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## *At the Bedside*

# New Approaches with Surrogate Decision Makers

*Edmund G. Howe*

### ABSTRACT

A first principle in ethics consultation is that reasoning is essential. A second principle is that the religious and cultural views of patients and their surrogates are usually respected. What can be done when these principles collide—when patients or surrogates have religious or cultural views and beliefs that clinicians find unreasonable or even offensive? Mediation may provide some approaches to assist us in providing the most ethically appropriate assistance.

In this issue of *The Journal of Clinical Ethics* (*JCE*), two articles discuss how to improve ethical outcomes when clinicians work with surrogate decision makers. In "Surrogate Decision Making and Intellectual Virtue," Gregory L. Bock presents criteria that he hopes will help clinicians better decide when to implement a surrogate's wishes for a patient.<sup>1</sup> In "Who's at the Table? Moral Obligations to

Equal Priority Surrogates in Clinical Ethics Consultations," Meghan O'Brien and Autumn Fiester address and answer the question asked in their title, among other issues.<sup>2</sup> How a surrogate's wishes for a patient are assessed and followed—or not—by clinicians is critically important. After all, the surrogate may determine whether the patient lives or dies.

In this introduction to the winter 2014 issue of *JCE*, I will discuss Bock's criteria for considering surrogates' religious beliefs and describe a way to test an ethical conclusion. I will discuss how to better respect surrogates' ultimate concerns and how to use a sliding scale when deciding whether to act on surrogates' decisions. I will suggest how clinicians may be able to form a bond with surrogates so that they can, together, make better decisions—and leave the bedside with the best possible positive relations with surrogates, even when they were initially in opposition. Finally, I will present specific approaches to achieve these ends, approaches that are also useful in other contexts.

Overall, I suggest that while seeking to advance a way to decide what to do—as Bock does—is a top priority, it may be that before clinicians determine an outcome, they should do their utmost to work with all of the parties involved in decision making, in the hope of finding an outcome with which they can all agree.

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## THE GAINS AND LIMITS OF REASONING

Reasoning is essential in ethics. The best example may be the principle of consistency. If the morally relevant elements of a problem are the same in different situations, persons should respond similarly in each situation, or it is more likely that their actions are arbitrary. Still, the use of reason alone may not be enough. To elaborate, I will consider two different ways that reasoning may help, and then give some ways it may not.

### Some Ways to Use the Principle of Consistency

#### *Bock's Criteria*

Bock references an article published in *JCE* in 2009, Stewart Eskew and Christopher Meyers's "Religious Belief and Surrogate Medical Decision Making."<sup>3</sup> Eskew and Meyers assert that clinicians "must keep patients' well-being as primary, even if that means sometimes undertaking the difficult task of challenging [surrogates'] religious motivations." They assert that surrogates' religious beliefs should be "tolerated, but not without questioning."

Bock goes further. When a surrogate's treatment decision appears to be seriously mistaken, and the surrogate says the decision is justified by religious belief, Bock suggests that clinicians ask: What would an open-minded person believe if he or she were in the surrogate's culture and circumstances? Bock notes that this approach "does not rule out a determination that beliefs in other cultures are irrational . . . it is possible to be discriminating and remain culturally sensitive." But, Bock notes, "What matters is the procedure one uses to arrive at such a judgment. . . . because of the tendency to impose on others the particular beliefs of the dominant culture."

Bock considers the two cases that Eskew and Meyers presented in *JCE*. In the first case, a 65-year-old woman who is dying is deeply sedated, yet is still in pain. When her breathing becomes labored, her adult son learns that her pain meds may be shortening her life, and he asks her physicians to stop the meds so that God's will may be done. Her physicians comply with his request. Should they have? In the second case, a young woman with limited cognition needs immediate surgery for a kidney blockage, requiring blood transfusion. Her surrogate decision makers are her parents, who are Jehovah's Witnesses.<sup>4</sup> The young woman had previously attended church with them and had been baptized. Her parents try to find a "bloodless" hospital, but are not confident that one will be found, and decide to take their daughter home to die. Her clinicians comply with their request. Should they have?

Bock's principal goal is to better enable clinicians to escape our unconscious moral biases. He is concerned that, due to clinicians' asymmetric power, their biases may skew patients' outcomes. Thus, he asserts that, as difficult as it might be to admit, there is no universally recognized set of religious beliefs that will automatically disqualify another person as irrational. It can be a challenge to clinicians, when working with a surrogate whose beliefs seem objectionable, to stretch their imaginations maximally.

#### *The "Men from Mars Test"*

When clinicians must decide when and whether to implement a surrogate's decision, the Men from Mars Test may be helpful. Many readers already know this test, but I will describe its use for those who don't. During an ethics committee meeting, members of an ethics committee may come to an ethical conclusion regarding a case brought to the group. To use the Men from Mars Test, they should insert their conclusion into this formula: "When A, B, and C exist, and they are the only morally relevant factors, do X." The second step is to imagine similar cases (both real cases that they know or that could occur), and also cases that could occur *only in science fiction*.<sup>5</sup> Third, after imagining several cases, the case that is closest to the case before the ethics committee should be inserted into the same A, B, C, and X formula.

Both cases should include the same morally relevant factors (A, B, and C), and only those factors. Finally, if factors A, B, and C for the two cases are the same, but the conclusion, X, is not, the conclusions are inconsistent, and the committee should go back to the drawing board.<sup>6</sup>

An illustration may help. Here is the case before the ethics committee. A baby is born with Down syndrome and has another condition that is incompatible with life, but that can be corrected with surgery. (This may sound familiar, as it occurred at Johns Hopkins just decades ago.) The infant's parents refuse to allow the surgery. (This happened as well.) The infant is not given food and dies after about two weeks.<sup>7</sup> You are on the ethics committee that approves this outcome. You put this outcome into the A, B, C, and X formula. This could be phrased as: "When a person's IQ will definitely be lower, it is morally permissible to let the person die."

Here is the comparison case, from science fiction. Men from Mars take over Planet Earth. Their average IQ is 200. I get appendicitis, and I will die without surgery. My IQ is average for the Earth: 100. The Men from Mars decide that since my IQ is much lower than theirs, I will not have the lifesaving ap-

pendectomy, and I die. Most of us would feel profoundly upset at the outcome of both of these cases, but it is possible that the members of the ethics committee in the first case do not find the outcome problematic. If this ethics committee uses the Men from Mars Test, they have another chance to get it right.

#### *Why Any Amount of Reasoning May Not Be Enough*

These considerations illustrate some of what reasoning in ethics has to offer. Reasoning may be able to show that a particular clinical outcome is not consistent, much less the best possible outcome. Reasoning may serve as a check on whether a moral judgment is wrong. But reasoning may be limited for many reasons. Here are some.

*Consistency may be used inconsistently.* Consistency, used correctly, can indicate that an outcome was reached in an arbitrary way. Consistency may also be applied in different ways. For example, we set speed limits but rarely enforce them literally; that is, a speeding ticket is typically not issued when a car is travelling 52 miles an hour in a 50 mile per hour zone. In this context, inconsistency furthers two incompatible goals: speed limits decrease speeding, and not enforcing them frees policemen to do more important things. In the same way, medical policies and practices are often inconsistent, but may serve to the greatest extent possible to further incompatible goals.<sup>8</sup>

*The doctrine of double-effect.* The doctrine of double-effect seems to be, for many, an almost sacred principle in ethics, perhaps in part due to its use and association with religious beliefs. When a particular action has both good and bad outcomes, assessing our intentions may help us resolve what we should do. But, in doing this, we may misconstrue our true, underlying intentions.

The use of the principle of double-effect is exemplified in the first case described by Eskew and Meyers, the 65-year-old woman with end-stage ovarian cancer. Her condition deteriorated until she was dependent on a ventilator and fully sedated, but her behavior indicated that she continued to experience pain. Her care team wanted to increase her meds to reduce her pain, even though it might shorten her life.

The doctrine of double-effect holds that if one intends a good effect, then what one does is likely, or at least more likely, to be okay. But it is possible to use this reasoning, unknowingly, to support a conclusion that is wrong. For example, a care team may want to end a patient's life for a "good enough" reason—for example, to relieve suffering, as for the patient described above. Some members of the care

team might not be able to accept this intent, but they might be able to accept it if they believe that they are only intending to relieve the patient's pain.

Given this, some believe that it is better not to use the doctrine of double-effect at all, but rather, when two ends are in conflict, such as relieving pain and risking death, to simply line up the pros and cons, and then decide what the outcome should be.<sup>9</sup>

At the 2014 annual meeting of the American Society of Bioethics and Humanities in San Diego, Eduard Verhagen, a Dutch physician, provided an example of this when he described the use of neuromuscular blockers in the Netherlands to end a patient's life, to relieve suffering. He stated that the doctrine of double-effect is "merely a distracting tradition that fails to acknowledge the reality of many factors."<sup>10</sup> He said that he and his countrymen would rather hasten a patient's death than let a patient die terribly. Verhagen also reported that when an infant's medical condition is hopeless and the infant's parents experience unbearable suffering because they believe the infant is suffering, this is a criterion, although one rarely used, for active euthanasia. This is an example in which clinicians can go the furthest to respect the ultimate concerns of surrogates, which will be discussed more later.

*Respecting surrogates' religious beliefs.* Using reasoning to consider whether or not to act on a surrogate decision maker's religious beliefs may help clinicians to not respond unknowingly on the basis of our their personal biases. This is the goal of Bock's criteria. Such assessments may, though, involve concepts that are problematic. For example, Bock agrees with Eskew and Meyers that, when a surrogate's decision is based on a religious belief, the surrogate's reasoning about the belief should be consistent. Bock states that internal consistency is "the least one can expect of decision makers when their choices potentially harm others."

Bock reconsiders Eskew and Meyers's case of the woman with ovarian cancer who is heavily sedated but still in pain. The woman's husband and two sons had been making treatment decisions together for the patient, but her husband and younger son deferred to the older son when he ordered his mother's physicians to stop her pain meds, for religious reasons. The older son believed that his mother's physicians were "tools of God" and he asked them for every intervention. But when his mother's breathing became labored, he asked her physicians whether her pain medications could be contributing to her difficulty in breathing. When told they might be, he said he wanted the medications withdrawn, so God could work his will. Although

the patient's husband and younger son stated that the patient would not want to be kept alive in this condition and would not want to die in pain, they deferred to the wishes of the older son, the meds were withdrawn, and the patient died in pain.

Bock points out that the older son's reasoning, based on religious belief, doesn't make sense: if God is all-powerful, then he is able to work his will regardless of the administration of pain meds. Others have described the difficulties encountered in trying to use reason to work through conflicting religious beliefs, for example, how can a good, omnipotent God permit evil?<sup>11</sup> My point here is modest: attempting to use reason to work through a surrogate's decision that is based on religious belief may not be as straightforward as it might seem.

### *Reasoning May Require Context*

Antonio Damasio, an eminent neurologist, describes the case of Phineas Gage, a man who became famous in the 1800s when he survived an explosion in which an iron rod pierced his cheek and exited through the top of his head.<sup>12</sup> Miraculously, Gage retained his capacity to reason, but he could not make decisions. For example, he could list the reasons, pro and con, for making an appointment with his doctor at one time or another, but, having done this, he could not decide which time to choose. This example suggests that, in at least this instance, making a decision may require more than just reasoning. This is probably true for us all. As Damasio puts this in a later work, "An understanding of the neurobiology of *emotion* and *feelings* is a key to the formulation of principles and policies capable of reducing human distress and enhancing human flourishing. In effect, the new knowledge even speaks to the manner in which humans deal with unresolved tensions between sacred and secular interpretations of their own existence."<sup>13</sup>

This limitation of reasoning can be clearly seen in people who have what is now called autism spectrum disorders (ASDs).<sup>14</sup> People with ASDs tend, for example, to take what they experience more literally than other people do, missing contextual meanings more than other people do. They may, due to this tendency, be geniuses, although they may also be socially challenged. I think of a friend's son who would pick up the phone when I called his father. "Is your father there?" I would ask. "Yes," he would reply. Then there would be silence. He had answered my question, but he did not understand that, in this *context*, I was asking to speak to his father. A common social limitation is illustrated by a snippet from a recent novel, *The Rosie Project*. Don Tillman, the

main character, is a genius, and an adult with an ASD. He likes a woman, and she likes him. She asks him if he finds her attractive. He reasons that she must be seeking to discern whether he, at heart, regards women as objects and, therefore, she must be testing him. Thus, he responds, "I haven't really noticed."<sup>15</sup> This doesn't bode well for their romance.

Another example is from a parent of a child with an ASD, as she gives advice to other parents of children with ASDs: "In the heat of the moment, it is always better to avoid certain things. . . . One might say when angry, impulsively, for example, 'This is the last time I am going to tell you. . . .' " A child with ASD may take this literally, she reports, and may say something in response such as, "Thank heavens for that!"<sup>16</sup>

### **Inequity**

Eskew and Meyers emphasize that a surrogate's decision that is based on religious belief should not only be rational, but should be coherent—that is, it should be consistent with the surrogate's other religious beliefs. As an illustration, Bock works through the internal inconsistencies in the stated beliefs of the older son who wanted his mother's pain meds withdrawn: (1) The son believes that a person should not suffer when there are means available to prevent suffering, but refuses pain medication for his mother. (2) The son says that God is omnipotent, but that the use of pain medication can frustrate God's plans to heal. (3) The son believes that he must honor his parents, but ignores his father's wishes and allows his mother to suffer, even though this would not be what she would have wanted.

Eskew and Meyers state that when a surrogate's views are inconsistent, his or her decisions should be "overruled": "Internal consistency is surely the least one can expect of decision makers when their choices potentially harm others."

Bock writes that the older son's decision to remove his mother's pain meds might seem okay if he were able to mount a more "sophisticated defense" of his beliefs. Bock asks: What if the son had said that God is omnipotent and *could* heal his mother, even with pain meds, but he can't allow that because he believes that God wants human obedience? Or what if the son said that God prohibits *any* treatment that could shorten a human life—a view that might warrant even more respect?

Either of these two more sophisticated defenses might suffice. This reveals a practical problem, however: a surrogate who has a greater level of sophistication may be more able to present a religious belief that seems logically reasonable, and this sophisti-

cated surrogate's views may prevail when those of a less sophisticated surrogate would not. This is a problem of equity.

It may be appropriate for faith to trump reason in some instances. A person without extensive education who is a devout believer, for example, may have faith alone as guidance. From a theological and personal perspective, does this person's faith need to be justified? Would it be a category mistake to require, request, or measure faith to a "logical account"?

Sophistication that manifests itself by being well reasoned may fit well with the present, rightful intention to protect patients, but a more critical, underlying question might be asked: Is the genuineness of faith a matter of sophistication? The issue, in part, is what a person should do, based on faith—when should it guide or compel, particularly when a person's faith may affect another, for example, an incapacitated patient. This begs the question of when and whether requesting advice from a patient's or surrogate's rabbi, priest, Muslim cleric, or other leader of a religious community is indicated. This is especially difficult should the religious leader's views differ from widely accepted religious doctrines. Some have suggested, due to this concern, that religious advisors be screened to help insure that the religious views they impart are in line with the tenets of the religious organization they represent.<sup>17</sup>

On perhaps a still deeper level, we might ask: What privileges us—and should privilege us—in matters of faith, or even, sometimes, logic?

Since sophistication and belief can affect equity, in the last section of this article I will describe a way that clinicians can establish greater equity for surrogates. Such greater equity may be an indirect benefit of an intervention that should be made for another ethical reason: to ensure surrogates are adequately informed. Differences in surrogates' levels of sophistication may be an inadequate ground for granting one surrogate's beliefs greater respect than another's, especially since their decisions can be matters of life or death.

#### HOW CAN CLINICIANS DO BETTER?

Reasoning may provide unparalleled checks on what could and should be concluded ethically. Bock's criteria and the Men from Mars Test exemplify this. Reason alone, though, has limits. As noted above, clinicians may use concepts in different ways and use logic to support their biases without knowing it. The greatest problem with the use of reason-

ing may be that, when clinicians work with parties who are at odds—for example, a patient's family members, or members of a care team—it risks creating winners and losers. Is there an alternative process by which they may do better?

One possibility for clinicians who are working with parties who are in conflict is to initially adopt a mediation-like perspective that is geared toward helping all parties to agree—if possible. As Lance Wahlert and Autumn Fiester write, "Our view is that mediation is always the better alternative to litigation, offering a way of avoiding the risk of a win-lose legal decision. . . ." <sup>18</sup> An intervention that heals conflict may enable warring parties to not only avoid litigation, but to come to agreement, in time. This healing process may require more than reasoning alone. As Edward Bergman notes, conflict resolution is enhanced "through the patient's perception of having been understood in ways unattainable through pure cognition."<sup>19</sup>

Clinicians can use three shifts in perspective to further the process of conflict resolution: (1) explore, with surrogates, their ultimate concerns and then afford these concerns greater moral weight; (2) try to implement these concerns using a sliding scale; and (3) have as positive a relationship with surrogates as possible, especially if and when the parties making treatment decisions are in opposition.

#### Explore Surrogates' Ultimate Concerns

In the United States, we traditionally try to respect the religious beliefs of anyone we encounter. Some people have religious beliefs that are absolute, which makes it difficult to explore their views with them and to attempt to find some common ground. One way to find common ground with a surrogate who has absolute beliefs is to ask about the surrogate's "ultimate concerns." In doing this, clinicians may be able to unearth the underlying values shared by all parties, and, later, this might serve as the "bedrock" for some compromise that all parties could accept, rather than enter litigation, where the courts will make the decisions.

What are ultimate concerns? Here is an example of a soldier's ultimate concerns regarding his fellow soldiers. First, he said that each soldier in his group was committed to each other, over a period of months, and each would have given his life to save another at any moment. Then he said, "I love my wife, but my love for these soldiers goes beyond this. If, after we were back in the states, I was on the East Coast and one of these soldiers called me, that his car had broken down in the in the West, in the desert, I would walk there, all that way, to help him. . . ." <sup>20</sup>

When talking with a surrogate about his or her ultimate concerns, clinicians could ask deeper questions such as, “What do you fear most?” and “What do you hope for?”<sup>21</sup> By doing this, clinicians may unearth deeper beliefs that are similar among all of the parties in a conflict. These could be, for example, mutual concern about what the patient would most want, what would most maintain the dignity of the patient, or what would most reduce the patient’s suffering. With this newfound knowledge may come greater respect, and, with more respect, a greater willingness to compromise on a resolution that all can accept.

As Fiester puts it, conflicting parties could “come to view each other as reasonable, caring, committed, and well-intentioned, although caught in the worst of dilemmas; that newfound understanding could go a long way in dissolving suspicion of any self-serving or less-benevolent motives on either side.”<sup>22</sup> Parties in conflict may be more willing to accept such a compromise, although it might be short of what each ideally would want, because a compromise solution will allow them to avoid the risk of something worse: for example, that the courts will decide. As Bergman notes, “The term *consensual* signifies a resolution that all parties can accept as preferable to alternative outcomes in the event consensus can’t be reached.”<sup>23</sup>

In the case of the son who told his mother’s physicians to stop her pain meds, his ultimate concern may have been to help her die in the way she wanted. If he were able to recognize this and then share it, it might have moved him to accept giving some pain relief to his mother, a resolution more acceptable to the rest of his family and to the medical team.

Here is an example from my own experience. I saw a man who was very troubled about his mother. The man’s father had lapsed into a coma and was dying, and his mother was overwhelmed and felt unable to visit her husband. As I listened to the son, I smiled, and then explained why I was smiling. “This may be a no-brainer,” I said. “I am smiling because once I share this, you may feel instant relief: What would your father want for your mother?” The answer, of course, was that his father would want what was best for his mother. He smiled because he felt the relief I had anticipated. While he still had concerns about his mother, thinking about his father’s love for his mother freed him from his concern about his mother’s not going to visit.

The ultimate concerns that a surrogate says are the patient’s concerns may be the *surrogate’s* concerns. As O’Brien and Fiester say, “the evidence suggests that surrogates are more likely to make a

decision in accordance with their *own* values. . . .” Contrariwise, however, a patient’s ultimate concern may be to do whatever the *surrogate* would want. Clinicians might not think to ask about this possibility.

Giving greater moral weight to surrogates’ ultimate concerns, whether or not these concerns are religious, is a way that clinicians can increase equity for surrogates. (According to the Pew Forum on Religion and Public Life, those who say they do not believe in God in United States may be less than 10 percent of the population.<sup>24</sup>) Even when surrogates’ ultimate concerns are not religious in nature, they warrant equal respect.

### Using a Sliding Scale

O’Brien and Fiester suggest using a sliding scale to determine medical treatment when a patient is incapacitated and unbefriended. That is, the more routine the medical intervention, the less the scrutiny required. Perhaps when clinicians work with a surrogate whose values they oppose, they can use this approach. Often a surrogate’s views are accepted or rejected—all or nothing. But when the stakes for the patient are not life and death, it may be possible to implement a surrogate’s views to a greater extent. Using a sliding scale, clinicians might feel more inclined to—and perhaps be more ethically justified in—making some choices they now don’t often make. Here are examples of choices that clinicians might make when the stakes for a patient are lower, intermediate, and higher. These examples indicate changes that clinicians can implement even now, and are only a few among innumerable others that they could make.

### Lower Stakes

When the stakes are much lower than life or death, clinicians might give religious and cultural beliefs less scrutiny, and/or greater moral weight, as O’Brien and Fiester advise for incapacitated unbefriended patients. When a surrogate’s decision is based on a core religious belief or a secular ultimate concern, clinicians should accord it greater moral weight, and, when the stakes are not life or death, clinicians might be more inclined, justifiably, to comply. A secular example of an ultimate concern that a surrogate may have is an elective procedure for a patient that will not determine the patient’s life or death. For example, parents came to an ethics committee I sit on, requesting minor facial surgery for their infant, so that they could share closeness with her as they fed her, even though they knew that, due to other anomalies, she would soon die.

### *Intermediate Stakes*

When a patient is dead, the stakes are less than life or death. An example is keeping a patient on a ventilator when he or she has been determined to be dead by neurological criteria. This decision may come from religious belief, or a family may want a patient to remain on a ventilator so that distant family members can visit the patient before ventilatory support is removed. Such decisions may require more scrutiny, but less scrutiny than decisions regarding patients' life or death.

In these instances, clinicians may be more willing to hold off on taking a patient off the ventilator a day or two longer, even when the reason for a surrogate's request is secular, and despite the increased cost. (I will consider costs briefly at the end of this section.)

### *Highest Stakes*

The highest stakes involve life or death, for example, the case from Eskew and Meyers, of the son who chose, for religious reasons, to keep his mother alive as long as possible, although this increased the amount of pain she experienced. Here is a secular example. A patient with dementia who lacks awareness of self and environment needs dialysis to survive, and her family members want to keep her alive as long as possible.<sup>25</sup> They want dialysis for the patient, even though her dementia will probably only get worse, and she is currently unable to express her tolerance of dialysis, or of not receiving dialysis.

A factor in treatment decisions that has not been raised yet is cost. In some contexts, resources are expended without question to honor patients' religious beliefs and ultimate concerns. For example, one study reports that patients with advanced cancer whose religious beliefs helped them to cope were almost three times more likely to receive ventilator support and other life-prolonging measures in the last week of life.<sup>26</sup> Another study on patients' cultures reports that the resources spent for the care of Hispanic patients in the last six months of life were 57 percent greater than that spent for white non-Hispanic patients.<sup>27</sup>

### **Clinicians' Bonding with Surrogates, Especially When Their Views Differ**

When ethical conflicts arise, clinicians may oppose a surrogate's views. One example is the son who stopped his mother's pain meds. Another example is when clinicians view a patient's continuing treatment as futile. Commonly, if and when this occurs, clinicians see themselves as facing the task

of resolving a dual or mixed loyalty.<sup>28</sup> Such dual loyalty is common in other contexts, and most often in forensic work. Clinicians who do forensic work frequently serve interests that are not those of the "patient," but are those of the state. (It may be more accurate to see these persons as "evaluatees.") Such double agency is perhaps best represented by psychiatrists who are tasked with evaluating a person who is accused of a criminal act for insanity. The psychiatrist must warn the accused person that the psychiatrist is not working for the accused, but for the state. These psychiatrists commonly adopt a so-called role-specific ethic. According to this ethic, their ethical duty is to do what their role requires.

When clinicians must triage patients during a mass disaster, they may likewise face dual loyalties. Their role may be to triage patients so that the greatest number of patients may be saved, but this may conflict with saving the patients who are worst-off, who will die without their care. Clinicians who meet with surrogates whose beliefs they do not share also may have dual loyalties: this was the case for the physicians who complied with the instructions of the older son, to stop his mother's pain meds.

It may seem inevitable that clinicians will respond to conflicting loyalties by adopting a role-specific ethic (that is, an ethic that says it is right to do what their role requires). But is it inevitable? Philip Candilis, Richard Martinez, and Christina Dording assert it is possible to resolve conflicting loyalties—and that clinicians who face conflicting loyalties should enter into situations that present this conflict in an altogether different way.<sup>29</sup> They describe a case in which a surrogate may have wanted the patient to die earlier, to receive money from the patient's will sooner. Even in this case, they hold that clinicians should become—and remain—the ally of every surrogate. They write, "Nowhere is the tension of clinical and forensic ethics more evident than in discussions of the incompatibility of being both therapist and forensic expert for the same individual."

They acknowledge a core problem with role-specific ethics: "Role morality guides professionals in their expert activity. . . . Often, however, role morality espouses professional behavior that incorporates minimal obligations to the evaluatee. . . . frank harm to both the evaluatee and the relationship may result."<sup>30</sup> This may also harm a clinician, who must be "an expert in one place, a clinician in another, [and] a complete person at home. . . ."<sup>31</sup>

Surrogates likewise may be harmed by the requirements of this role, when it seems that they must compromise their own morally important beliefs

when they make treatment decisions on behalf of a loved one. When surrogates must make decisions that are not in some measure in accordance with their own values, how can they live with such dissonant values, especially in matters of life and death?

What does it require to act for another in a way that is against one's own moral beliefs? One example is that of a literary executor who promises an author that the author's papers will be destroyed after the author's death. But after the author dies, the executor reconsiders, questioning the author's real intentions, or fears, or what the author really wanted/would have wanted/should have wanted. The executor may believe that the author's work should survive because it will greatly benefit society. And so the executor breaks the promise to the author.

When a person must betray his or her own beliefs to serve the interests of a loved one, it might be helpful to use a form of the Men from Mars Test and speak to the loved one internally, as though the loved one could hear and respond: "I love you deeply and would give my life to save yours, but I know that your knowing that I did this would be the source of great suffering for you. What should I do?"

When a clinician opposes the decision of a surrogate, it may be possible to avoid the harms associated with role-specific ethics. If possible, it might be very advantageous, for three reasons. First, the surrogate would do better. Second, the relationship between the surrogate and clinician would improve. Third, the decisions made for the patient by the surrogate and the clinician, *together*, should improve.

Such positive alliances are common outcomes in the practice of mediation. As Bergman states, "Mediation is generally viewed as an effective dispute resolution that incorporates . . . *potential for continuing relationships*," that stems "from the parties' ownership of consensual outcomes."<sup>32</sup> This last comment leads us to the question: How, specifically, might this be accomplished? Such consensual outcomes must lie within the law and within acceptable ethical standards. Where this latter line should be drawn is where Bock's analysis becomes most critical.

#### APPROACHES THAT CLINICIANS CAN TAKE NOW

Clinicians and surrogates may be able to work together to forge treatment plans for patients, even when clinicians see treatment as being futile. Most patients want their surrogate to be able to work with the medical team to agree on a treatment plan. Why might a surrogate be willing to work with a clini-

cian in this kind of situation? Although the outcome of collaboration may fall short of what the surrogate may most want, it still may be better than the worst that could occur. As Bergman says, "The term *consensual* signifies a resolution that all parties can accept as preferable to alternative outcomes in the event consensus can't be reached."<sup>33</sup> When a clinician works to achieve an alliance with a surrogate, the clinician should make it clear from the start that finding a resolution that all can accept may require compromise. Here are other general guidelines and specific interventions at different stages of patients' illness.

#### General Guidelines

When the values of the clinician and the surrogate are in opposition, the likelihood that they will find an outcome they can both accept will increase if, from the start, the clinician spells out the possible consequences of not reaching an agreement, for example, litigation. While the surrogate could experience such an "opening line" as a threat, it states what is real: a mediation-like ethics consultation would not be convened otherwise. To reduce the likelihood of misinterpretation, the clinician can say that although such a perception is possible, it is not the case, and unfortunately there is no way the clinician can't eliminate the possibility of this interpretation. In acknowledging the dual edges of this opening statement, a clinician may gain credibility and assuage much, or all, of a surrogate's fear. (This same approach, of stating ahead of time that misperception is possible, can be used in many situations in which ambiguity exists.)

If the clinician does this, it must also be clear, from the outset, that what is agreed upon can succeed only if it is acceptable to the institution and to the clinicians who must implement it, and the agreement is within the law. A second absolute guideline is that whenever the clinician detects what seems to be a negative response from the surrogate, the clinician should address this perception immediately.<sup>34</sup> That is, even when only a glimmer of discontent seems to be brewing, the clinician should stop, at once, whatever he or she may be doing, and, in a nonthreatening and maximally supportive way, ask the surrogate about it, even when, for example, the surrogate just crosses his or her arms or just moves back in his or her seat.

The most difficult but critical skill to acquire in these situations is to respond in a way that is sufficiently supportive, to build trust. A key to doing this is to believe that, in every way, the surrogate's possible negative response is due to something the cli-

nician may have done, or missed—and to convey this to the surrogate. It is crucially important that clinicians believe this, so they don't inadvertently convey a message, nonverbally, that contradicts the concern they express. Clinicians should convey, above all else, that they are concerned that they have said or done something awry, that this is the last thing they want to do, and that they don't know what they may have done. They can ask: "Can you tell me? If you can't or don't want to, that is fine, too, for me." To be able to do this effectively requires extraordinary interpersonal skills. Those of us who lack these skills may, though, still succeed. Even when clinicians fall short of being able to offer this support, so long as they feel this concern and genuinely convey it, the surrogate is likely to give them the benefit of the doubt.

A third guideline that this last point brings up is that clinicians must not be judgmental, even when the surrogate seems to have beliefs that they find immoral.<sup>35</sup>

An example might be the surrogate described by Candilis, Martinez, and Dording, who appeared to prioritize benefitting personally from the patient's will—which would only be possible after the patient died. If clinicians feel contempt for a surrogate (or, for that matter, anyone) it is unlikely that they will be able to engage that person successfully.

What, then, can clinicians do? The best guidelines may be from John Maltzberger and Dan Buie, who address this as it pertains to clinicians who feel what they call *countertransference hate*, in response to patients who feel suicidal. These authors tag the many ways that clinicians may experience this feeling. Clinicians may, for example, have difficulty paying attention, have self-doubt, feel they want to rescue the patient, feel hostile, devalue the patient, and/or want to abandon the patient.

The best protection from anti-therapeutic acting out, they say, is clinicians' ability to remain aware they have such feelings and impulses. The authors point out that very few patients are incapable of developing the trust necessary to set aside an attitude of hate.<sup>36</sup> Clinicians should probably expect that this is also true of most surrogates. Clinicians must accept that it is probably not possible to respond optimally and, at the same time, treat a surrogate with disrespect. If other persons detect a clinician's disrespect they may resent it and feel that next time, *they* may be the person who the clinician will disrespect. When clinicians do not respect a surrogate's beliefs or views, they may have to accept that this is a compromise they may have to make, just as the surrogate may have to compromise.

How might clinicians respond to a surrogate such as the one who wanted the patient to die sooner so the surrogate could receive an inheritance sooner? Clinicians might ask to meet with the surrogate one on one. Mediators may refer to this as calling for a "caucus."<sup>37</sup> Clinicians could say that the surrogate's view might be one that most people, or at least many people, would have in similar situations, but that many people might not be as courageous as the surrogate in openly expressing this view. And that, while this view may be common, it may be a view that most people don't express, possibly because they feel others will judge them negatively. (In this respect, I think of a patient who told me that a "positive" he gained, as his father was dying, was a deeper faith in God, but he had not dared to share this before with anyone, because he thought that feeling this way was just wrong, and that other people would feel this way as well.)

In talking privately with the surrogate, clinicians might say that if the surrogate shares his or her view with the others participating in the mediation-like ethics consult, the other parties may not be able to see the issue as the surrogate does—or to accept it—and so they may be less able to agree to the outcome that the surrogate, the patient, and the care team would really most want. At that point, clinicians could ask the surrogate what he or she thinks of this possibility, and whether or not the surrogate agrees.

### Specific Guidelines

Several specific interventions with surrogates may be most helpful at different stages of a patient's illness. For example, in this issue of *JCE*, Lena Hoff and Göran Hermerén, in "Identifying Challenges to Communicating with Patients about their Immanent Death," list interventions that clinicians might take, step by step, when acting as ethics consultants.<sup>38</sup> Also in this issue of *JCE*, Lauren Sydney Flicker, Susannah L. Rose, Margot M. Eves, Anne Lederman Flamm, Ruchi Sanghani, and Martin L. Smith, in "Developing and Testing a Checklist to Enhance Quality in Clinical Ethics Consultation," provide a checklist that will, in most cases, be most useful, and all that is necessary for an optimal consultation and result.<sup>39</sup>

Still, when it can be inferred that a surrogate's core values most likely differ greatly from the values of others, clinicians may do better if they are willing to depart from such ordered interventions. The paradigmatic example is when a surrogate is from a different culture. (Although we should keep in mind that even our neighbors' views may be very different than our own.) In this situation, a clini-

cian might begin by asking the surrogate how he or she feels that someone like the clinician, who is from such a different culture, is pursuing these questions with him or her.

Asking this communicates that the clinician sees this and feels this concern. Similarly, clinicians can follow this by asking the surrogate what is important to know about *this* family's religious and cultural beliefs.<sup>40</sup> Clinicians should keep in mind that even when people share the same culture, their views and values may wholly differ. They may even want to say this. They can then ask about what the surrogate already knows, and explain *why* they are asking, because explaining why they are doing what they are doing, in virtually all cases, is an expression of respect: "I am asking this to be sure what others have told you is complete and correct."

It is important to respond to all of the parties involved in a mediation-like ethics consultation. This includes looking at and listening to each person in the same way, as opposed to responding more to those with more power, such as doctors.<sup>41</sup> This conveys to a surrogate that the clinician is worthy of the surrogate's trust. In addition, a clinician can go beyond this and promote trust by furthering the equality of a surrogate in ways that may be controversial.<sup>42</sup>

Clinicians can say what is true: that those making the decisions may base their decisions only on what they believe the *patient* would want, rather than on what the surrogate wants. Clinicians can also say (since it is true), that while decisions may be made based on the legal priority of a surrogate—such as the patient's spouse—a surrogate may share views with the spouse, and both could, alternatively, reach a compromise.

Clinicians may share all of the information they have that a surrogate may not know and that they suspect may be useful to the surrogate. This may, in extreme cases, be most controversial. For example, thinking of current events, clinicians could share with a surrogate that she or he could take a brain-dead patient to New Jersey, so the patient could stay on a ventilator, or that a patient wanting to die on a specific date could go to a state, like Oregon, that allows this.

An example of a very difficult situation is when a patient has experienced sudden, traumatic quadriplegia and wants to end his or her life by stopping a ventilator. Clinicians might say to the patient's surrogate that the patient *may not now be able to know* how he or she will feel about this later—although later, once the patient knows more about how he or she feels, it may be harder to die.<sup>43</sup> (This advice en-

courages waiting until later to choose whether to die, but also *not* to wait. All this is, however, critically important information.<sup>44</sup>) Later, clinicians may want to explicitly ask the surrogate whether he or she has concerns regarding the patient's *quality of life*. Taking the initiative to ask may make it easier for a surrogate to say what she or he feels.<sup>45</sup> Clinicians may want to ask the surrogate about her or his concerns about the patient's quality of life repeatedly, as the patient nears the end of life. Researchers report that patients with advanced cancer may do better (and have significantly lower health costs) in the final weeks of life if they still have conversations with members of the medical team.<sup>46</sup> Surrogates' need for these same continuing conversations may be as great or even greater.

Clinicians should consider informing a surrogate, as the patient is dying, that they will continue in some way to check in on what the surrogate needs—and then do this. It is not uncommon that patients and surrogates are abandoned by their clinical team once the patient enters hospice care, even though patients and surrogates may still need their clinicians, and maybe need them more than ever at that point.

While clinicians may tend not to do this, to escape their own grief, because they lack time, or because they aren't paid, they should try to squeeze in some moments with patients and surrogates, even if just over the phone to say little more than hello.<sup>47</sup> Seeing a patient and the surrogate at a last visit may greatly help the surrogate feel closure later.<sup>48</sup> When clinicians inform a surrogate that they will do this, in advance, it may reduce the surrogate's fear to a surprisingly significant extent. Such a disproportionate return on effort may be an example of the kinds of needs people have, and thus the kinds of interventions that are optimal, that go "beyond reason."

## CONCLUSION

Efforts like Bock's are critical to increasing the extent to which clinicians can treat incompetent patients in the most ethically possible way. The best place for such insights, though, may be after attempts to meet all of the parties' most heartfelt needs have been exhausted. Therefore, I have specifically considered ways clinicians can add to their own clinical "repertoires," doing more to elicit a surrogate's ultimate concerns and then seeing if they can implement a surrogate's concerns to a greater extent, using a sliding scale approach. I have also urged, when possible, to put a clinician's relationship with a surrogate first, since this may be best for all parties,

even the patient, since the surrogate may then make better decisions.

I have earmarked key guidelines, general and specific. Chief among these is to immediately explore any and all indications that a surrogate feels a negative emotion. A close second is to take specific initiatives to ask a surrogate about any unexpressed concerns. The take home point, put most simply, is that when conflict exists, clinicians may do best by using mediation-like approaches initially, and “do ethics” only if and after this fails.

#### NOTES

1. G.L. Bock, “Surrogate Decision Making and Intellectual Virtue,” in this issue of *JCE*.

2. M. O’Brien and A. Fiester, “Who’s at the Table? Moral Obligations to Equal-Priority Surrogates in Clinical Ethics Consultations,” in this issue of *JCE*.

3. S. Eskew and C. Meyers, “Religious Belief and Surrogate Medical Decision Making,” *The Journal of Clinical Ethics* 20, no. 2 (Summer 2009): 192-200.

4. This patient had cerebral palsy, but is unclear whether this in any way should affect the question posed here. There are realities that ethical analysis should ignore. To include them, in fact, may be impose one’s own bias unwittingly. For an illuminating example of this unwitting possibility, see L. Wahlert and A. Fiester, “Commentary: The Questions We Shouldn’t Ask,” *Cambridge Quarterly of Healthcare Ethics* 21 (2012): 282-4.

5. Some clinicians raise objections to using hypothetical cases that couldn’t be real. Such cases are, however, the bread and butter of those who do ethics.

6. “We narrow the scope as Henry Richardson puts it, ‘by spelling out where, when, why, how, by what means, to whom, or by whom the action is to be done or avoided.’” T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics*, 7th ed. (New York: Oxford University Press, 2013), 17, citing H.S. Richardson, “Specifying, Balancing and Interpreting Bioethical Principles,” *Journal of Medicine and Philosophy* 25 (2000): 285-307, 289. “Specification requires that a moral agent extend norms by both narrowing their scope and generalizing to relevantly similar circumstances.” Beauchamp and Childress, *ibid.*, 20.

7. This case was depicted in a film funded by the Joseph P. Kennedy Foundation and the Guggenheim Foundation, which is often shown in ethics classes. A particularly painful part of this film depicts the infant’s doctor taking a call from the baby’s father, asking if the child has died yet. *Who Should Survive? One of the Choices on Our Conscience*, movie, directed by W. Schuman (Washington, D.C.: Guggenheim Foundation, 1971).

8. I wish to thank to Tristram Englehardt for this insight and example.

9. I wish to thank Patricia King for this insight.

10. A. Janvier, C. Mitchell, and E. Verhagen, “Neuromuscular Blockers at the End of Life: Moral Courage or Moral Outrage?” paper presented at the ASBH 16th Annual Meeting, 16-19 October 2014, San Diego.

11. See, e.g., A. Plantinga, “The Free Will Defense,” in *The Philosophy of Religion*, ed. B. Mitchell (New York: Oxford University Press, 1971), 105-20.

12. A. Damasio, *Descartes’ Error: Emotion, Reason, and the Human Brain* (New York: Avon Books, 1995).

13. A. Damasio, *Looking for Spinoza: Joy, Sorrow, and the Feeling Brain* (Orlando, Fla.: Harcourt, 2003), 8.

14. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed. (*DSM-5*) (Washington, D.C.: American Psychiatric Publishing, 2013), 50-9.

15. G. Simsion, *The Rosie Project* (New York: Simon & Schuster, 2013), 150.

16. B. Boyd, *Parenting a TEEN or YOUNG ADULT with Asperger Syndrome (Autism Spectrum Disorder): 325 Ideas, Insights, Tips and Strategies* (Philadelphia: Jessica Kingslet Publishers, 2014), 94.

17. J.J. Walter, “Respecting Patients’ and Surrogates’ Religious Views at the End of Life,” presentation to the Ethics Committee, Walter Reed National Military Medical Center Ethics Committee, 7 November 2014, Bethesda, Md.

18. L. Wahlert and A. Fiester, “Mediation and Surrogate Decision-Making for LGBTQ Families in the Absence of an Advance Directive,” *Bioethical Inquiry* 9 (2012): 365-7, 367.

19. E.J. Bergman, “Managing Conflict in Clinical Health Care with Diminished Reliance on Third Party Intervention; Forging an Ethical and Legal Mandate for Effective Physician-Patient Communication,” *Cardozo Journal of Conflict Resolution* 15, no. 2 (2014): 473-99, 491.

20. This statement is paraphrased from what one soldier says in the documentary film, *Korengal: This Is What War Feels Like*, in which soldiers describe stresses they have undergone during current conflicts in the Middle East. This film was made by Sebastian Junger, the author and filmmaker of *The Perfect Storm* and *Restrepo*. It was shown at the Uniformed Services University of the Health Sciences in Bethesda, Maryland on 16 September 2014. *Korengal: This Is What War Feels Like*, movie, directed by S. Junger (London, New York: Gold Crest Films, Outpost Films, 2014).

21. E.J. Bergman, N.J. Diamond, “Sickle Cell Disease and the ‘Difficult Patient’ Conundrum,” *American Journal of Bioethics* 13, no. 4 (2013): 3-10, 7, citing J. Halpern, *From Detached Concern to Empathy: Humanizing Medical Practice* (New York: Oxford University Press, 2011), 123-4.

22. A.M. Fiester, “Ill-Placed Democracy: Ethics Consultations and the Moral Status of Voting,” *The Journal of Clinical Ethics* 22, no. 4 (Winter 2011): 363-72, 370.

23. E.J. Bergman, “Surmounting Elusive Barriers; The Case for Bioethics Mediation,” *The Journal of Clinical Ethics* 24, no. 1 (Spring 2013): 11-24, 11.

24. “About four-in-ten atheists and agnostics (including 14% of atheists and 56% of agnostics) say they believe in God or a universal spirit.” “Nones on the Rise: Religion and the Unaffiliated,” *PewResearch: Religion & Public Life Project*, 9 October 2012, <http://www.pewforum.org/2012/10/09/nones-on-the-rise-religion/>, accessed 18

November 2014.

I am grateful to James J. Walter for many insights regarding religion and culture and related references; see Walter, note 17 above.

25. I. Ying, Z. Levitt, and S. Jassal, "Should an Elderly Patient with Stage V CKD and Dementia Be Started on Dialysis?" *Clinical Journal of the American Society of Nephrology* 9, no. 5 (May 2014): 971-7.

26. A.C. Phelps et al., "Association between Religious Coping and the Use of Intensive Life-Prolonging Care Near Death in Patients with Advanced Cancer," *Journal of the American Medical Association* 301, no. 11 (18 March 2009): 1140-7.

27. A. Hanchate, A.C. Kronman, and Y. Young-Xu, "Race and Ethnic Differences in End-of-Life Costs," *Archives of Internal Medicine* 169, no. 5 (9 March 2009): 493-501; see also, M. Kagawa-Singer, L.J. Blackhall, "Negotiating Cross-Cultural Issues at the End of Life," *Journal of the American Medical Association* 286, no. 23 (19 December 2001): 2993-3001.

28. J. Bruckner, "Physical Therapists as Double Agents: Ethical Dilemmas of Divided Loyalties," *Physical Therapy* 67 (1987): 383-7.

29. P.J. Candilis, R. Martinez, and C. Dording, "Principles and Narrative in Forensic Psychiatry; Toward a Robust View of Professional Role," *Journal of the American Academy of Psychiatry and Law* 29 (2001) 167-73, 169.

30. *Ibid.*.

31. *Ibid.*, 173.

32. Berman, "Surmounting Elusive Barriers," see note 23 above, p. 11.

33. *Ibid.*

34. P.M. Niedenthal, "Embodying Emotion," *Science* 316 (2007): 1002.

35. I wish to thank Autumn Fiester for illustrating the extent to which clinicians can and should go to convey this absolute commitment.

36. J.T. Maltzberger and D.H. Buie, "Countertransference Hate in the Treatment of Suicidal Patients," *Archives of General Psychiatry* 30 (May 1974): 625-33, 632.

37. Bergman, "Surmounting Elusive Barriers," see note 23 above, p. 12.

38. L. Hoff and G. Hermerén, "Identifying Challenges to Communicating with Patients about their Immanent Death," in this issue of *JCE*.

39. L.S. Flicker et al., "Developing and Testing a Checklist to Enhance Quality in Clinical Ethics Consultation," in this issue of *JCE*.

40. M. Kagawa-Singer and L.J. Blackhall, "Negotiating Cross-Cultural Issues at the End of Life," *Journal of the American Medical Association* 286, no. 23 (19 December 2001): 2993-3001; 2995. For example, Korean-Americans and Mexican-Americans are less likely than European-Americans to believe that clinicians should tell patients about metastatic cancer. L.J. Blackhall et al., "Ethnicity and Attitudes Toward Patient Autonomy," *Journal of the American Medical Association* 274, no. 10 (1995): 820-5, 824. This may also be true for patients from Italy, Greece, China, Ethiopia, Spain, France, and Latin, and

Eastern European families. *Ibid.* and H.R. Searight, "Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians," *American Family Physician* 71, no. 3 (1 February 2005): 515-22. Hispanic, Chinese, and Pakistani families may believe that surrogates should, for example, protect patients from knowing that they have a terminal condition. Navajo Native American and Chinese patients and surrogates may believe that discussion of death may bring it about. *Ibid.*

41. As Fiester notes, "Mediation levels the playing field in an arena . . . that can . . . grant values to the powerful." Fiester, "Ill-Placed Democracy," see note 22 above, p. 370.

42. Beauchamp and Childress report a study, for example, in which 14 percent of U.S. physicians said that they do not feel obligated to disclose to patients information about morally controversial procedures. Beauchamp and Childress, *Principles of Bioethics*, see note 6 above, p. 44, citing F.A. Curlin et al., "Religion, Conscience, and Controversial Clinical Practices," *New England Journal of Medicine* 356 (February 2007): 593-600.

43. I wish to thank Anita Silvers for this insight.

44. Some refer to this kind of intervention now as "neopaternalism," "libertarian paternalism," and/or less formally, "nudging." Beauchamp and Childress, *Principles of Bioethics*, see note 6 above, pp. 218-9. What place, if any, this "soft nudging" should have is currently subject to much controversy. Highly different views were presented, for instance, by M. Gorin, J. Blumenthal-Barby, Y. Saghai, and P. Ubel, "Doing With, Doing For, and Doing To: Nudges and Participatory Influence," paper presented at the ASBH 16th Annual Meeting, 16-19 October 2014, San Diego.

An example is offered by Eskew and Meyers, "Religious Belief and Surrogate Decision Making," see note 3 above, p. 7, note 1. They state, in regard to the case involving the mother and her son, "Thus the team should have tried to convince the son that the physicians' knowledge and the tools at their disposal, including pain medications, were gifts from God." In the context in which they said this, the son's saying this would have made his religious view and reasoning seem more reasonable, so this "soft nudging" would have enabled the son to meet Eskew and Meyers's criteria for consistency, thus increasing the likelihood that the physicians would not give the mother pain meds, which was what the son wanted.

45. Searight, "Cultural Diversity at the End of Life," see note 39 above, p. 520.

46. B. Zhang et al., "Health Care Costs in the Last Week of Life," *Archives of Internal Medicine* 169, no. 5 (9 March 2009): 480-8.

47. A.I. Black et al., "Abandonment at the End of Life From Patient, Caregiver, Nurse, and Physician Perspectives," *Archives of Internal Medicine* 169, no. 5 (9 March 2009): 474-9, 478. I can hardly count, I say with deep regret, the number of times I have met with patients whom I knew were dying, and it did not occur to me, at that moment, that that visit would be our last visit.

48. Black et al., *ibid.*