagnose a worsening of his or her condition. In the medical assistant case, 56 percent selected "very likely" or "likely." In both cases, factors listed included: a high likelihood of follow up, given a close working relationship; the straightforward nature of the diagnosis; and a lack of insurance. Respondents were more likely to prescribe for the physician than for the medical assistant, and the difference was statistically significant (p<.001). The other case involved a nurse who requested warfarin and was unable to reach her physician.

FIGURE 1 Hypothetical scenarios involving prescription requests by co-workers

1. A secretary who works down the hall from your academic office, and who you know only casually, asks you about her dental abscess. She asks if you can prescribe something. Would you prescribe antibiotics for her?

2. Your nurse, with whom you have worked for several years, asks your advice. She complains of loss of appetite, inability to initiate and maintain sleep, and "feeling blue." She was successfully treated in the past with Zoloft (sertraline hydrochloride), and she asks you to prescribe it until she can see her primary care physician. Would you prescribe this medication for her?

3. A physician recently hired into your group practice complains of cellulitis at the site of a recent mosquito bite. On exam she has an 8 x 6 cm area on her right forearm which is red, warm, and painful. In the center is a small ulcer with purulent drainage. There is no fluctuance.* She is not yet covered on the group insurance plan. She asks you for antibiotics. Would you prescribe antibiotics for her?

4. You and your secretary have worked together for years and interact socially as well as professionally. She complains to you about insomnia because of problems at home, and asks you to prescribe Ambien (zolpidem tartrate). Would you prescribe this medication for her?

5. Your nurse is about out of her warfarin, which she takes because of protein C deficiency and a history of 2 pulmonary emboli. She has left several messages with her physician's office, to no avail. She tells you that her INR was 2.7** three weeks ago and she has had no abnormal bleeding. She asks you to refill her warfarin. Would you prescribe this medication for her?

6. The medical student assigned to your rotation comes to work sick, complaining of fever, severe sore throat, and malaise. You examine him and find his temperature is 102 and his pulse 110. Examination of his oropharynx reveals enlarged erythematous tonsils with purulent exudates.*** He has several 1-2 cm cervical lymph nodes. He asks you for an antibiotic prescription. Would you prescribe antibiotics for him?

7. A nurse aid who works in your office returns after two weeks of recovering from a knee injury. He is still using a crutch, and after a day of work he is in a lot of pain. He tells you Percocet (acetaminophen with oxycodone hydrochloride) worked at home during his recovery but now he is out. He asks you to write a prescription for Percocet to use after work. Would you prescribe Percocet for him?

8. A 59-year-old nurse complains of lower back pain. She states she's never had back pain before and thinks she overdid it at the gym. She has exercised 5-6 times per week for many years. She asks for a prescription for a muscle relaxant to see if that helps. Would you prescribe a muscle relaxant for her?

9. Your new medical assistant complains of cellulitis at the site of a recent mosquito bite. On exam she has an 8 x 6 cm area on her right forearm which is red, warm, and painful. In the center is a small ulcer with purulent drainage. There is no fluctuance.* She is not yet covered on the group insurance plan. She asks you for antibiotics. Would you prescribe antibiotics for her?

10. The receptionist in your office calls you on Saturday to ask for a refill of her Wellbutrin (buproprion) she takes for anxiety. She ran out yesterday and is starting to get anxious. She can't get in contact with her psychiatrist. Would you prescribe this medication for her?

11. A nurse in your office is diagnosed with hypertension, and her doctor puts her on an angiotensin receptor blocker. Her medication has the highest co-pay at $75 per month. She asks you to write a prescription for something that meets the $10 co-pay amount. Would you write this prescription for her?

12. A nurse you work with is 20 weeks pregnant, has had an upper respiratory infection for several days with fever, and needs some relief. She tells you a Z-Pak (azithromycin) is generally considered safe for pregnant women. Would you write her a prescription for this medication?

13. A 55-year-old hospital chaplain who you see time to time on rounds pages you. He states he has a history of gout but hasn't had an attack for years. He now thinks he is having an attack, and he can't even get his shoe on. His doctor retired some months ago and he is hoping you will prescribe indomethacin, which always worked in the past. Would you prescribe this medication?

14. Your physician partner calls you on Saturday to ask for a refill of her Wellbutrin (buproprion) she takes for anxiety. She ran out yesterday and is starting to get anxious. She can't get in contact with her psychiatrist. Would you prescribe this medication for her?

15. A respiratory therapist at your hospital who you have known for years asks you for a Z-Pak (azithromycin). She is 50 years old and complains of a 3-day history of runny nose, malaise, scratchy throat, and a cough productive of yellow sputum. She denies fever, chills, and dyspnea. On your exam, her temperature is 101. Her throat is red but without exudate, and she has paranasal sinus tenderness. Would you prescribe antibiotics for her?

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* The area is not boggy to the touch, which would indicate a collection of pus under the skin.

** This means that she had a normal blood level of anticoagulation medication.

*** The tonsils were covered with purulent fluid.

Among respondents who chose "very likely" or "likely" and listed one or more factors, the most frequently listed factor (33 percent) was the risk to the nurse in not having prompt access to the medication.

In another group of scenarios, respondents leaned heavily toward not writing the prescription, with 75 percent or more choosing "unlikely" or "very unlikely." This group (in order, Scenarios 10, 11, 2, 1, 4, 8, 12, and 7) has several features worth noting. Almost all of the scenarios that involved medications that were either controlled or psychoactive were in this group. Among respondents who listed factors in scenarios involving these drugs, many listed either legal concerns or the potential for abuse of the medications. This indicates that a medication's being controlled or psychoactive was often given strong weight against prescribing for a co-worker. Among the scenarios in this group that did not involve controlled or psychoactive medications, one involved a dental abscess and one involved a pregnant woman. Many of the respondents who chose "unlikely" or "very unlikely" in these two cases listed as factors that the medical condition was outside of their expertise. The remaining case in this group involved a request for a medication with a lower co-pay than the one prescribed by the co-worker's physician. A number of respondents who stated "unlikely" or "very unlikely" listed as a factor that the prescribing would constitute an interference with the practice of the other physician. Other factors against prescribing that were listed in these scenarios included not knowing the requester well (dental abscess case), the need for a more complete evaluation, and the need for follow up.

In other scenarios (14, 6, 13, and 15), a majority of respondents indicated that they would not prescribe, but the percentages indicate a considerable amount of controversy about these cases. Factors against prescribing identified by respondents for these scenarios included the following: alternatives were readily available (for example, student health for the medical student), a need to know more about the patient's history, and uncertainty concerning whether there is a need for the requested medication. A factor identified in support of prescribing in some cases was the low risk of side-effects for the medication in question. For the scenario involving buproprion for a physician partner, 44 percent chose "very likely" or "likely." Many of these listed as factors that the requester was known well and that the requester was a physician. In a parallel case involving buproprion for a receptionist, only 25 percent chose "very likely" or "likely"; the difference between the two cases is statistically significant ($p<.001$).

Taking into consideration all 15 scenarios, the factors mentioned frequently by respondents are listed in figure 2. Many of these factors were stated in multiple scenarios.

TABLE 1 Demographics and responses to questions

Characteristics and questions	No. responding "yes"	(%)
Gender (*n*=113)*		
Male	75	68
Female	36	32
Level (*n*=113)		
Faculty	67	59
Resident	46	41
Have you ever been asked for a prescription by a co-worker? (*n*=113)	77	68
Have you ever written a prescription for a co-worker who asked you for one? (*n*=77)**	67	88
Have you been asked to write a prescription for a co-worker in the past 3 months? (*n*=77)**	45	59
Have you written a prescription for a co-worker in the past 3 months? (*n*=45)	38	84
Have you ever refused to write a prescription for a co-worker? (*n*=77)**	46	61

* 2 respondents did not indicate their gender.
** 1 respondent did not answer.

DISCUSSION

Our study reveals that most physicians in our sample (68 percent) have been asked for

prescriptions by co-workers. Among those who have been asked, a large percentage (88 percent) reported having written such a prescription. For three of our scenarios, a majority of respondents indicated that they probably would write the prescription. In four other scenarios, approximately 30 to 40 percent of respondents indicated that they probably would prescribe. These results indicate a willingness of many faculty and residents to write prescriptions for co-workers, at least in selected cases. This willingness to write exists despite ethical concerns that can be raised when there is not a thorough history, examination, or testing to confirm a diagnosis. These results invite discussion of whether it is ethical to write prescriptions for co-workers, and, if so, under what circumstances.

To explore the ethics of prescription writing for co-workers, it is important to identify the arguments for and against this practice, but there has been little discussion of such arguments in the literature. However, previous discussions of the related issue of serving as physician for family members and friends provide some relevant considerations. Like prescribing for co-workers, being a doctor for family or friends can differ from a normal doctor-patient relationship in several important ways. The American Medical Association (AMA) guidelines on this topic state, "Physicians generally should not treat themselves or members of their immediate families."[5] The AMA gives several reasons in support of this position:

1. Objectivity may be compromised if the physician's personal feelings unduly influence professional judgment,
2. Physicians may fail to probe sensitive areas when taking the medical history or may fail to perform intimate parts of the physical examination,
3. Physicians may be inclined to treat problems that are beyond their expertise or training, and
4. If there is a negative medical outcome, tension may develop in the family relationship.

The AMA recognizes exceptions to the guideline in emergencies, in isolated settings in

TABLE 2 Likelihood of physician writing a prescription in hypothetical scenarios

Vignette #	Type of co-worker	Medical condition	Medication requested	Circumstances	Physicians "very likely" or "likely" to write rescription (%)
3	Physician partner	Cellulitis	Antibiotics	Awaiting insurance	67
5	Your clinic nurse	Hypercoagulability	Warfarin	MD has not returned call	56
9	Medical assistant	Cellulitis	Antibiotics	Awaiting insurance	56
14	Physician partner	Anxiety	Buproprion	Weekend	44
6	Medical student	Pharyngitis	Antibiotics	--	39
13	Chaplain	Gout	Indomethacin	Former MD has retired	35
15	Respiratory therapist	URI	Azithromycin	--	31
10	Receptionist	Anxiety	Buproprion	Weekend	25
11	Nurse	Hypertension	ARB	Desires lower co-pay	21
2	Nurse, known well	Depression	Sertraline	Drug worked in past	20
1	Secretary	Dental abscess	Antibiotics	--	16
4	Secretary, known well	Insomnia	Zolpidem	Problems at home	13
8	Nurse	Lower back pain	Muscle relaxant	Age >50	9
12	Nurse	URI	Azithromycin	Pregnancy	9
7	Nurse's aid	Knee injury	Acetominophen & oxycodone	--	4

which no other physician is available, and for treatment of short-term, minor problems. The guidelines of the American College of Physicians (ACP) are similar to those of the AMA.[6] The ACP agrees with the reasons given by the AMA against writing such prescriptions, and it adds that counseling on sensitive issues may be incomplete when a physician treats family or friends.

These guidelines include several points that reasonably can be carried over to prescribing for co-workers. Objectivity could be compromised, particularly if there is a close relationship with the co-worker. The medical history and physical examination may be cursory or not performed. Physicians might be asked to prescribe for medical conditions they do not ordinarily treat. A negative medical outcome could cause tension in the co-worker relationship. Moreover, counseling on sensitive issues could be incomplete. In a given situation, some or all of these reasons might apply to a request from a co-worker. Some of the exceptions noted by the AMA in regard to doctoring family and friends could also apply to requests from co-workers. There could be emergencies in the work setting, and co-workers sometimes work together in remote areas.

When we apply these considerations to prescribing for co-workers, it seems reasonable to conclude that generally there are important reasons against such prescribing, but also that there can be situations in which an exception is justifiable. Only 12 percent of our respondents selected "very unlikely" or "unlikely" in every scenario. Thus, most respondents seemed to be taking an approach of deciding on a case-by-case basis. Given this data and the apparent reasonableness of allowing at least some exceptions, we suggest that it is important to identify the factors that should be considered in deciding whether to write such a prescription. We suggest these include all of the factors in figure 2.

One of the relevant factors is the legal implication of writing such a prescription. By legal standards, beginning a course of treatment, such as writing a prescription, entails that a doctor-patient relationship exists.[7] This means that the physician is subject to liability if there is an adverse outcome resulting from failure to follow the standard of care. Additional legal concerns arise when a controlled substance is requested. Federal laws pertaining to the prescribing of controlled substances are based on the Controlled Substances Act of 1970.[8] A key provision of this law is that physicians are expected to write prescriptions for controlled substances for *a legitima*te medical purpose while acting in the usual course of professional practice.[9] Many states incorporate this federal standard into their medical licensing board regulations.[10] Some states interpret "acting in the usual course of professional practice" to require a diagnosis based on a documented medical history and physical examination, a written treatment plan tailored to the individual needs of the patient, and complete and accurate records of the care provided.[11] In these jurisdictions, physicians who prescribe controlled substances to co-workers are potentially subject to disciplinary action by their state boards.

To promote further discussion of this issue, the authors propose an approach to handling

FIGURE 2 Factors to consider in responding to requests

Ease of access to alternative physician
My area of competency
The need to know more about co-worker's medical history
The need for a more thorough examination
Whether more is needed than just a medication (e.g., tests, treatments)
Urgency of co-worker's need
Risks of the requested medication
Controlled drug or psychoactive drug with risk of abuse
The need for follow up
Whether I see the co-worker regularly at work
Co-worker's level of medical knowledge
Whether co-worker has health insurance
How well I know the co-worker
Impact on future relationship with co-worker
Impact on work setting (e.g., quick recovery puts co-worker back to work)
Interfering with another physician's care
Liability risk

requests for prescriptions from co-workers (see figure 3). First, when a co-worker makes a request, an attempt should be made to determine whether alternative treatment is readily available. Alternatives might include the following: the co-worker visits an emergency department, minor care clinic, or student health; the co-worker makes an appointment with a personal physician; or the physician recommends an over-the-counter medication until the co-worker can see a personal physician. If an alternative is agreed upon, the physician could offer help if applicable in carrying out the alternative.

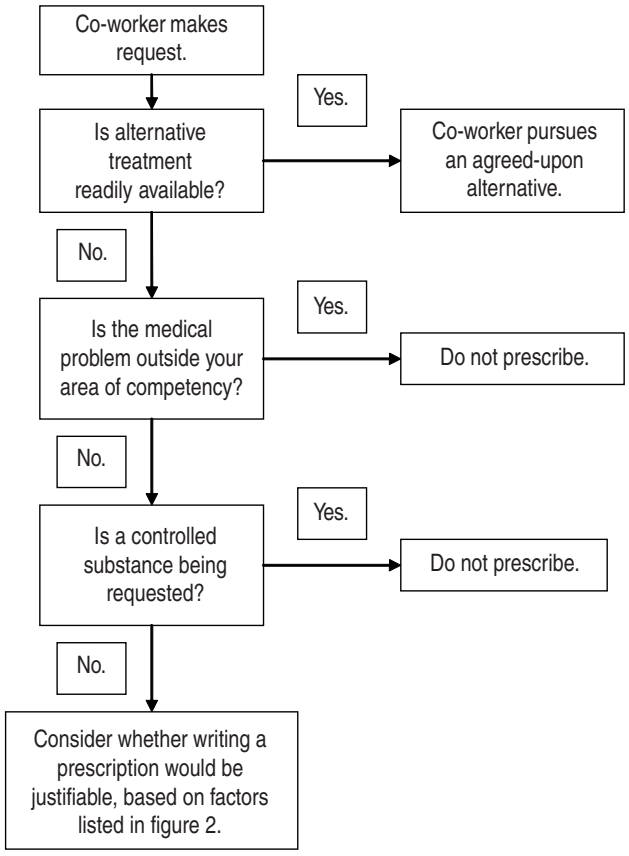
Second, if none of the alternatives mentioned above is feasible, consider whether the medical problem is outside one's area of competency. If it is, then the physician should not prescribe. A referral could be made to a qualified physician, if the co-worker so wishes.

Third, if the medical problem is within the physician's area of competency but involves a request for a controlled substance, the physician should not prescribe. The legal and ethical reasons for not prescribing could be discussed with the co-worker. A referral to a qualified physician, if needed, would be appropriate.

Fourth, if the requested medication is not a controlled substance, the physician should consider whether the case constitutes an exception in which writing the prescription would be ethically justifiable. Such a judgment should take into consideration the factors in the particular case. Relevant factors that might be present in a given case are listed in figure 2. Various combinations of factors could potentially make prescribing justifiable. For example, if not treating carries significant risks to the requester, the risks of the medication are reasonable in comparison to not treating, and an ongoing working relationship would permit follow up, then prescribing could be justifiable. An illustration might be the warfarin case (Scenario 5), provided an appropriate test of coagulation is obtained. On the other hand, various combinations of factors could make prescribing inadvisable. For example, if the medication has significant side-effects and the diagnosis is questionable, then prescribing would not be warranted. An example might be the nurse's request for a muscle relaxant (Scenario 8).

Our study has several limitations. The response rate from residents was low, and the nonresponders may have had different experiences and attitudes compared to responders. We surveyed only internal medicine faculty and residents at a single institution; this sample may not reflect geographical variations or practices in nonacademic settings; 40 percent of our respondents were residents, who may not have as many years of experience to be asked by a co-worker to write a prescription, compared to faculty members. Also, responses in actual situations may differ from what respondents state they would do in hypothetical scenarios. Moreover, some of the study questions depended on recall by respondents, which may not have been accurate. Finally, the study obtained self-reports

FIGURE 3 Proposed process for handling requests for prescriptions for co-workers



about activities that may have been perceived as controversial; despite the anonymity of the study, this may result in underreporting of prescribing activities.

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CONFLICT OF INTEREST

The authors declare that they do not have a conflict of interest.

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Harvard Ethics Consortium

The Ethics of Reality Medical Television

Thalia Margalit Krakower, Martha Montello, Christine Mitchell, and Robert D. Truog

ABSTRACT

Reality medical television, an increasingly popular genre, depicts private medical moments between patients and healthcare providers. Journalists aim to educate and inform the public, while the participants in their documentaries—providers and patients—seek to heal and be healed. When journalists and healthcare providers work together at the bedside, moral problems precipitate. During the summer of 2010, ABC aired a documentary, *Boston Med,* featuring several Boston hospitals. We examine the ethical issues that arise when journalism and medicine intersect. We provide a framework for evaluating the potential benefits and harms of reality medical television, highlighting critical issues such as informed consent, confidentiality, and privacy.

Television viewers have been fascinated by the human drama of fictional illness and injury, beginning with *Dr. Kildare* in the 1960s and continuing with *M.A.S.H.* in the 1970s and 1980s. More recently, reality television has combined with this long-standing interest in medical drama, and camera crews have begun to film patients at the bedside, surgeons in the operating room, and birthing mothers in labor. The ABC documentary *Boston Med,* which aired in the summer of 2010, was widely admired and critically acclaimed, and presses home the need for exploring the ethical issues involved in this kind of filming. The eight-part series, available at *www.http://abc.go.com/watch/bostonmed/SH5570013,* focuses on three prestigious Boston hospitals, following physicians, nurses, and patients through events that are satisfying and harrowing without flashy editing or obvious manipulation. Following the genre of "reality television," the show features purportedly unscripted interaction, documenting actual events and filming ordinary people. While engaging and technically adroit, reality television in the medical arena raises ethical questions that should be carefully considered by physicians, hospital administrators, medical staff, journalists, producers, and the viewing public.

Thalia Margalit Krakower, MD, is an Instructor of Medicine at Harvard Medical School in Boston, *thalia.margalit@gmail.com.*
Martha Montello, PhD, is an Associate Professor of History and Philosophy of Medicine at the University of Kansas School of Medicine in Kansas City, Kansas, *mmontell@kumc.edu.*
Christine Mitchell, RN, MS, MTS, is Director of the Office of Ethics at Children's Hospital Boston, and is Associate Director of Clinical Ethics at Harvard Medical School, *Christine.Mitchell@childrens.harvard.edu.*
Robert D. Truog, MD, is a Professor of Medical Ethics, Anesthesiology, and Pediatrics and is Director of Clinical Ethics at Harvard Medical School; is Senior Associate in Critical Care Medicine at Children's Hospital Boston; and is Executive Director of the Institute for Professionalism and Ethical Practice in Boston, *Robert.Truog@childrens.harvard.edu.*

Several months after the series aired, we identified and explored the ethical issues facing *Boston Med* and the genre of reality medical television through a public forum sponsored by the Division of Medical Ethics at Harvard Medical School.[1] In addition to watching segments from several episodes, we convened a panel discussion that included the producer from ABC News, the wife of one of the featured patients, the chief medical officer of one of the participating hospitals, the associate chief nurse of another, and several other participating administrators and healthcare providers. We also solicited comments from the local medical community to gain insight into the motives and experiences of the patients, clinicians, and families who participated in the televised series.

COMPETING CODES OF ETHICS

When a hospital opens its doors to a camera crew, and journalists join patients in times of crisis to record physicians and nurses at work and at home, which code of ethics should be followed, and by whom? When journalism and medicine intersect, which ethical principles apply? While being filmed in their interactions with patients, should physicians be held to the usual rules of confidentiality, consent, privacy, honesty, and autonomy on behalf of patients? Should journalists be accountable to those same rules and principles as they cross into and become active agents in the medical sphere, or are they held only to their own code of journalistic ethics?

Journalists and health providers abide by their respective professional codes of ethics, with influence from individual moral intuition. While physicians and nurses are primarily responsible for protecting and serving patients, journalists must balance a duty to inform the public with a duty to not harm private persons. Which responsibility should take precedence? When documentary filmmakers were interviewed in a study conducted by the Center for Social Media at American University, many said that, in the absence of any firm or widely accepted standard, ethical dilemmas are resolved on an *ad hoc*, individual basis. In general, they expressed a primary commitment to "do no harm" and "protect the vulnerable," although how individual journalists prioritize those goals while providimg information to the public may be highly variable.[2] Such situational ethics may be particularly vulnerable to subjectivity, individual self-interest, and *ad hoc* values.

INFORMED CONSENT, PRIVACY, AND CONFIDENTIALITY

Clinicians may react with caution or even criticism when viewing *Boston Med* because physicians and other healthcare workers are accustomed to explicit rules and standards of privacy, confidentiality, truth-telling, and informed consent that are not defined as rigidly or precisely in the ethics of journalism. The Society of Professional Journalists (SPJ) *Code of Ethics* does not specifically address informed consent, but adheres to several important principles that show a similar impulse:

- Show compassion for those who may be affected adversely by news coverage.
- Be sensitive when seeking or using interviews or photographs of those affected by tragedy or grief.
- Recognize that private people have a greater right to control information about themselves than do public officials and others who seek power, influence or attention.
- Show good taste. Avoid pandering to lurid curiosity.[3]

Hinged on compassion and sensitivity, the SPJ *Code of Ethics* cautions journalists to use common sense and widely accepted values. The emphasis is on the moral behavior of the individual journalists. Prescriptive guidelines are absent from this code.

The imperative of informed consent in clinical and research ethics is considered by the medical community to be central to sound practice. It specifies that patients who are competent to make decisions must receive adequate disclosure of the risks, benefits, and alternatives of certain choices; show evidence of understanding the information; and make decisions that are voluntary.[4] Medical ethics acknowledges the dynamic nature of patients' wishes and stipulates that consent may be withdrawn

in both the research and clinical spheres until a "point of no return" has been reached. While both journalists' ethics and medical ethics attend to the interests of persons/patients, they are generally applied differently; only the medical code of ethics articulates inviolable moral boundaries for protecting and empowering the potentially vulnerable person.

For *Boston Med*, the process of gaining initial contact with patients varied. During the public forum, producer Terence Wrong said,

> Sometimes we go to clinics and the administrative assistant . . . or the nurse practitioner or the physician's assistant will say, "There is an ABC documentary being made about the medical care here. Would you be willing to talk to the producers about it?" And usually always adds, "In no way will your care be affected one way or another." The hospital put cards in waiting rooms and posters and things that specifically made that point. You don't have to do this. It's not going to affect your care one way or another.

Jeannette Pollet, whose husband was a featured patient on *Boston Med*, said one of his treating doctors asked them to consider participation, and that they were provided with a simple consent form (not publicly available). She said,

> We weren't told good reasons, bad reasons. It was one simple form, and we were told we would not be able to see the film ahead of time. In other words, when it aired, I had no idea what was going to show. And we were filmed in the patient's room, in the hallways, many different environments with and without the doctors. But, no, it's really "would you be interested?" and no stipulation, no payment; so no other motivating factors that would have coerced us, so to speak.

Producer Wrong reported that most of those approached consented to being filmed, although the rate of consent varied widely among patients according to their medical problem. For example, he said that about 99 percent of potential transplant patients approached gave consent, but only about half of teenagers or those considering plastic surgery consented. In the emergency department, about 80 to 90 percent of those approached consented.

Patients were reportedly given the right to refuse filming, and cameras were quickly turned off without further question. In curious contrast, other participants (patients, physicians, and the hospitals) were told that once they agreed to be filmed, they would not be able to see what was filmed, or rescind consent. Wrong said this was necessary to maintain the integrity of the documentary, to protect it from censorship.

Wrong said that he felt physicians' commitment to medical ethics caused them to respect journalistic ethics:

> As a news organization, our standards and practices are that we can't show you the report before it airs and you don't have the right to essentially censor any part of it. And this is applied to all of our reports across the board, and as a precedent, it would be terrible if we gave in anywhere on that. You can think of an interview with a politician, you can think of any context you want. And I particularly bristle at that, kind of reflexively, because I spent 15 years as a foreign news producer going to countries where we had to turn in our tapes to the ministry of information for review before being allowed to leave the country. So, of course, the hospitals never insisted on that. One of the great joys of working with teaching hospitals and doctors is they do have a very highly developed ethical set of precepts that they operate under. So they treated our precepts with the utmost respect the entire time.

Wrong described his filmmaking style as cinéma verité, in which the camera renders an unmediated view of reality—as if there were no camera. The technique seeks to make the camera invisible as it captures individuals at deeply personal and unguarded moments. Given this, *Boston Med* challenged three fundamental requirements of informed consent: competence, voluntariness, and disclosure.

Competence

A competent patient must be able to understand a medical decision, express the rationale

for the decision, and understand the risks and benefits associated with the decision. Most patients and providers featured in *Boston Med* were competent by these standards to make decisions regarding their participation. Ethical safeguards are typically developed to protect more-vulnerable patients and subjects.

A 49-year-old man with a history of heroin and alcohol abuse is seen in the emergency department while inebriated. The doctors and staff in the ED are pictured chuckling at his offbeat behavior, and a resident is quoted as saying, "This guy's pretty entertaining." The camera focuses on the man's "born to lose" tattoo while he dances and sings inappropriately on his gurney. He is later filmed kissing his lunch.

In the moment, a patient like this would be considered incompetent to make almost all medical decisions. During the panel discussion, Wrong said producers contacted patients later, to confirm their consent. In the case of a patient with a dynamic level of competence, should the crew have filmed the patient—as they did in this case—with the hope of obtaining valid consent later? If so, what is the likelihood that a patient would later be able to adequately remember the details of an inebriated moment, without seeing the film, and to be able to understand the implications of his consent?

Voluntariness

Morally sound autonomous consent may be threatened by manipulation, coercion, and persuasion. The producers of *Boston Med* explained to participants that their care would not be affected, nor would they be paid. As noted above, there were noteworthy differences in consent rates for transplant patients (99 percent) and plastic surgery patients (approximately 50 percent). Such disparity may provide a valuable window into the psychology and motivations of those consenting. Although it is impossible to know the driving forces behind these differences, perhaps those in more desperate clinical situations were more vulnerable to implicit coercion or manipulation, or the unspoken possibility that participation would improve their odds. In 2004, the American Medical Association Council on Ethical and Judicial Affairs addressed this area of consent with the "Ethics of Physician Participation in Reality Television for Entertainment," in which it recommends consent be obtained by a third party, not a member of the production team, to minimize coercion or conflicts of interest.[5] In the case of *Boston Med*, although the idea was often introduced to patients by their medical providers, producers obtained patients' consent.

Disclosure

In the clinical context, informed consent requires that physicians disclose the risks and benefits of a proposed procedure. With regard to risks associated with participation in *Boston Med*, the producers provided assurance that care would not be affected by participation or refusal to participate—a promise worth examining. Although in cinéma verité awareness of the camera is minimized, how can one promise that it will have no effect on what happens?

In the opening episode of the series a patient in dialysis arrests and a "code blue" is called. In the ensuing chaos, the code leader attempts to intubate the patient. Although she is ultimately successful, there is a delay in establishing an airway. The effect of the camera in the room may be difficult to identify or measure, but it is possible the presence of a camera and crew changed or hampered resuscitation. Several times in the series, staff spoke directly to the camera while performing work duties, suggesting it was not always an inert factor in the room, and at least part of their attention was directed to being filmed. Cinéma verité records moments of life and death; it is reasonable to ask whether it affects the outcome of care, positively or negatively.

Surrogate Decision Makers for Consent

Several patients died during the series. The deaths and resuscitation attempts were filmed.

An 18-year-old, asthmatic young man is brought to the emergency department in cardiac arrest. The scene segues to his resident physician's reflection on her need to be more aggressive and self-assured. The patient's face is shown without obstruction, intubated, while his chest is compressed by a machine and he undergoes last-ditch procedures such as needle thoracostamies. The camera pans to his sneakers while the team combs for different avenues of resuscitation and discusses his recent acceptance to college. His family is brought to his bedside, and their raw grief is captured on film, again without concealing their identities.

Can consent to be filmed be provided postmortem? Should parents be allowed to consent for their child? In the medical realm, the AMA advises, "consent by a surrogate medical decision-maker is not an ethically appropriate substitute for consent by the patient because the role of such surrogates is to make medically necessary decisions, and whether to film for public broadcast is not a medical decision."[6] The SPJ *Code of Ethics* advises journalists to "be sensitive when seeking or using interviews or photographs of those affected by tragedy or grief."

Those Who Did Not Consent

Participants were involved to varying degrees. Some physicians, nurses, and patients were featured and followed in the series; others were more peripherally involved; some faces were shown in the background. Faces of patients in the background were blurred for anonymity, but doctors' and nurses' faces were not.

A team of residents and nurses are shown being scolded by a consulting physician for administering a drug that he believed was unnecessary and may have caused the patient harm.

Should the producers—or hospital administration—have required that every member of the team consent to participation? Many patients who did not consent were included in the series with blurred faces.

An intoxicated man who presents to the emergency department is mocked by several staff members and then reprimanded by his nurse for his dangerous behavior. He is shown with his face blurred, but his voice unaltered. At the end of this interaction, his nurse is filmed saying, "I liked it much better when he was unconscious."

Although that patient's face was not identifiable, his voice may have been. Should this particularly vulnerable and potentially humiliating moment have been filmed without his consent simply because his face was not visible?

Privacy

Patients' right to privacy is a fundamental ethical and legal principle. Patients serve as their own gatekeepers—allowing or denying access to their personal information and their bodies. In contrast, the *Boston Med* crew often filmed scenes (moments in private persons' lives) first, particularly in emergency settings, and then requested consent later. To what extent should patients' privacy have been honored? Should hospitals be allowed to offer access to patients' personal and intimate moments, including death?

BENEFITS AND HARMS

In addition to these traditionally deontological concerns about informed consent, privacy, and confidentiality, it is useful to weigh potential benefits versus harms for the primary stakeholders: patients, staff, hospitals, the public.

Patients

While the stated goal of the production crew was to have no effect on the care provided, this depends on the possibility that providers are not influenced by the presence of cameras and crew, or by the possibility they will appear on national television—as a hero or as an embarrassment. Many times caregivers address the camera while working, including a nurse dispensing medication and a surgeon operating, both moments that are vulnerable to error.

At the public forum Theresa Gallivan spoke from a nursing and clinical operations perspective: "Were there operational challenges? Yes. The presence of cameras and crew, of course, caused a degree of disruption to . . . normal clinical operating procedures, particularly in an extraordinarily busy environment." Although she reported these disruptions were "manageable," how much disruption in a life-and-death circumstance is morally tolerable? At the same time, it is conceivable that caregivers were on their "best behavior" on film, or provided extra attention to patients on camera.

Potential benefits of participation. Some patients may have benefited from personal altruism. Jeanette Pollet reflected on her late husband's decision: "My husband felt like if he could just help one person, it would be well worth it." In retrospect, she said, they helped others by raising awareness of her husband's rare illness and the need for organ donors.

Potential harms of participation. At times careproviders mocked patients from behind a curtain, in full view of the television audience.

Patients and families had no way of knowing, when they gave their consent, that such moments would be aired. When patients stand to gain nothing, and it is clear that they unknowingly risk public humiliation, should we act upon their consent? Consent is a necessary but not sufficient requirement for intervening in a patient's care. If a patient consents to a procedure that would be more likely to cause harm than to benefit, it is a physician's duty to protect that patient and withhold the procedure. Should journalists show "compassion for those who may be affected adversely by news coverage" and preserve the confidentiality and dignity of the patients, in spite of their consent? Witnessing their own experiences in retrospect—and on national television—may be painful or challenging in ways that patients may not be able to anticipate.

A chief cardiothoracic resident "consents" a young mother prior to aortic valve replacement and aortic aneurysm repair. He quotes to her a 1 to 2 percent chance of "something bad happening," but reassures her, "Dr. Cohn is the guy you want, he's been doing this for 40 years." We watch the surgery and see Dr. Cohn walk in after the resident has started the surgery and scold his resident for "screwing this all up . . . your technique sucks."

Although the patient had a positive outcome in this case, it is possible that seeing this surgery might cause her retrospective distress. Do filmmakers and hospital administrators have an obligation to warn a patient about potentially embarrassing material that will be aired? Do they have a responsibility to follow up with a patient who was filmed, to answer questions or offer psychological support if necessary?

Staff

Potential benefits of participation. Some providers may find that participation in a series like *Boston Med* is gratifying for the ways it may help current or future patients. Several physicians who participated in the series reflected on the benefits of their experience at the public forum. They cited positive feedback from patients and advocacy groups for raising awareness. Another physician reflected that she found her participation gratifying because she was able to publicly share the wisdom that she learns from her patients.

Potential harms of participation.

At 22 hours of life, baby Michael is transferred to his third hospital, where he will receive expert care for his life-threatening, congenital heart defect. His new parents anxiously await his reparative surgery that was originally scheduled for his fourth week of life, but it is emergently scheduled for the next day after he starts showing early signs of congestive heart failure. They place all their faith in his surgeon, who makes a critical, human error during the surgery, further complicating the baby's course. After weeks of the baby's struggle in the intensive care unit,, the surgical error is ultimately discovered. His surgeon swiftly and openly explains and apologizes for his error, which Michael's parents graciously forgive.

Although such vignettes may benefit the public by making them aware of the reality of medical error and how it is handled, it may come at considerable cost for clinicians whose lapses in skill and judgment are put on public display. Filming such events could significantly impact and even profoundly damage a clinician's reputation and future livelihood.

Another clinician commented on the erosion of barriers she set up to prevent access to her personal life. Elizabeth Blume, MD, said:

> The ABC videographers hung out with us for three or four months. They were part of our team. We knew about their families. We developed relationships with them. And, for me, as a relatively senior clinician who went in with very strict boundaries that I wanted to maintain–and I will admit that those were supported actually by a husband who wanted nothing to do with this and kids who actually were not that interested either—even with all of that, it was hard to maintain those boundaries. The crew wanted the story. They wanted me on the sideline cheering the soccer team. They wanted me doing homework at night. The boundaries were hard, even coming from where I was coming from. It was hard to maintain those boundaries.

Over time, the relationships between the journalists and their subjects were dynamic, given the intimacy of their shared space. Boundaries blurred as cameras wove together professional and personal worlds. Consent may have been given before participants could predict

how they would respond being filmed, but once the event was aired, consent couldn't be "taken back." Some participants said they regretted that participation exposed their personal lives.

The Public

Potential benefit. A series like *Boston Med* may raise awareness of rare illnesses, increase organ donation, and empower patients. Terence Wrong explained his mission, through projects like *Boston Med,* is to help align the public's expectations with medical reality—a valuable goal, given that many well-known medical shows like *ER, Chicago Hope,* and *Rescue 911* typically portray wildly unrealistic outcomes from common interventions.[7] It is possible that, by witnessing real medical encounters, the public will be better prepared to interact with the medical system as more informed consumers of healthcare, with a more complex understanding of their careproviders, including the deep emotional investment that many physicians and nurses make in their patients.

Potential harms. But, in addition to seeing the compassionate care provided by many providers, the public also witnessed offensive and unprofessional care.

After a man presents to the emergency department with a stab wound inflicted by his wife, a resident physician looks to the camera and flippantly jokes, "All I'm sayin', is you better not mess with your woman."

In another scene, one obstetrics resident sends another obstetrics resident this prank page: "47 yo morbidly-obese woman, quadriplegic, with Tourette's syndrome needs a pelvic exam."

Although Wrong argues that it is important and honest to share the humor that physicians use to cope with stress, scenes like these may diminish the public's trust in physicians and hospitals. Patients and families may lose faith in their healthcare providers after seeing unprofessional and disrespectful behavior by physicians and nurses in these elite hospitals.

The primary goals of *Boston Med* are to educate the public and to realign its expectations with reality. But which reality is captured by this documentary—that of the patients, doctors, nurses, hospitals, or filmmakers? The process of whittling down 400 hours of videotape for each hour that was aired unavoidably introduces the risk of distorting reality and so misaligning expectations. John Grierson, a leader in documentary filmmaking, referred to the genre as "creative treatment of actuality."[8] Should documentary filmmakers maximize the transparency of values, conflicts of interests, and biases that frame their narrative choices?

The AMA implores physicians involved in reality television to prevent misleading information from reaching the public. In the case of *Boston Med*, patients and their providers were filmed in real crises, in actual medical settings, without scripts. But to attract and keep viewers, certain narratives were featured. In particular, as Wrong explained, "There's a host of criteria [for what you show], how relatable is the story. At the most basic level, it's a narrative and people like to have the beginning, they like to have the middle, and then they like to have the resolution. We do skew slightly towards positive outcomes because if every show was all about negative outcomes, nobody would watch it at all." From his perspective, producing a program that is well received by viewers must be balanced with the goal of accurately representing the provision of medical care.

The Hospitals

Potential benefits of participation. From the perspective of the hospitals, one hoped-for benefit of participation was to increase trust. Anthony Whittemore, MD, Chief Medical Officer of Brigham and Women's Hospital, explained his motives for supporting his hospital's decision to participate in *Boston Med:* "We welcomed the opportunity to open our doors and show the public a complex organization. I think the documentary [is] an opportunity to educate the public about our shortcomings, about our efforts to deal with them, and I think it's a major contribution in our effort to be much more transparent about our business."

Another potential benefit could be self-reflection. Seeing both inspiring and downright unprofessional behavior by staff may provide leaders of these hospitals and the staffs a glimpse into areas that call for change, growth, and development.

Potential harms of participation. At the same time, by revealing themselves to the camera, the hospitals risk damaging publicity when errors and unprofessional behavior are aired alongside moments of excellent care. They risk losing the trust of patients and employees, as well as the respect of the public. At the panel, one physician participating in *Boston Med* opined:

> The series was a bad idea. Catering to the worst aspects of voyeurism for the public. It seemed that the focus was all too often on the personal lives of the staff. I was asked if I could have a camera crew come to my house and film my family, something that struck me as totally nuts and which I refused. While the team was generally very nice and respectful, I would have to say that this series seemed to be something with a preset agenda, looking to stir up drama and theatric events. Ultimately, it seems that the hospital catered to the lowest common denominator here, selling out the Harvard name and the plight of the patients for what seemed to be free advertising on a national stage.

CONCLUSIONS

Boston Med brought cameras to the bedside, filming beyond the curtains of patients' rooms, revealing their most intimate experiences, both traumatic and triumphant. The journalists' expressed goal was pure observational documentary, honoring the narratives they captured by not scripting, editing, or censoring them. The SPJ *Code of Ethics* recognizes the need for sensitivity, compassion, and respect for the relative privacy of private persons. Wrong suggests that physicians, already committed to a highly developed ethical framework, are apt partners with journalists, as they respect another profession's canon of ethics.

The field of medical ethics rests on a deep commitment to the sanctity of caring for the vulnerable. It has continually evolved, throughout history, around an understanding of patients' best interests. Our medical culture now accepts that patients own their bodies and their stories and may choose to withhold and share their bodies and personal information as they wish. They can refuse care–even when it is life-saving—even after having previously consented. Exams and procedures performed without consent are forms of assault. In contrast, documentary filmmakers juggle responsibilities to private persons, viewers, and their own art, often relying on "situational ethics" to navigate ethical conflicts.

Journalists and filmmakers work to inform. Physicians and nurses work to heal. When their work intersects at a patient's bedside, we need to be clear about which ethical framework should be followed. When the professions follow parallel ethical tracks, a gap is created where morally questionable situations can arise. The two professions collaborate best when they achieve an understanding and integration of their differing ethical obligations.

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Not a "Reality" Show

Terence Wrong and Erica Baumgart

ABSTRACT

The authors of the preceding articles[1] raise legitimate questions about patient and staff rights and the unintended consequences of allowing ABC News to film inside teaching hospitals. We explain why we regard their fears as baseless and not supported by what we heard from individuals portrayed in the filming, our decade-long experience making medical documentaries, and the full un-aired context of the scenes shown in the broadcast. The authors don't and can't know what conversations we had, what documents we reviewed, and what protections we put in place in each televised scene. Finally, we hope to correct several misleading examples cited by the authors as well as their offhand mischaracterization of our program as a "reality" show.

At ABC News we are bound to uphold the division's "standards and practices" policies, which contain a strong ethical component. These policies, basic journalistic ethics, and common sense governed our actions throughout the production of *Boston Med.* Although ethical journalism and ethical medicine don't always overlap, they share common values. In particular, we would never want something to happen or not happen just because we were there. We would never want the quality of care impacted. Still, ethicists and journalists start from a fundamentally different place. Journalists hope patients will consent to waive their privacy, while ethicists are geared to protect it.

Prior to filming at a hospital, we meet with hospital administrators and clinicians in an effort to arrive at ground rules that will allow both missions (ours and theirs) to go forward with a good chance of success and minimal conflict. Krakower, Montello, Mitchell, and Truog raise some valid concerns. I'd like to use this opportunity to correct some inaccuracies and give behind-the-scenes context to the patient and doctor vignettes that were broadcast. In the end, the authors of the preceding articles can't know what was excluded from the final broadcast or the rigorous background work that went into what was finally included. In other words, they lack the context for each case they cite. Even with more information, it would be challenging to deconstruct the elaborate unseen infrastructure of meetings, documents, and other arrangements that allowed the several dozen scenes that were ultimately broadcasted.

Terence Wrong is Executive Producer for Special Series at ABC News in New York City, *Terry.Wrong@abc.com.*
Erica Baumgart is a Supervising Producer in the Special Series Unit at ABC News in New York City, *Erica.D.Baumgart@abc.com.*

The first point to correct is the label in Krakower, Montello, Mitchell, and Truog's title, "The Ethics of Reality Medical Television." Until now, no one has referred to our ongoing hospital documentary series as a "reality" program, not ABC News, not the hospitals themselves, nor the journalists who write about television in newspapers and magazines. "Reality" is a fairly loaded label, and to many it carries with it more than a whiff of exploitation and the sensational. Television professionals know that reality shows usually involve a paid cast of characters, signed up under highly restrictive contracts, and brought to a set or controlled location where they will act out scripted scenarios. The dialogue may be improvised, but often little else is.

Now let's consider *Boston Med*. It is produced by a veteran broadcast journalist with 29 years working in television news and documentary. Half of my career was spent reporting from overseas in war and crisis zones. For example, I was ABC's lead producer at the Berlin Wall the night it fell. I have no background in "reality" television. As previously mentioned, we are obliged to follow news division guidelines. About the environment or "location" where we produce this series: it is a hospital, and we do not control a single room or thing that happens there. We don't create scenarios and our "cast" are caregivers and patients who we observe as they go about the normal business of delivering and receiving care. We follow minimally intrusive methods of filming, consistent with traditional cinéma verité documentary making. Mostly, this comes down to a lone videographer in scrubs (with a hospital ID that says "Press") working in a unit, shouldering a small camera with no lights or cables. Our original hospital series, *Hopkins 24/7*, won a duPont-Columbia University Award for journalistic excellence. The next edition, simply called *Hopkins*, won a Peabody. *Boston Med* won a CINE "Special Jury" Award for being one of three top *documentary* series that year.

The authors state that "patients stand to gain nothing" by consenting to be filmed. How do they explain the hundreds of letters we have received from patients thanking us for showing their surgery or treatment in the series? They often keep the program as a keepsake and a way to explain their medical ordeal and struggles to others. In the case of minors, we have been doing this long enough to see them grow up and express gratitude that there is a visual record of what was often a turning point in their lives. Sometimes, it helps patients understand what their parents endured emotionally. Often, families ask us for the footage. We have even received those requests from the families of physicians who have passed.

Krakower and colleagues state that once patients gave us consent to be filmed, they couldn't later rescind their permission. In fact, this has never been the case. Patients may revoke their consent at any time up until the actual broadcast, a full year after they were filmed. Moreover, patients are often contacted multiple times by our staff during the intervening period until the broadcast. Besides getting an update on their progress, we usually seek additional information related to their treatment or condition. During these conversations, we always ascertain that they are still comfortable being portrayed. To date, we've maintained long-standing relationships with many patients and families. Sadly, sometimes families request footage as a keepsake to memorialize patients who have passed away. This can be incredibly meaningful to the family. Caregivers may also decline to be filmed or drop out of the documentary at any time. We maintain a file during production on who specifically has "opted out."

Krakower, Montello, Mitchell, and Truog state that the patients and staff "were told that once they agreed to be filmed, they would not be able to see what was filmed, or rescind consent." ABC News—and all other reputable news organizations, large and small—adhere to the principle that subjects of a work or of reporting must not read, view, or be able to influence the work being done about them before broadcast or publication. This is basic to balanced and objective reporting, whether for a documentary or a news report.

Another concern raised is related to the question of patients' "competence" to give informed consent to being on television. Frankly,

over the course of making each edition of this series, we have always been struck by how well patients understand the essence of the program we are making. Many of the patients who consent to be filmed articulate the hope that portraying their care will inform the public about a particular disease process or perhaps give heart to other patients fighting the same disease. We believe this is exactly what sharing their individual stories accomplishes. Anecdotally, 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. Talk about things coming full circle. In one case, we were actually filming a pre-surgical consult when the patient cut the doctor off and said, "I know all about what's going to happen, I saw that lady have the operation done in *Hopkins*."

Unfortunately, Krakower and colleagues are forced to make judgments based on the few minutes of each case that were included in the *Boston Med*. It's not their fault that they couldn't be there with us during filming or editing, but it does mean they were sometimes deprived of the larger context and facts that actually contradict or mitigate their point. Here's one example they cite:

> A 49-year-old man with a history of heroin and alcohol abuse is seen in the emergency department while inebriated. The doctors and staff in the ED are pictured chuckling at his offbeat behavior, and a resident is quoted as saying, "This guy's pretty entertaining." The camera focuses on the man's "born to lose" tattoo while he dances and sings inappropriately on his gurney. He is later filmed kissing his lunch.

Actually, the man had a bipolar diagnosis and was off his meds. The young resident in question had spent close to an hour with the man, displaying great compassion and eventually giving into his playfulness and joking, hence his comment, "This guy's pretty entertaining." When we visited the patient at home a year later to make sure he was still comfortable being portrayed, he was on his meds. We reminded him in detail of exactly what his conversation with doctors had been and how he appeared. He said he thought the caregivers did an amazing job caring for people like him, that he was a "frequent flier" in that particular emergency room, and that he was comfortable with the public seeing how patients with mood disorders like his are treated humanely.

Krakower, Montello, Mitchell and Truog also mention the case of another patient with altered mental status. This one, however, is belligerent and abusive to staff. The authors claim that his dignity may have been violated by exposing his surly behavior. However, it was precisely to protect him from these retrospective feelings that we blurred his face and altered his voice. These authors incorrectly state that his voice was "unaltered," and might give his identity away. They are wrong about this. Perhaps they may not know that the latest audio software can now disguise voices without making them sound robotic. Finally, the authors should know that we were thanked by ER staff for showing that scene because they believed it captured the difficulty and unpleasantness that they sometimes confront when trying to deliver care to unreceptive patients.

Several times Krakower and colleagues raise disturbing questions, but are unable to support or answer those questions with examples from the program. In the same vein of misunderstanding that led the authors to call us a reality show, they ask at one point if the producers of *Boston Med* engaged in a *quid pro quo*, perhaps unspoken, with patients to get their consent by promising or implying that they might receive better care if they agree to be filmed: "perhaps those in more desperate clinical situations were more vulnerable to implicit coercion or manipulation, or the unspoken possibility that participation would improve their odds."

In fact, both in our conversations with patients and on the consent form they signed, it was stated clearly that participating in the series would not help or harm their care in any way. Caregivers and producers were always at pains to repeat and emphasize this principle at the outset of any filming. Perhaps this is a good place to mention that most of the producers and

not a few of the videographers are themselves from medical families. I am happy to say that those who produce medical series have not just a passion bordering on reverence for the medical profession, but they consider medical documentary work a calling.

Another worry for Krakower and colleagues is whether caregivers may have been distracted from delivering their most focused care because they were too conscious of—or too complicit with—the camera. I would answer by saying that it is unfortunate that the authors were unable to watch the hundreds of hours—weeks and months worth of footage—filmed with each caregiver that was not broadcast. In practice, after a day or two, caregivers who don't relax and just go about their business, who don't lose the "butterflies in the stomach" feeling, either "opt out" of being filmed or we decided to stop observing them. It is also my conviction that no one remains camera-conscious over such a sustained period of observation. To support the notion that we might have affected care negatively, the authors cite the example of a young ED resident who struggles to do an intubation during a code. After describing the scene, they make the following comment: "The effect of the camera in the room may be difficult to identify or measure, but it is possible the presence of a camera and crew changed or hampered resuscitation. Several times in the series, staff spoke directly to the camera while performing work duties, suggesting it was not always an inert factor in the room. . . ."

Fair enough, but during the incident they cite, at no time did the resident in question address anyone other than her coworkers. She never addressed the camera or said anything that one would imagine her saying if the camera weren't present. She is surrounded by half a dozen colleagues supporting her efforts, and they are all working frantically. Krakower and colleagues do not mention a single case in which care appears to have been affected negatively. This seems like a good place to point out that, in our agreement with the hospital, and in introductory meetings with the full clinical staffs of each unit—especially nursing—it was stressed that anyone on the care team can ask us to leave a room or an area at any time with no explanation required. During filming, this does happen, and in each situation we comply immediately and withdraw.

One more point about residents in training who are depicted being "pimped" or constructively criticized by demanding attendings. Far from being humiliated, they are mostly grateful that their own families and friends can now see and understand the rite of passage that their training entails. As with the patients who undergo major surgeries, we tend to remain in contact with the residents who appeared in our past series. They too, for the most part, regard the program as a keepsake and remain happy with their decision to participate.

Another matter that troubles the authors concerns "surrogate decision makers for consent." In such cases, patients may die or be incapacitated in such a way that they cannot give consent to be filmed. In these instances, sometimes consent is obtained from a family member, legal guardian, or healthcare proxy. One can almost see the hand wringing as the authors ask: "Should parents be allowed to consent for their child?" It is strange that the authors believe a family member can be trusted to give consent for a surgery that may be life-altering or even life-ending, but can't be trusted to permit a loved one to be filmed. I'd like to emphasize that even with family consent, if patients recovered enough and regained their power to grant consent, we always sought to obtain it, and, if refused, we refrained from broadcasting the case. In the case of minors, sometimes even when parents consented, upon review, we decided to exclude the case, and decided that broadcasting it would be inappropriate. We have to exercise good judgment and sensitivity. We never forget that this is delicate work and, as Krakower and colleagues state, dealing with grief-stricken families is an area where it is wise to move slowly and leave everyone adequate time to reflect on decisions or choices.

Krakower and colleagues also cite the case of physician error shown in the series during a heart surgery. They posit that exposing this incident could damage the reputation of the physician. In fact by the time we aired this segment,

the physician in question was no longer on the Massachusetts General Hospital faculty with privileges. In addition, the pediatric heart surgery program at the hospital had been largely suspended and was under review. The particular case in question had been covered in detail in the local newspapers. Our segment, however, mentioned none of this fallout. In fact, the surgeon is depicted as ethical, humane, and candid in how he dealt with the error. The family in question refused to have another surgeon do the subsequent corrective surgery and remained confident that the original "honest" surgeon should do the correction, which is precisely what happened.

The authors are concerned that the confidence of young doctors in training could be adversely effected by having their mistakes portrayed, or by showing "pimping"—the process of interrogation and criticism at the hands of established attendings. During a cardiac surgery, an attending tells a resident, "your technique sucks." This resident went on to become an attending surgeon at a major hospital and at no time did he ask us not to use that scene. Residents, like other hospital staff, can "opt out" and choose to cease participation at any time. Incidentally, the fourth-year emergency medicine resident who struggled to intubate her patient also went on to a successful career as an attending, and graduated Harvard Medicine with high honors. Those who participated in the filming were supportive of the notion that showing the good, the bad, and even the ugly, educates viewers about the mission of a teaching hospital and the process of making a doctor. They put their faith in us to show that missteps occur when learning is going on.

Krakower and colleagues also worry about patients' reactions to portraying the teaching or pimping that goes on. They write, "Although the patient had a positive outcome in this case, it is possible that seeing this surgery might cause her retrospective distress." They fail to consider the equally probable possibility that the patient may have watched the scene when it was broadcast and said, "Boy, my surgeon was a tough taskmaster, he sure was on top of that resident. I bet I got top-level work done on me."

Staff demeanor is another area that gives the authors qualms. In particular, they seem bothered by what they regard as inappropriate humor. The authors lament moments that were broadcast, in which a caregiver may have made a sarcastic remark about a particularly troublesome or unruly patient. They characterize this as the patient being "mocked." First, it should go without saying that we never put words in anybody's mouth or prompt them to say anything. Second, doctors and nurses are not saints, and ERs are not full of well-behaved, courteous patients. Not infrequently, staff have to deal with verbal and even physical assault. They are exposed to highly infectious patients who spew bodily fluids, make unwanted advances, act belligerently and sometimes violently. Some of the patients are intoxicated with drugs or alcohol and others are psychotic. It is understandable that these type of encounters may engender black humor on the part of caregivers: it is a coping mechanism. Choosing to broadcast moments like these, rather than air brush them onto the edit room floor, gives a realistic portrait to viewers of what staff must contend with, and, paradoxically, deepens their humanity. That said, in the great majority of cases we cover, caregivers behave with compassion, sensitivity, and a practically superhuman degree of self-control.

The authors express their disapproval that we seek to include windows into the personal lives of the caregivers we profile. In particular, they quote pediatric cardiologist Elizabeth Blume saying, "It was hard to maintain boundaries" in her explanation of why she chose not to invite the camera into her home. However, the quote by Blume has been used out of context. She made her remarks at a symposium about *Boston Med* that was held at the Harvard Medical School and organized by one of the authors. I was present when she spoke. A fuller rendition of Blume's comments would have included her conclusion that after watching how other physicians were portrayed at home with their families, she regretted not letting the ABC team portray her in a more fully rounded way, and see her discussing homework with her daughter at the kitchen table.

Patients' privacy is of course the main bugaboo. The authors wonder about emergent cases where patients are clearly not in a position to give consent to be filmed, and they ask, "To what extent should patients' privacy have been honored?" The correct answer is: patients' right to keep their medical information confidential from the public should be absolute. To us, this means that no patients should ever be identified in a broadcast without having consented to being identified and having the details of their medical treatment exposed. In some instances we will conceal patients' identity altogether. We do this by making sure that neither face, nor voice, nor tattoos, nor any other identifying aspect of the individual—specific facts such as age, gender, or the circumstances of injury—will compromise patients' medical privacy. Even if we don't report it, should we even be in a position to learn of patients' medical condition without their consent? After all, "ER tourists" such as third-year medical students, instrument salesmen, and hospital administrators are not part of patients' immediate care circle. In our case, hospitals decided there is a benefit to educating the public and allowed us to observe. Taken into consideration is our status as a deeply experienced medical documentary unit that has worked for over a decade in some of our nation's most august medical institutions. We are trained in Health Insurance Portability and Accountability Act (HIPAA) and hygiene protocols. We undergo background and health checks, and our vaccinations are up to date.

Krakower and colleagues sum up with an anonymous quote attributed to a physician: "The series was a bad idea catering to the worst aspects of voyeurism for the public."

Professional journalists and documentarians tend to hold anonymous quotes in low regard. In fact, as for what physicians thought of the series, faculty from Massachusetts General Hospital and Brigham Women's Hospital were in attendance at the Harvard Medical School symposium arranged to consider *Boston Med*. Also in the audience were family members related to patients who were portrayed in the series. Not a single speaker regretted their participation in the broadcast or offered a negative assessment. On the contrary, the prevailing sentiment was overwhelming: the series had been a comfort to them personally—sometimes documenting the last days of a loved one—and had served the public interest by providing an inside look at how top medical centers confront their work.

Since we were first asked to respond to Krakower and colleagues, we have broadcast another edition of our medical series, this time examining institutions in New York. We continue to be invited into top medical centers across the country. Presumably, ethicists at those hospitals will be concerned about protecting patients and staff from programming that they may perceive as exploitative. We share their concern and do our utmost to maintain rigorous standards and self-scrutiny. However, what is not debatable are the empirical benefits of the series, including: spikes in the recruitment of emergency medical technicians and nurses, applications to medical school, thousands of viewers signing organ donor cards, and the many anecdotal stories we hear from patients who tell us that the series gave them courage to get through difficult times. Above all, we continue to believe that the greatest service performed by this type of programming is to give our viewers—all of them potential patients—a more realistic portrait of both the achievements and limitations of modern medicine.

NOTES

1. Krakower, M. Montello, C. Mitchell, and R.D. Truog, "The Ethics of Reality Medical Television," in this issue of *JCE*.

First, Do No Harm

Neal Baer

ABSTRACT

In a television news documentary series such as *Boston Med,* doctors' duty to their patients may be at odds with the duty of TV journalists to their audience. If this happens, who should win out? The patients. If there is any possibility that harm is being done to patients, we must put them first, and turn off the cameras.

ABC News's *Boston Med* raises fundamental questions about the ethics of peeking into the private relationship between patients and their healthcare providers. Can a camera crew, spending months following attendings, residents, and nurses, truly not affect patient care? Are the filmmakers merely "flies on the wall" objectively recording the moving and sometimes harrowing moments that comprise a typical day in the emergency room (ER)? Or can their very presence put patients' care at risk, especially since their mission is to tell a good story?

The producer of *Boston Med* claims that his motive for making the series is to inform the public about what really goes on behind the scenes in the American healthcare industry.[1] No doubt this is true, and the public would benefit by having a more comprehensive understanding of the complexities of delivering good care to those who have the means to pay for it (and those who do not). But does a camera crew also imperil care by its very nature of breaking into the patient-doctor relationship, and can reality medical television ever guarantee, no matter how noble its objectives, that it will do no harm to the patient?

Neal Baer, MD, is Clinical Professor of Preventive Medicine at the Keck School of Medicine at the University of Southern California in Los Angeles, and is Executive Producer of *Under the Dome,* CBS Television, in Studio City, California, *nealbaer@mac.com.* This article was written at the request of Harvard Medical School Division of Medical Ethics.

REALITY TELEVISION VERSUS DRAMATIC TELEVISION

I was writer and executive producer of the television series *ER*, *Law & Order: Special Victims Unit*, and *A Gifted Man*, and medical dramas have given me the opportunity to portray many trenchant issues of our times: abortion, end-of-life decisions, the vaccination of children, testing for HIV, the consequences of drug and alcohol abuse, and access to good healthcare—to name only a few. By accurately portraying these issues, we can illuminate topics that were once taboo, bringing them out into the open for the public to discuss and debate, and destigmatizing those who may be suffering in silence. TV dramas are a way to confront the often messy elements of our lives, and these stories can inspire us to think more deeply and perhaps more openly about issues that often divide us.

Reality television can also stimulate discussion about important health issues by opening the door to real situations confronted by real people, not actors. But can it possibly be true, as the producer of *Boston Med* insists, that "in no way will care be affected one way or another"[2] by a team of filmmakers shooting private conversations between patients and doctors, as well as the patients' medical procedures?

As filmmakers, we need and relish those moments that engage viewers, pull them into the story, and make them identify with our characters. Dramas by their very nature are confected—actors *portray* characters; bits of film are shot from a variety of perspectives and then edited together to make a compelling scene; music is added to heighten the emotion or to make moments resonate. Reality television too is confected, often from hundreds of hours of footage. Moments are selected for their emotional resonance, time is compressed, and much footage is discarded. There is no objectivity in that selection; the filmmaker is making choices to move in for a close-up, focus on a participant's eyes or hands, or to turn the camera off when nothing "interesting" is going on.

Recently, while making a documentary, I longed for the moments when something highly emotional or unexpected happens. That's why so much footage is never used in documentaries or on reality shows: it's boring. If reality television were truly real, cameras would have to be mounted to shoot endless rolls of footage, which would be unedited and projected on multiple screens. And that would bore us to tears and still not be objective, since someone had to decide where to place those cameras. So reality medical shows like *Boston Med* are highly crafted, and they seek the unexpected, the twist or turn, the emotional, in order to make a show that will appeal to an audience. And in seeking the emotional, these programs are looking to exploit some of the toughest moments of people's lives, where they or loved ones often hang on the precipice of death. A savvy doctor who participated in the filming noted, the "series seemed to be up to something with a preset agenda, looking to stir up drama and theatric events."[3] One can't fault *Boston Med* for wanting "drama and theatrics" to make a compelling show, but the participants in these shows must be aware, before they consent to being filmed, that brief moments of emotion—both tragic and elated—will end up on screen, and that the producers not only welcome these moments, but need them.

But does the fact that reality shows aren't really reality, but are a compilation of selected moments, affect the patient-doctor relationship, potentially disrupting or even imperiling the guiding principle of doing no harm? How can it not? The camera crew enters into what is typically a confidential, trusting relationship between the patient and doctor. How are we to know whether or not patients withhold information because they are on camera, even if they have previously signed a release? And how do we know that the knowledge of being on camera does not affect a physician or nurse performing a procedure? Since we can't possibly assess the effect that being filmed has on patients and doctors, it seems wise and prudent for patients, healthcare providers, and hospitals to think hard about the repercussions of allowing camera crews into the clinic, ward, or ER.

We should also give careful consideration to why some patients consent to being filmed and why others do not. Most transplant patients consented to being filmed, and Krakower and colleagues[4] speculate it was because the patients were in desperate clinical situations, in contrast to plastic surgery patients, who consented to being filmed only 50 percent of the time.[5] Another likely explanation is that transplant patients, often having gone through the ordeal of waiting on a transplant list for an organ, want the general public to become more aware of their plight, and to be willing to donate their organs, whereas plastic surgery patients are less interested in the general public being a party to their cosmetic procedures. No doubt some patients and doctors also consent to being filmed because they like the attention their stories will bring to their illnesses or to themselves. Presenting people's true-life stories on television can empower individuals, making them feel that "they matter." But the need for attention should

never overshadow the primary reason the patient enters the hospital: to get well.

The questions that must be asked are: What public good comes out of reality medical television? Does that public good trump the possibility that the presence of a camera crew will impede the delivery of services? Even when patients, doctors, and nurses give consent, they can't later withdraw consent or see how their lives will be edited for a mass audience. Understandably, television journalists must uphold their ethical standards and "maintain the integrity of an observational documentary and protect it from censorship."[6] Nevertheless, doctors must accede to patients' wishes at every step of treatment, agreeing to withdraw care whenever patients make that decision. Thus, doctors' duty to their patients is at odds with the duty of TV journalists to their audience. Who should win out? Patients, who often cannot know the outcome of their treatment, must win out. Even if patients have consented to being filmed, they should have the right to withdraw their consent if they feel filming is impeding their care, if it is making them uncomfortable, or if they have changed their mind after learning more about the course of their illness; otherwise harm is being done to them. And if there is *any* possibility of that occurring, we must put the patients first, and turn off the cameras.

NOTES

1. T. Wrong and E. Baumgart, "Not a 'Reality' Show," in this issue of *JCE*.
2. Ibid.
3. T.M. Krakower, M. Montello, C. Mitchell, and R.D. Truog, "The Ethics of Reality Medical Television," in this issue of *JCE*.
4. Ibid.
5. Ibid.
6. Terence Wrong, quoted in Krakower, Montello, Mitchell, and Truog, see note 3 above.

Watching *Boston Med*

Walter M. Robinson

ABSTRACT

The author reflects on the ABC news documentary series *Boston Med*—both what it achieved, and what it could have achieved.

When I watched *Boston Med*, I was startled by the world it portrays. As the other commenters have noted, television shows of this type are the result of editing down many hours of filming; they are, as Neal Baer writes, "highly crafted, and they seek the unexpected, the twist or turn, the emotional, in order to make a show that will appeal to an audience."[1] The other commenters have taken on the issues of consent, informed or otherwise, to filming, and I leave it to them to parse out the answers to these issues.[2] What interests me here are the decisions made by the filmmakers in constructing the series. Since the show is a constructed version of events, edited from what may be hundreds of hours of filming, we are free to judge the show's constructed version of "reality" in comparison to our own experience.

From my perspective as a clinician and ethicist who trained and practiced for many years in the hospitals depicted in *Boston Med*, I find much of the filmmakers' constructed reality a cynically false rendering. In *Boston Med*, clinicians are most often depicted as callous, competitive, self-absorbed, or arrogant, and patients depicted as cartoonish saints or sinners. Out of the many hours of filming, the makers of *Boston Med* have constructed what they must believe to be a set of truths about American medicine; they are truths I did not recognize. For the most part, the filmmakers draw caricatures of clinicians, and create compassionless, mocking cartoons of people with serious illness. The filmmakers cannot respond that they are simply showing what happened; as Baer notes, they will have made scores of choices of what to show and what to leave out, and they bear responsibility for the results.

The show constructs two kinds of patients: good ones and bad ones. Good ones are eternally grateful to the staff, unfailingly polite, willing to wait forever. In particular, good patients must placate and please the doctor to get attentive care. In the show's most extreme example, good patients do not sue, even when a physician makes a serious error. Good patients applaud when the doctor walks in the room, comment on his or her attractiveness or charm, and exclaim their "faith" in the doctor; in the world of *Boston Med*, good patients see the doc-

Walter M. Robinson, MD, MPH, is a Visiting Fellow at the Hastings Center, Garrison, New York, *wmacr@mac.com*.

tor as a religious figure. In contrast, bad patients make specific requests and pursue them because they have educated themselves on their own condition. Bad patients have mental illness or addictions that disrupt the flow of medical care. Bad patients complain about extensive waiting or duplicate testing. Bad patients do not behave. They kiss their sandwiches. The show suggests that because they are bad patients, the public should feel free to mock them.

The white-hat black-hat simplicity of that depiction is foolish enough, but more disturbing is the suggestion that this contrast arises from the clinicians, rather than from the filmmakers' search for cheap theatrics. No scene is included in which an observer rejects this false moral dichotomy, save for one discharge nurse who knows the mother of a chronically ill child is stressed beyond her limits and demonstrates a caring and compassionate response; that response is far more common than any of the callous attitudes the show depicts, but it is less dramatic, I suppose, than the ones the filmmakers chose. Another brief moment shows a skilled emergency room nurse speaking with a patient in a firm but lighthearted way, skillfully diverting his concerns and reassuring him at the same time, containing his behavior so that the work of the emergency room can get done. In my experience, this happens scores of times every day, on every ER shift. It is a hallmark of excellent nursing, but it is evanescent in the world constructed by *Boston Med*.

Boston Med seeks out clinicians making fun of or being irritated by patients, and presents such scenes without context. The depiction of an encounter between a woman, her mother, and a young surgical resident is typical. No mention is given of the diagnosis, the reason for presenting to the emergency room, or the disposition. The women are styled as drug-seeking, irrational pains-in-the-neck for the young doctor. He says their suffering is not part of his job. But what else did he say? Was he concerned that he felt indifferent to their suffering? Was this a moment of frustration or a pattern? Were the filmmakers serious about telling the story of this encounter, or did they just want the viewer to feel the cheap thrill of superiority? Wouldn't anyone serious about getting the full story explore it more?

All of this could have been otherwise. *Boston Med* saves for last an episode on face transplantation that demonstrates what the rest of the series might have been. The sorrow and hardship of deciding to donate organs, especially facial tissue, is shown with sufficient time to get a clear picture of the family's struggle. The episode explores the entirely human reluctance of the family to make the donation, and then shows the family respecting the donor's wishes, to honor issues that were important to him. The suffering of the recipient and his family after his disfiguring accident is shown in a way that preserves their dignity and avoids the sideshow motif the filmmakers previously used to depict a patient with mental illness. This episode also illustrates the highly professional work of the transplant team. Their discussions with the donor's family and the recipient demonstrate compassion and candor. These clinicians function as a team without the juvenile competitive attitudes highlighted in the rest of the episodes. The subtlety and complexity of these scenes demonstrate that the television format, with its commercial pressures, does not in fact demand sensationalism. A well-told story will captivate without melodrama.

This last episode demonstrates what all of *Boston Med* could have been, and makes clear the effects of choices the filmmakers made in the first seven episodes. The series as a whole could have illustrated the hard work and complex choices made under uncertainty by physicians and nurses working in premier Boston hospitals. It could have shown those doctors and nurses handling the stress of their work without sensationalism. It could have presented patients as we know them to be, fully rounded people struggling with illness, complex and burdensome care, and the bureaucracies of healthcare and insurance, as well as negotiating their relationships with the changing set of clinicians, for better and worse. Sick people and their families could have been honestly portrayed as having good and bad days, as do we all. Physicians and nurses, young and old, could have been presented as struggling, not always

successfully but at least earnestly, with the difficult work of caring for the sick. Yes, we physicians and nurses are flawed in just the sorts of ways all humans are, and some of us are arrogant and haughty and let our stress interfere with our compassion. But the stylized, hyped-up world of *Boston Med* is not a true one; it is a simulacrum of the truth designed to tease, not inform.

By choosing the tell the story of these hospitals in a more mature way, the makers of *Boston Med* could have sparked a renewed public involvement in medical training or organ donation or chronic illness or the cost of care or the burden of illness. There are dozens of well-made documentaries that strive to do just that, likely with less of a budget and less access to these institutions than *Boston Med*. Instead, the filmmakers wasted the opportunity to present a thoughtful look inside the world of the modern hospital. They chose to portray people as types, as stock characters, using a style that depends on the melodramatic moment rather than the well-considered narrative of character and deed. They spent hours in the hospitals, but failed to see the real human drama going on in these institutions. *Boston Med* describes the lives of patients and clinicians in the way reality television describes life: sensationally, poised to reveal and savor the hasty reaction, more concerned with the melodramatic transgression than the slow and hard labor of living with illness or working in a modern research hospital.

NOTES

1. N. Baer, "First, Do No Harm," in this issue of *JCE*.

2. T.M. Krakower, M. Montello, C. Mitchell, and R.D. Truog, "The Ethics of Reality Medical Television," in this issue of *JCE*.

Law

Legal Briefing: Shared Decision Making and Patient Decision Aids

Thaddeus Mason Pope and Melinda Hexum

ABSTRACT

This "Legal Briefing" column covers recent legal developments involving patient decision aids. This topic has been the subject of recent articles in *JCE*.[1] It is included in the 2010 Patient Protection and Affordable Care Act.[2] And it has received significant attention in the biomedical literature, including a new book, a thematic issue of *Health Affairs,* and a recent article in the *New England Journal of Medicine*.[3] Moreover, physicians and health systems across the United States are increasingly integrating decision aids into their clinical practice.[4] Both federal and state laws play a significant role in promoting this expanded use. On the other hand, concerns about liability could stymie development and implementation. We categorize legal developments concerning patient decision aids into the following five sections:

1. Development of decision aids
2. Effectiveness of decision aids
3. Federal regulation of decision aids
4. State regulation of decision aids
5. Legal concerns regarding decision aids

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

Melinda Hexum, MS, is a Second-Year Law Student and Associate Editor on the Board of the *Hamline Law Review* at Hamline University School of Law.

1. DEVELOPMENT OF PATIENT DECISION AIDS

Over the past two decades it has become increasingly clear that the traditional informed consent process is deficient. It often fails to ensure that patients have the information and understanding necessary to make truly informed decisions regarding their medical treatment.[5] This is particularly the case in the context of "preference sensitive treatment," situations in which no single treatment option is "correct" or clearly indicated over all others by the available medical evidence. Take, for example, the birth of a child with a disorder of sex development. Is it a boy or a girl? Should there be surgery? What kind? When?[6] In such instances, there is more than one good option, more than one reasonable path forward. The best course of treatment for a particular patient depends on that patient's preferences, values, and cultural background.

In its 2001 *Crossing the Quality Chasm* report, the Institute of Medicine recommended greater use of decision aids to ensure that pa-

tients' treatment decisions are consistent with their preferences and values.[7] Today, there is a discernible shift away from traditional informed consent processes, toward shared decision making processes incorporating the use of decision aids. Indeed, the use of patient decision aids is perhaps the most rapidly growing means of addressing the failure of traditional informed consent.

Decision aids are educational "tools" that help patients understand the various treatment options available to them, including the risks and benefits of each choice.[8] The tools include evidence-based educational literature with graphics, photographs, and diagrams. They also take the form of videos, website-based interactive programs such as sequential questions with feedback, and "structured personal coaching."[9] But despite their self-directed and self-paced nature, decision aids do not supplant physician-patient conversation about treatment options. Instead, they supplement it, by better preparing patients to engage in that conversation.

Aids are already available for a large number of conditions, including breast cancer, prostate cancer, osteoarthritis, and childbirth.[10] Many more decision aids are being developed by nonprofit and for profit companies and government entities. Nonprofit developers include: Advance Care Planning Decisions,[11] the Cardiff University Decision Laboratory,[12] Healthwise,[13] the Informed Medical Decisions Foundation,[14] and the Mayo Clinic.[15] For-profit developers include: Dialog Medical,[16] Emmi Solutions,[17] Health Dialog,[18] Krames StayWell,[19] the Patient Education Institute,[20] and Welvie.[21] Government developers include the U.S. Agency for Healthcare Research and Quality and the United Kingdom National Health Service RightCare.[22]

2. EFFECTIVENESS OF PATIENT DECISION AIDS

Increasing focus on the aids is motivated by significant and growing evidence that they offer substantial benefits. Notably, a 2011 Cochrane Review of 86 studies found that patients who used decision aids were more knowledgeable about treatment options, less conflicted about their decision, and more likely to play an active role in decision making than patients who did not.[23] Consequently, the patients who used decision aids may be better able to align their care with their preferences and values.

Furthermore, decision aids do more than improve patients' knowledge and satisfaction. They reduce the cost of care. Patients using decision aids are more likely to choose conservative treatment options, are less likely to choose surgical interventions,[24] are less likely to be admitted to the hospital.[25] And they are less likely to choose cardiopulmonary resuscitation.[26] One study estimates that implementing decision aids for 11 procedures would yield $9 billion in savings in 10 years.[27] On the other hand, there remain some significant hurdles to implementation. For example, clinicians must be incentivized and trained to use them.[28]

3. FEDERAL REGULATION OF PATIENT DECISION AIDS

Given that decision aids are a relatively recent development in clinical practice, it is not terribly surprising that there is relatively little government oversight of the development and use of such tools.[29] The most notable source of federal law that directly deals with patient decision aids is Section 3506 of the 2010 Patient Protection and Affordable Care Act (ACA).

The express purpose of Section 3506 is to facilitate shared decision making.[30] It aims to do this in three ways. First, Section 3506 directs the U.S. Department of Health and Human Services (DHHS) to contract with an entity that will "synthesize evidence" and establish "consensus-based standards" for evaluating decision aids. This entity must then develop a "certification process" to endorse decision aids that meet those standards.[31] Second, Section 3506 promotes the development and clinical use of patient decision aids by directing DHHS to make grants or contracts to develop, update, produce, and test patient decision aids and to "educate providers on the use of such materials."[32] Third, Section 3506 directs DHHS to provide grants for the implementation and effective use of decision aids.[33]

Unfortunately, the Center for Medicare Services (CMS) has not yet moved forward on the first aim by selecting an entity to certify patient decision aids. However, CMS *has* moved forward on supporting the initiation of decision aid demonstration projects. For example, MaineHealth and the Mayo Clinic have been selected as "Shared Decision Making Resource Centers" to "disseminate best practices and other information to support and accelerate adoption, implementation, and effective use" of decision aids.[34] Furthermore, there are a number of other federal programs that authorize the funding of research on decision aids.[35]

For example, Section 3021 of the ACA establishes the Center for Medicare and Medicaid Innovation (CMMI).[36] The CMMI is charged with testing and evaluating "innovative payment and service delivery models" to identify approaches that will provide cost savings or improve the quality of care for populations served by Medicare, Medicaid, or the Children's Health Program (CHIP).[37] CMMI tests and evaluates models to determine if they either decrease program costs without reducing the quality of care, or increase the quality of care without increasing spending. When CMMI identifies such models, it has the authority to promulgate rules implementing these models on a nationwide basis, through federal health programs.[38]

One of several models specifically identified by Section 3021 as an opportunity for CMMI to address costs or the quality of care is in assisting individuals to make "informed health care choices by paying providers of services and suppliers for using patient decision-support tools" that "improve applicable individual and caregiver understanding of medical treatment options."[39] Thus, it is likely CMMI will address payment and delivery models involving patient decision aids.

Indeed, part of CMMI's work includes making grants to organizations that will implement "the most compelling ideas to deliver better health, improved care, and lower costs to people enrolled in Medicare, Medicaid, and Children's Health Insurance Program."[40] In 2012, CMMI awarded the first batch of the "Health Care Innovation Awards." While none of the awarded projects appear to specifically focus on patient decision aids, many address the larger issue of shared decision making and probably involve the use of decision aids.[41]

Like CMMI, the Agency for Healthcare Research and Quality (AHRQ) has promoted the development and implementation of patient decision aids. Its Effective Health Care Program funds "effectiveness and comparative effectiveness research for clinicians, consumers, and policymakers," including studies related to development, testing, or implementation of patient decision aids.[42] Additionally, it has made publicly available two decision aids, "plain-language guides," that it contracted to develop—one for postmenopausal osteoporosis, the other for "clinically localized" prostate cancer.[43]

A potential source of federal funding for the development, testing, or implementation of patient decision aids is the Patient-Centered Outcomes Research Institute (PCORI).[44] The ACA mandated the establishment of PCORI as a nongovernmental, nonprofit corporation, and charged it with funding comparative clinical effectiveness research.[45] This will increase the availability and quality of evidence that patients and healthcare providers need to make "informed health decisions." In May 2012, PCORI indicated that one of its national priorities for research funding will be "communication and dissemination research," including support of "shared decision making between patients and providers."[46] This strongly suggested that PCORI would support decision aid research. PCORI's subsequent award of its first cycle of grants has confirmed this. Of 25 grants initially awarded, at least two directly deal with assessing the efficacy of decision aids for improving medical decisions by patients and their families.[47]

Lastly, federal regulations promote the implementation of patient decision aids by accountable care organizations (ACOs) that partake in the ACA's Medicare Shared Savings Program (MSSP).[48] Under the MSSP, groups of physicians, hospitals, and other healthcare providers contract with the Centers for Medicare and Medicaid Services to accept responsibility for the "quality, cost and overall care" of an assigned group of Medicare beneficiaries.[49] As an

incentive to provide quality, cost-efficient care, providers will continue to be paid under the Medicare fee-for-service model, but will be eligible for "shared savings" payments if the ACO meets certain cost and quality benchmarks.[50]

One of the quality benchmarks required of ACOs is that these organizations "define processes to promote . . . patient engagement."[51] CMS regulations issued in 2011 clarified this requirement, explaining that measures that would promote patient engagement "may include, but are not limited to, the use of decision support tools and shared decision making methods with which the patient can assess the merits of various treatment options in the context of his or her values and convictions."[52]

4. STATE REGULATION OF PATIENT DECISION AIDS

Since patient decision aids have been reported to both improve care and reduce costs, federal policy makers have not been the only ones incentivizing their use. State policy makers have also been enacting legislation and administrative regulation that promotes the use of decision aids.[53] Most notable among these states is Washington.[54] In 2007, Washington enacted legislation that called for a demonstration project. It also incentivized the use of decision aids by creating a legal safe harbor.[55] A "regular" signed consent form constitutes *prima facie* evidence that the patient gave her or his informed consent to the treatment administered. The patient has the burden of rebutting this by a preponderance of the evidence (showing it 51 percent likely that her or his consent was not informed). A signed acknowledgment of shared decision making also constitutes *prima facie* evidence that the patient gave her or his informed consent to the treatment administered. But the patient has the heavier burden of rebutting this presumption by clear and convincing evidence (showing it 70 to 80 percent likely that his or her consent was not informed).

Washington enacted further legislation in 2011 and 2012. The 2011 statute directs the Washington Health Care Authority (HCA) to convene a collaborative to "identify health care services for which there are substantial variations in practice patterns or high utilization trends." For such services, the statute directs the collaborative to "consider strategies that will promote improved care outcomes, such as patient decision aids."[56] The 2012 statute, enacted in March, outlines a process for certifying decision aids.[57] By the end of 2012, the HCA had promulgated regulations defining the process by which it will certify patient decision aids.[58]

Washington is not alone. In 2012, Massachusetts established a Center for Health Information and Analysis. Among other things, this center must "maintain a consumer health information website" containing "information comparing the quality, price and cost of health care services." The statute mandates that, to the extent possible, this website must include decision aids "on but not limited to, long-term care and supports and palliative care."[59]

In 2009, Vermont enacted legislation calling for a shared decision-making demonstration project.[60] In 2010, the Vermont Blueprint for Health commenced a one-year shared decision-making pilot in the Barre Hospital Service Area.[61] Similarly, in 2009, Maine enacted legislation calling for an "advisory group of stakeholders" to "develop a plan to implement a program for shared decision making."[62] In 2011, the group issued its final report, recommending a demonstration project.[63]

At the regulatory level, in 2010, the Maine Board of Licensure in Medicine incorporated shared decision-making principles into its guidelines on informed consent.[64] That same year, the Minnesota Department of Health incorporated such principles into its certification requirements for healthcare homes.[65]

Several other states have also explored promoting the use of decision aids. Legislation has been considered in Connecticut and Oklahoma.[66] In Minnesota, bills in 2009 and 2011 proposed requiring shared decision making for certain surgical procedures before reimbursement could be paid by a health plan company under contract with the state commissioner of human services or finance.[67] More legislation and regulation is sure to be considered and enacted by additional states over the next few years.

5. LEGAL CONCERNS ASSOCIATED WITH PATIENT DECISION AIDS

Regardless of whether the trend toward shared decision making and the emergence of patient decision aids effectively address all the problems associated with the traditional informed consent framework, it is clear that these changes have important legal implications. The relative newness of decision aids means that there is little systematic oversight of their development or use. But federal and state governments' intent to facilitate shared decision making, along with concerns regarding harm to patients from biased or inaccurate decision aids, make it likely that this will be an evolving area of law and regulation in the near future. Below, we summarize legal issues that are likely to emerge as the use of decision aids becomes more prevalent in clinical practice.

Lack of Oversight of the Quality of Patient Decision Aids

While patient decision aids have been promoted as a positive movement toward both more meaningful informed consent and more cost-effective care, there is also an emerging recognition that some kind of quality-control measures are needed to ensure that decision aids do not do more harm than good.[68] There are several features of patient decision aids that increase the likelihood of misinformation or bias, relative to other types of patient educational materials.[69]

First, the aids are generally developed by third parties that are not involved in providing care to patients,[70] including professional associations, government agencies, hospitals and health centers, nonprofit organizations, and for-profit companies.[71] There is concern that for-profit corporations and other decision-aid creators "have little incentive to maintain the integrity of their products other than market pressures to maintain good business practices. But in other contexts, such as environmental regulation, products liability, and pharmaceuticals, it has become clear that market pressures are often insufficient to protect consumers."[72] Additionally, the American Medical Association has expressed concern about the use of patient decision aids "by insurers and others" as a vehicle to steer or "nudge" patients toward less-expensive treatment options on the basis of biased or misleading information.[73]

The creation and use of decision aids that are biased or misleading is exacerbated because they are generally used by patients outside interactions with their physicians, meaning that "physicians may have limited opportunities to mediate or interpret the information" provided by third parties in decision tools.[74] Further complicating the issue, patient aids are frequently used in medical decisions that "involve moral and political controversies that may impact the way information is provided to patients" (for example, reproductive issues).[75] The interaction of these elements raises concerns regarding quality and objectivity that are not yet addressed in a systematic way by private or government oversight.[76] Commentators have expressed the same concern about the development of clinical practice guidelines.[77]

Fortunately, there is a growing recognition of the need for some kind of formal credentialing process.[78] A few nongovernmental organizations have already begun compiling and assessing the quality of available patient decision aids.[79] Notably, the International Patient Decision Aid Standards Collaboration (IPDAS) has developed a detailed set of evidence-based criteria to guide evaluation of the quality of decision aids.[80] These criteria include: (a) describing the health condition, (b) listing the options, (c) listing the option of doing nothing, (d) using visual diagrams, (e) using stories that represent a range of positive and negative experiences, (f) reporting the source of funding used to develop the materials, and (g) describing the quality of scientific evidence presented.

Similar to IPDAS, the Ottawa Hospital Research Institute (OHRI) has compiled a library of decision aids that meet a few basic criteria. To be included in OHRI's database, a decision aid must: (a) provide information about the "options and outcomes that are relevant to a patient's health status," (b) report the date it was most recently updated and be no more than five

years old, (c) "provide references to scientific evidence used," (d) report conflicts of interest, and (e) be publicly available.[81]

The ACA's mandate for the creation of an entity to establish criteria for certifying patient decision aids itself promises to provide at least some standardized indicia of quality to guide physicians' use of such tools. However, this mandate has yet to yield a certifying entity, let alone standards or evaluation of specific decision aids. And the Washington HCA has not yet begun rating decision aids. This means that, at the moment, the issue of patient decision aids is largely devoid of oversight or standardization, absent the activities of nongovernmental organizations.

Does Use of Decision Aids Expand Liability for Healthcare Providers?

Under state common law or statute, physicians face liability for medical malpractice under a theory of informed consent if a patient is harmed as a result of a physician's failure to disclose information necessary to make an informed medical decision.[82] While the use of decision aids is intended to make the informed consent process more meaningful and effective, there are concerns the aids potentially create new opportunities for malpractice liability.

One concern is that physicians who use patient decision aids could be held liable for deviating from an existing standard of care, represented by the "traditional" informed consent process.[83] Washington, at least, addressed such concerns by creating statutory protections for physicians who engage in shared decision making with patients through the use of decision aids.[84] Under Washington law, a patient who signs "an acknowledgment of shared decision making" to consent to a particular treatment has to present a higher level of evidence to succeed in an informed consent suit than a patient who signed a regular consent form.[85] While such a law may make careproviders more willing to incorporate decision aids into their practice, Washington's strategy of providing *greater* liability protections for physicians who use aids to facilitate shared decision making may not be necessary. Use of such aids has the potential to improve physician-patient communication and overall satisfaction of patients with treatment decisions, which might reduce the incidence of medical malpractice claims in general.[86]

Nadia Sawicki articulates another concern: that physicians will be found liable to patients harmed by decision aids that provided inaccurate or outdated information or presented information in a biased manner.[87] Under the "learned intermediary doctrine," it is possible that physicians' special knowledge regarding the practice of medicine may absolve "product manufacturers and information providers" from liability. With drugs and devices, for example, courts have generally refused to impose a duty to warn on manufacturers, because physicians are in the best position to evaluate risks and benefits and to communicate with patients. However, the learned intermediary doctrine is generally applied to pharmaceutical company package inserts. It is unclear whether it will readily extend to decision aids, particularly when the information provided by third parties is itself inaccurate or misrepresented.

Can Patients Recover from Creators of Inaccurate or Biased Decision Aids?

Another legal question raised by the increasing use of decision aids is whether patients harmed by inaccurate, biased, or otherwise defective aids will have any kind of meaningful redress against the creator or manufacturer of the aid. Sawicki argues that patients will be unlikely to succeed in a product liability suit against a manufacturer, because courts have generally determined that product liability does not apply "where injury arises as a result of the words or ideas within a book, pamphlet, brochure, or similar product."[88] Other possible theories for lawsuits against creators of aids, such as negligence or negligent misrepresentation, also may be unlikely to succeed.

One of the problems with such suits in the decision aid context is the difficulty associated with proving causation under the current legal standards.[89] A patient suing for negligence based on a claim of inadequate informed consent gen-

erally has to prove that a "reasonable patient" would have not chosen the procedure had the defendant accurately conveyed its risks.[90] This "objective" standard for causation would likely be problematic in the context of patients suing the creators of decision aids, because decision aids are intended for use in "preference-sensitive" medical decisions,[91] situations in which "clinical evidence does not clearly support one treatment option over another."[92] Thus, it is inherently unclear what treatment a "reasonable patient" would choose, since that decision depends on a patient's values and preferences, not objective medical evidence.[93]

Such quandaries have led commentators to call for courts and legislatures to abandon the "objective" causation standard in the context of informed consent suits in favor of a standard that recognizes the importance of the individual patient's values and preferences.[94] Under a "subjective" causation standard, instead of determining whether a hypothetical reasonable patient would still have consented with disclosure, the jury determines whether *this particular patient* would still have consented.[95] In at least the short term, however, the take-home message is that patients who are harmed by biased or inaccurate decision aids will likely have difficulty finding legal recourse against the creators or manufacturer of these tools, unless current legal standards are altered to accommodate the changing face of informed consent.

CONCLUSION

Since its origins in the early 1970s, the doctrine of informed consent has been largely a creature of the common law. Depending on the jurisdiction, a physician must disclose either what a reasonable patient would deem material or what a prudent physician would disclose under the circumstances. The imminent federal certification of decision aids under Section 3506 may soon displace these state standards and impose much-needed consistency and uniformity to informed consent processes. We may finally close (or at least narrow) the persistent gap between the legal principles and the clinical reality of informed consent.

NOTES

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3. P.A. Ubel, *Critical Decisions: How You and Your Doctor Can Make the Right Medical Choices Together* (New York: HarperCollins 2012); "New Era of Patient Engagement," *Health Affairs* 32, no. 2 (2013): 202-426; E.O. Lee and E.J. Emanuel, "Shared Decision Making to Improve Care and Reduce Costs," *New England Journal of Medicine* 368, no. 1 (2013): 6-8.

4. C. Hsu et al., "Incorporating Patient Decision Aids into Standard Clinical Practice in an Integrated Delivery System," *Medical Decision Making* 33, no. 1 (2013): 85-97; J.C. Brehaut, "Informed Consent Documents Do Not Encourage Good-Quality Decision Making," *Journal of Clinical Epidemiology* 65, no. 7 (2012): 708-24; M. Hostetter and S. Klein, "Helping Patients Make Better Treatment Choices with Decision Aids," *Quality Matters* (October-November 2012). Notably, Dialog Medical's iMedConsent solution is being used in "more than 200 hospitals, and in thousands of physician practices." *http://www.dialogmedical.com/products/,* accessed 15 February 2013. And 10 healthcare organizations, including Massachusetts General Hospital, are implementing and testing decision aids as "demonstration sites" for the Informed Medical Decisions Foundation. Decision aids are also being used in clinical trials. B.W. Palmer et al., "Effectiveness of Multimedia Aids to Enhance Comprehension of Research Consent Information: A Systematic Review," *IRB: Ethics and Human Research* 34, no. 6 (2012): 1-15. Myrtus is evaluating how digital patient decision aids might simplify enrollment and enhance patients' understanding during the informed consent process for human subject research. *http://www.mytrus.com/,* accessed 15 February 2013.

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7. IOM, Crossing *the Quality Chasm: A New Health System for the 21st Century* (Washington, D.C.: National Academy Press, 2001).

8. 42 U.S.C. § 299b-36(b)(1).

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nostic Support System?" *Medical Decision Making* 33, no. 1 (2013): 108-18; D.L. Frosch et al., "Authoritarian Physicians and Patients' Fear of Being Labeled 'Difficult' among Key Obstacles to Shared Decision Making," *Health Affairs* 31, no. 5 (2012) 1030-8.

29. Even before the ACA, the Empowering Medicare Choices Act would have required the U.S. DHHS to promulgate regulations establishing standards and requirements for shared decision making under Medicare, based on the results of a pilot program. H.R. 2580, 111th Cong., 1st Sess. (2009) (Blumenauer, D-Ore.); S. 1133, 111th Cong., 1st Sess. (2009) (Wyden, D-Ore.). The companion bills ultimately died in committee.

30. The stated purpose of this section of the Affordable Care Act is to "facilitate collaborative processes between patients, caregivers or authorized representatives, and clinicians that engages [sic] the patient, caregiver or authorized representative in decision making, provides patients, caregivers or authorized representatives with information about treatment options, and facilitates the incorporation of patient preferences and values into the medical plan." 42 U.S.C. § 299b-36(a).

31. 42 U.S.C. § 299b-36(c).

32. 42 U.S.C. § 299b-36(d).

33. 42 U.S.C. § 299b-36(e).

34. 42 U.S.C. § 299b-36(e).

35. In addition to those measures described below, Section 3013 of ACA authorizes DHHS to award grants to develop, improve, update, or expand "quality measures." 42 U.S.C. § 299b-31. Section 3013 directs DHHS to prioritize those measures that allow the assessment of "use of shared decision making tools." 42 U.S.C. § 299b-31(c)(2).

36. ACA § 3021, codified at 42 U.S.C. § 1315a(a).

37. ACA § 3021, codified at 42 U.S.C. § 1315a(a).

38. ACA § 3021, codified at 42 U.S.C. § 1315a(c).

39. ACA § 3021, codified at 42 U.S.C. § 1315a(b)(2)(B)(ix).

40. CMMS, CMMI, "Health Care Innovation Awards," *http://innovation.cms. gov/initiatives/Health-Care-Innovation-Awards/*, accessed 15 February 2013.

41. CMMS, CMMI, "Healthcare Innovation Award Project Profiles," *http://innovation.cms.gov/Files/x/HCIA-Project-Profiles.pdf,* last updated 30 July 2012. A search of the document for "decision" turned up a handful of projects with a focus on implementation of shared decision-making models, including: (1) MedExpert International, Inc.'s Quality Medical Management System, (2) the Trustees of Dartmouth College's "Patient and Family Activators" project, and (3) Welvie, LLC's "Shared decision-making for preference-sensitive surgery" project.

42. 42 U.S.C. § 299b-7; *http://www.effectivehealthcare.ahrq.gov/index.cfm/who-is-involved-in-the-effective-health-care-program1/,* accessed 15 February 2013; *http://gold.ahrq.gov/projectsearch/grant_search.jsp*, accessed 15 February 2013. Search in abstract title field for "decision aid" or "decision tool" for AHRQ-funded projects related to patient decision aids.

43. *http://effectivehealthcare.ahrq.gov/index.cfm/tools-and-resources/patient-decision-aids/,* accessed 15 February 2013.

44. R. Fleurence et al., "How the Patient-Centered Outcomes Research Institute Is Engaging Patients and Others in Shaping its Research Agenda," *Health Affairs* 32, no. 2 (2013): 393-400.

45. ACA § 6301, codified at 42 U.S.C. § 1320e.

46. Patient-Centered Outcomes Research Institute, "National Priorities for Research and Research Agenda" (21 May 2012) *http://www.pcori.org/assets/PCORI-National-Priorities-and-Research-Agenda-2012-05-21-FINAL.pdf*, accessed 15 February 2013.

47. Patient-Centered Outcomes Research Institute, "PCORI PFA Cycle I Awardees" (21 December 2012) *http://www.pcori.org/assets/PFA-Awards-Cycle-1-2012.pdf*. At least two studies sought to assess whether decision aids improved the quality of decision-making or clinical outcomes (for pediatric type I diabetes, Shared Medical Decision Making in Pediatric Diabetes, p. 17; for chest pain patients in the emergency department, Shared Decision Making in the Emergency Department: The Chest Pain Trial, p. 4). One study sought to develop a decision tool to inform the medical decision making of parents of children with disorders of sex development (Decision Support for Parents Receiving Genetic Information about Child's Rare Disease, p. 21).

48. ACA § 3022, codified at 42 U.S.C. § 1395jjj.

49. ACA § 3022, codified at 42 U.S.C. § 1395jjj(a-b).

50. ACA § 3022, codified at 42 U.S.C. § 1395jjj(b) & (d).

51. ACA § 3022, codified at 42 U.S.C. § 1395jjj(b)(2)(G).

52. DHHS, "Final Rule: Medicare Program; Medicare Shared Savings Program: Accountable Care Organizations," 76 Fed. Reg. 67,802, 67,828 (2 Nov. 2011).

53. A. Shafir and J. Rosenthal, *Shared Decision Making: Advancing Patient-Centered Care through State and Federal Implementation* (Informed Medical Decisions Foundation, 2012); D.L. Frosch et al., "Shared Decision Making in the United States: Policy and Implementation Activity on Multiple Fronts,"

German Journal for Evidence and Quality in Health Care 105, no. 4 (2011) 305-12.

54. J. King and B. Moulton, "Group Health's Participation in a Shared Decision-Making Demonstration Yielded Lessons, Such As Role of Culture Change," *Health Affairs* 32, no. 2 (2013): 294-302.

55. Wash. S.B. 5930 (2007), enacted as 2007 Laws Ch. 259, codified at Wash. Rev. Code §§ 7.70.060 & 41.05.033.

56. Wash. H.B. 1311 (2011), enacted as 2011 Laws Ch. 313, codified at Wash. Rev. Code § 70.250.050.

57. Wash. H.B. 2318 (2012), enacted as 2012 Laws Ch. 101, codified at Wash. Rev. Code § 7.70.060.

58. Wash. Admin. Code §§ 182-60-005 to -030.

59. 2012 Mass. Acts. Ch. 224 § 19, codified at Mass. Gen. Laws Ann. 12C § 20.

60. Vt. S.B. 129 (2009) (Lunge); enacted as 2009 Act 49.

61. Vermont Department of Health, "VERMONT2009: Shared Decision Making: Report to the Legislature on Act 49, Section 4" (15 January 2010), *http://www.leg.state.vt.us/reports/2010External Reports/252637.pdf,* accessed 15 February 2013.

62. Me. LD 1358 (2009) (Mills), enacted as 2009 Maine Laws Ch. 104. The original bill would have required health insurance carriers and the MaineCare program to implement shared decision making.

63. Shared Decision Making Study Group for the Dirigo Health Agency's Maine Quality Forum, *The Practice and Impact of Shared Decision Making* (February 2011) *http://muskie.usm.maine.edu/Publications/PHHP/Shared-Decision-Making_Final-Report.pdf,* accessed 15 February 2013.

64. "INFORMED CONSENT: Guidelines from the Maine Board of Licensure in Medicine," *http://www.docboard.org/me/administrative/POLICIES/INFORMED%20CONSENT.doc,* accessed 15 February 2013.

65. Minn. Admin. Rules 4764.0040.

66. Conn. H.B. 5193 (2009) (Sayers); Okla. S.B. 1002 (2012) (Adelson).

67. Minn. S.F. 696, 86th Legis. Sess. (2009); Minn. H.F. 1140, 86th Legis. Sess. (2009); Minn. S.F. 542, 87th Legis. Sess. (2011) (Berglin).

68. The AMA Council on Medical Services notes that "the clinical quality and ethical design of patient decision aids will become increasingly important as the concept of shared decision making gains popularity." See McAneny, note 9 above. Legal commentators have also indicated the need for "credentialed, neutral bodies" to approve the information provided by patient decision aids to address the real potential for "biased" or "misleading" decision aids. See King and Moulton, note 5 above.

69. N. Sawicki, "Patient Protection and Decision-Aid Quality: Regulatory and Tort Law Approaches," *Arizona Law Review* 54, no. 3 (2012): 621-72.

70. Ibid., 634-35.

71. Ibid., 633.

72. Ibid., 627.

73. See McAneny, note 9 above, p. 4.

74. See note 69 above, p. 634.

75. Ibid., 634-35.

76. Ibid., 626.

77. R. Avraham, "Clinical Practice Guidelines: The Warped Incentives in the U.S. Healthcare System," *American Journal of Law & Medicine* 37, no. 1 (2011): 7-40; M.J. Mehlman, "Medical Practice Guidelines as Malpractice Safe Harbors: Illusion or Deceit?" *Journal of Law, Medicine and Ethics* 40, no. 2 (2012): 286-300. Advance directives are also often developed by nonclinicians, yet meant for implementation by clinicians.

78. J.S. King and B. Moulton assert, "a rigorous accreditation process [for patient decision aids], such as the Cochrane System Review, is necessary to protect the interests of physicians and patients." They note, "While many creators of decision aids have spent significant time and resources developing their instruments and techniques, these efforts have largely been ad hoc and may differ substantially from one another. Additionally, these aids may be biased toward or against treatments." See King and Moulton, note 5 above, p. 490.

79. See Brehaut et al., note 4 above; J.E. Wennberg et al., "Extending the P4P Agenda, Part 1: How Medicare Can Improve Patient Decision Making and Reduce Unnecessary Care," *Health Affairs* 26, no. 1 (2007): 1564-74.

80. G. Elwyn et al., "Assessing the Quality of Decision Support Technologies Using the International Patient Decision Aid Standards Instrument (IPDASi)," PLoS ONE 4, no. 3: e4705, doi:10.1371/journal.pone.0004705.

81. Ottawa Hospital Research Institute, Decision Aid Library Inventory (DALI), *http://decisionaid.ohri.ca/cochinvent.php*, accessed 15 February 2013. For an exploration of the decision aids in the Ottawa Hospital Research Institute's Library, see *http://decisionaid.ohri.ca/AZinvent.php*, accessed 15 February 2013.

82. See note 1 above.

83 N.N. Sawicki, "Informed Consent Beyond the Physician-Patient Encounter: Tort Law Implications of Extra-Clinical Decision Support Tools," *Annals of Health Law* 21, no. 1 (2012): 1-10.

84. Wash. Rev. Code Ann. § 7.70.060.

85. Wash. Rev. Code Ann. § 7.70.060.

86. See King and Moulton, note 5 above; M.J. Barry, Jr., et al., "Reactions of Potential Jurors to a Hypothetical Malpractice Suit Alleging Failure to Perform a Prostate-Specific Antigen Test," *Journal of Law, Medicine and Ethics* 36, no. 2 (2008): 396-402.

87. See note 83 above, p. 9.

88. Ibid., 7; see note 69 above, p. 644-45.

89. See note 83 above, p. 8; see note 69 above, p. 647.

90. Only four states—New Hampshire, Rhode Island, Oklahoma, and Oregon—have case law or statutes that reject the objective "reasonable patient" standard. E.M. Tenenbaum, "Revitalizing Informed Consent and Protecting Patient Autonomy: An Appeal to Abandon Objective Causation," *Oklahoma Law Review* 64, no. 4 (2012): 697-758.

91. See note 69, p. 647; 42 U.S.C. § 299b-36 (intending to promote the use of patient decision aids for "preference sensitive care").

92. 42 U.S.C. § 299b-36(b)(2) (defining "preference sensitive care" as "medical care for which the clinical evidence does not clearly support one treatment option such that the appropriate course of treatment depends on the values of the patient or the preferences of the patient, caregivers or authorized representatives regarding the benefits, harms and scientific evidence for each treatment option.").

93. See note 69 above, p. 647.

94. See Tenenbaum, note 90 above.

95. *Scott v. Bradford,* 606 P.2d 554 (Okla. 1979).