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At the Bedside

How Clinicians Can Reduce "Bullied Acquiescence"

Edmund G. Howe

ABSTRACT

Clinicians and patients and their families may disagree about a course of treatment, and the ensuing conflict may seem intractable. The parties may request mediation, or use mediation-based approaches, to help resolve the conflict. In the process of mediation, and at other times, parties in conflict may feel so pressured to accept a resolution that they acquiesce unwillingly—and such resolutions often unravel. In this article I investigate how "bullied acquiescence" might happen, and how to avoid it.

In this issue of *The Journal of Clinical Ethics,* Laura Guidry-Grimes, with the assistance of staff from the Medstar Washington Hospital Center for Ethics, propose a new precedent. In "The Case of Ms D: A Family's Request for Posthumous Procurement of Ovaries" and commentaries, they argue that, in some circumstances, a person should be able to have a child "with" a partner who has died, even when the deceased did not give prior consent.[1] (For the sake of simplicity, I will refer to the article and commentaries as Guidry-Grimes's work.)

Also in this issue of *JCE,* Haavi Morreim, in "Story of a Mediation in the Clinical Setting," presents mediation approaches that she calls "Mediation 101," suggesting these approaches can be used by those who are not trained in mediation.[2] Morreim introduces the phrase used in the title of this article, "bullied acquiescence," to describe how medical staff can pressure patients and family members to make a decision they don't want to make. She gives the example of staff pressuring a family to agree to a do-not-resuscitate (DNR) order, only to have them rescind the DNR order shortly thereafter. The two articles suggest ways to reduce bullied acquiescence.

ASSIGNING GREATER MORAL WEIGHT TO PATIENTS' AND FAMILIES' FEELINGS

In this issue of *JCE,* Guidry-Grimes presents a case in which the family and partner of Ms D, who experienced sudden whole-brain death, asked the medical team to preserve Ms D's ovaries for possible later use in conceiving a child. The standard position in such cases is for staff to not assist unless the deceased had explicitly consented to postmortem reproduction, or there is evidence of specific conversations indicating this was desired. Such cases are rare, but I commend Guidry-Grimes's innovative thinking and courage in arguing for a new model.

In the case analysis, Guidry-Grimes pursues arguments both for and against posthumous extraction of Ms D's ovaries, and this may be how such arguments must be made, particularly when they set a new precedent. What I find most affecting in the case is, however, the intensity of Ms D's partner's desire to have a child with her. In the face of such intense feelings, should the manner and method of discussion change? If so, how? For example, it may be appropriate to acknowledge "intense feelings" explicitly, and recognize their moral weight in con-

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siderations that more typically would include only reason-based pros and cons.

Placing such weight on emotions is uncommon in ethical analysis. As Martha C. Nussbaum states, however, "If emotions . . . contain in themselves an awareness of value or importance, they cannot easily be sidelined in account of ethical judgment, as so often they have been in the history of philosophy."[3] Rather, she says, emotions must be "parts of this creative reasoning itself." Including the moral weight of emotions in ethical analysis is, she notes, "complex and messy." She is right. Emotions can enlighten or mislead, and we can never identify the role that feelings play in our thinking.[4] I will not review here the extensive history of thinking and controversy regarding emotions and reasoning.

Ms D's partner's intense feelings about having a baby may indicate what he needed to be happy—what he needed to *flourish*. The combination of intense feelings and the need to flourish may be key criteria on which the medical team might have considered giving greater moral weight to his request.

According Greater Moral Weight to Feelings

Ms D's partner and her family asked the team to extract her ovaries. Ms D's partner had planned to use his retirement savings to pay for *in vitro* fertilization (IVF) with Ms D. He expressed deep regret they had not taken this step sooner and had a child together before her death. He produced paperwork from their visit to a fertility clinic as evidence that Ms D would have wanted to harvest her ovaries after she died. His hope and regret are poignant**.** The strength of his feelings and of the feelings he evokes in us may be a first clue that we should consider making an exception to the usual way of doing things, as Guidry-Grimes argues.

Perhaps patients' and families' feelings should be viewed as existing on a sliding scale. On this scale, feelings would be accorded moral weight when they reflect what is most meaningful in the patient's or family member's life. In this case, the previous efforts of Ms D and her partner to begin IVF could be seen as indicating what they held to be most meaningful in their lives. Giving moral weight to their feelings would respect their sensibilities, regardless of the reasons underlying their feelings. If assigning greater moral weight to patients' and family members' feelings affects what the medical team will do, it would result in a much greater good, in the eyes of patients and families.

On the other hand, according greater weight to patients' and families' feelings would make it harder for clinicians to "draw the line" and deny a request, should that be necessary. Clinicians would have to sort out feelings that should be given greater moral weight from feelings that should not, or assign different moral weights to feelings, flourishing, and other relevant criteria, on a sliding scale. In some cases these distinctions may be highly arbitrary. Yet making such distinctions may be not only ethically justifiable, it may be *most* justifiable. That is, if placing increased weight on feelings could make a very important difference to patients and family members, most of the time, this approach may be preferable to using only reasoning, even though staff may sometimes have to draw an arbitrary line. Ethics often relies mostly, or only, on objective reasoning.

Guidry-Grimes takes into account Ms D's partner's feelings and the degree to which they are meaningful to him. She states that intentional reproductive decisions are "of our most intimate nature, our sense of self, and our family identity." Are there any aspects of who we are or any of our needs that are more precious? Lorraine Code goes so far as to argue it would be irrational to not place ethical weight on what we feel. She states, "theorists of knowledge" need to engage in critical analyses of the "suppression of subjectivity."[5] To know other people, she says, we can't possibly be "unresponsive, emotionless, and neutral."[6] She spells out how clinicians could put the importance of subjectivity into medical practice: a doctor, she says, must be willing to explain whatever a patient wants to know, to indicate other directions a patient might want to take, to respect a patient's decisions even when they conflict with the doctor's advice, and, most importantly, to not claim expertise "where [the doctor] has none."[7] In some respects such interventions are commonplace, in that they are what should be done to maximally respect patients' autonomy. These interventions foster an interpersonal regard that goes beyond respecting autonomy, since clinicians, Code says, must be aware of their own fallibility in working with patients towards a solution that is "mutually plausible."[8] We cannot, even if we wanted to, she concludes, become "mental monists."[9] Such "mutual plausibility" is the goal of mediation-based approaches, which I discuss later in this article.

Taking Feelings into Account

Perhaps the best reason clinicians should take patients' and family members' subjective feelings more into account is because, if clinicians don't, it is more likely that family members might experience abject terror. For example: family members come to the ward to visit their loved one, who then has a cardiac arrest before their eyes. To their hor-

ror, no one comes to provide cardiopulmonary resuscitation (CPR), despite their frantic calls. They are not aware that the patient enacted a do-not-resuscitate (DNR) order and told the staff not to tell the family. This is unusual, but it has happened.

In such cases, staff may not inform family that a patient has a DNR because the patient requested they not be told. Staff may then feel that they must, above all, respect the patient's request.[10] Staff may especially want to abide by a patient's request due to recent laws that, under some circumstances, make violating confidentiality a criminal offense. Not knowing the specifics of the law, staff may err by overly respecting confidentiality when in doubt. But family members who see a loved one suddenly have a cardiac arrest and call for help, who don't see CPR begun immediately, may find the experience terrifying. Moreover, staff probably could have anticipated the family's feelings of terror in this situation. This example illustrates the need for staff to do more than consider the feelings of patients and family members. It is possible that staff could *anticipate* harmful feelings, and they could anticipate the measures needed to prevent them.

When clinicians foresee harmful feelings, what can they do? In the above situation, for example, staff might try to persuade the patient to inform loved ones. If this fails, staff might go so far as to insure that all patients' visitors know that any patient might have a DNR order, without informing anyone but staff. This could be achieved by posting a notice that can be seen by anyone getting off the elevator onto the ward, so no one would escape knowing: "Visitors should know that patients on this ward may have a DNR order, and may ask staff not inform visitors that they do." Loved ones could then ask the patient about it, and, in this situation, it is implausible that any family member or loved one would not want to know. In taking this almost unprecedented initiative, staff would be able to anticipate the almost unimaginable emotional pain that a loved one might experience in this situation, and accord appropriate weight to it. This example, involving terror, clearly involves harm. I used it to indicate how important emotions may be. In this case, feelings may be so important that they suggest an innovation that is not routinely considered.

Another example is the so-called slow code—deliberate slowness in responding to a request for CPR when it would not benefit the patient—a practice most of us thought had been abandoned forever. Years ago, clinicians who merely mentioned the possibility of responding with a slow code in response to a family's request for CPR were greeted with contempt—as they would be today. Yet, in 2011, John Lantos and William L. Meadow offered a credible exception based on family members' feelings: in an extreme, rare instance, a slow code might be ethically optimal, and they spell out what the circumstance might be.[11] For example, family members may have been fully informed and thus aware that a slow code won't succeed, but they still want it. Wanting a slow code may not be rational, as the family knows it won't succeed, but it is what they want. Family members can make the same kind of emotionally based requests under other circumstances. For example, an ambulance arrives at a patient's home long after the patient's heart has stopped. The emergency medical technicians examine the patient and explain to the family that their findings are conclusive: their loved one has died and can't possibly be revived. But families still ask the EMTs to try resuscitate, and irrationally, perhaps, families later report that they feel relieved by the effort.

Given this, it might be warranted—and may be even preferable, in some circumstances—to respond to a request from a patient or family member, even when the request is "objectively" wholly irrational. In the instance of providing CPR, responding takes up staff time. But this "downside" may be outweighed by the exceptional respect that responding may connote to the patient or family member.

Here is another example. A patient was dying because the bleeding from an organ inside his body couldn't be stopped. He needed blood so regularly the hospital blood bank was being depleted. His medical team knew that he had only a few days, or a week at most, to live. The hospital blood supply was not so depleted that it placed other patients at risk. Still, some staff saw the use of blood as unwarranted, as giving blood under these circumstances was prolonging dying, not prolonging life. They contacted the ethics consultant and asked him to discuss the situation with the patient, hoping that the consult might cause the patient to agree to not have more blood.[12] The consultant took a mediation approach. He asked the patient whether he was presently finding value in his life, to be sure that he was. The consultant reasoned that it would make more sense to bring up the choice of stopping blood transfusions if the patient wasn't finding value in his life. The patient responded that he was finding his life valuable, although he knew he would be dying in a few days. The consultant thanked him and left.

The consultant could have tried more to do what the staff wanted—to persuade the patient to stop using blood. If he realized this was the staff's underlying agenda, though, the consultant could have cho-

sen not to do the consult. He might have told the staff, "You're asking me to do something other than ethics. My skill in is resolving ethical conflict, not persuading a patient to do something or giving bad news." On the other hand, the ethics consultant might have been more skilled in giving bad news than the staff were. Then perhaps he could have said, "Yes, I'll give the patient this bad news."

But I wish to consider an alternative even more nuanced: the ethics consultant might have chosen not to do the consult because of what agreeing to do it might connote to the patient. That is, the patient knew he was dying and continued to lose blood. He might infer from the consultant's visit that the staff wanted him to stop using blood, even though they knew that, if he agreed to stop, he would probably die sooner. Inferring this, the patient might feel emotionally abandoned by the medical staff. It could be argued that the patient might not have imagined his using this much blood was a concern. Or that whether the patient should have been told should depend on whether his use of so much blood could harm others. Another argument would be that saying this to the patient would respect his autonomy.

I explored the possibility that the patient might have felt abandoned by role playing with a colleague, which I often do to test out how others may respond emotionally. I was the consultant and she was the patient. I did what the real consultant had done, and, after the role play, I asked my colleague how she felt, as the patient. "Defeated," she said. If the ethics consultant had considered this possibility before agreeing to do the consult, and assessed the relative gains versus the harms of consulting, he might have decided not to do the consult.

ADDING MORE EXCEPTIONS

In addition to making exceptions based on patients' and family members' strong feelings, clinicians may want to place greater value on how some patients differ from others, which may lead to making additional exceptions. Here are some examples of how making this relatively small change may improve outcomes for patients and family members.

Responding to Subtle Differences

Ethical analysis relies on reason, and, to reason, it may be necessary to see each person within a group as essentially the same. We do this when speaking of respecting a person's autonomy or of treating people equally—in such instances, we treat two persons as if they have only common traits, or as if they were one. But in the clinical context, all persons are different. Thus, there is justification to tailor our treatment of each person based on their individual needs. When we make ethical conclusions that require us to generalize about people, we risk going too far, and, in the process, missing the individual's important, different needs. This may be another ground on which an ethicist like Guidry-Grimes may respond to a person like Ms D's partner by making an exception: his need and situation may be different. Thus our best response to him may be different.

The need to take difference into account to a greater extent when making ethical decisions is expressed well by Seyla Benhabib, who identifies and contrasts what she calls the "generalized self," used in conventional ethical discourse, from what she calls the "concrete self," which is always unique.[13] She writes, "The standpoint of the generalized other requires us to view each and every individual as a rational being entitled to . . . rights and duties. . . . The standpoint of the concrete other, by contrast, requires us to view each and every rational being as an individual with a concrete history, identity and affective-emotional constitution." Further, she writes, "In contemporary universalist moral psychology and moral theory, it is the 'generalized other' that predominates."

The problem with this, Benhahib states, is that ethical concepts such as fairness then become "thereby identified [only] with the perspective of the 'disembedded and disembodied generalized other.' "[14] Individuals have unique needs and motives that "carry within them the traces of early childhood experiences, phantasies, wishes, and desires as well as the self-conscious goals of the person. . . . The non-relational theory of the self, which is privileged in contemporary universalist moral theory . . . removes such needed interpretations from the domain of moral discourse."[15]

To add ways that persons may be significantly unique in our ethical judgements, we might scrutinize each patient and family for such differences; if they are present, we can try to take them more into account. One way to do this might be to make exceptions for the patient or family, or both.

Examples

In medicine, as in ethics, it is often necessary to establish categories to best proceed. A clear example is triage. During a large-scale disaster, when large numbers need treatment, it might be best to first determine which patients could live if given the right treatment, and which patients, even with treatment, will die. Such triage allows staff to prioritize treating patients who could live, saving many more lives.

Another example is categories regarding which patients can be admitted to the intensive care unit (ICU), that allow staff to prioritize the treatment of patients who will most likely benefit from admission. Following this concept, some hospitals do not allow patients with a DNR to be admitted to the ICU. But some patients may have conditions that require admission to the ICU if they are to be treated successfully and continue to live.[16] They may have pneumonia and only survive if admitted to the ICU.

In these cases, staff could make an exception. Rather than simply follow the policy that a patient with a DNR cannot be admitted to the ICU, the staff could ask the patient or family why the DNR was originally written. Then the staff could inform the patient or family that the reason for the DNR has changed, as it would, for example, if the patient needed treatment for pneumonia in the ICU. Once informed, the patient or family would have the option to rescind the DNR order and be admitted to the ICU for treatment. Lorraine Code, whom I quoted above, describes this kind of informing of patients and family members as necessary in every case. Then and only then can a DNR be applied as intended.[17]

This example indicates the gains that clinicians may be able to achieve by seeing patients as individually embodied, as Benhabib puts it. With this awareness, clinicians may better see the importance of making an exception.

Here is another example. A young girl with a genetic disorder, Werdnig-Hoffman's disease, was dying. This condition involves progressive, ascending paralysis. The child's paralysis had seeped up her body so that she was paralyzed from her feet up to her waist, and the muscles in her lungs were weak as well. She had developed pneumonia, and it would progress. As a result, even though she had been successfully treated with antibiotics on this admission to the hospital, her care team wanted to decide, before she was released from the hospital, what they should expect to do on her next admission. Specifically, they feared that she might need to be on a respirator to be treated successfully and survive, and should they plan to do this on her next admission? they asked the ethics committee. The pediatric pulmonary experts who were called in all said the team should not consider placing her on a respirator, even though she would die without it. They believed she was too young to understand what the respirator was and why she needed it, and she would have frequent pain from the suctioning. Finally, the experts said, she wouldn't be able to hug her parents.

I was a member of the ethics committee, and I went to her ward and bed after the committee meeting because I felt especially ambivalent about the meeting. I heard peals of laughter coming from her room as I entered. It surprised me, as this young girl, after all, was dying. All the experts agreed that she would die within months. "How come?" I wondered. Our committee had imagined that she and her family would be grieving because of the findings of the committee, and because she was dying. They weren't. The family, I think, was highly different from what the committee had imagined. They rollicked, I might say, as if they were having a party. I thought: If any child could experience joy while being hospitalized and on a respirator, it would be this girl. I wondered: Should I contact the ethics committee and ask them to gather again? But I did not. Since the experts were so convinced that being on a respirator would harm the girl, I thought that my new perception wouldn't change their minds. Perhaps, I thought, I was being overly optimistic.

I may have been wrong to not seek to reconvene the committee. Perhaps we should have seen this child as an exception—this is my story's point.It is paradigmatic of the kind of case in which we should consider individualizing treatment and go in a direction different than the usual. Ms D's partner, who wanted to have a child with her after she died, might be another. These examples show how we might identify the unique needs of patients and families by recognizing their individual lives and life histories, as Benhabib would describe it. We could alter our usual practice with even just one patient, in the same way that we might alter an ICU policy that does not allow admission of a patient with a DNR.

USING MEDIATION-BASED APPROACHES

In this issue of *JCE*, Haavi Morreim reports on a case in which she was the mediator. When she was first consulted, two security guards were posted outside the hospital room of baby "Henry," to prevent his parents from taking him home against the staff's medical advice (AMA). His pediatrician was about to call child protective services. Fortunately, he called Morreim instead. Morreim suggests that clinicians must, above all else, avoid causing "bullied acquiescence" in patients and their families. If clinicians use force, she says, sooner or later patients and families will "push back."

But "bullied acquiescence" presents greater risks. Patients may not return for treatment when they need it. Worse, they may feel bitter about their experiences with medical staff, and that may cloud the rest of their lives. At worst, like patients with posttraumatic stress disorder, they may suffer from

repetitive, intrusive flashbacks that prevent them from regaining joy in their lives. An additional risk is less well known: some people, recent research indicates, see others as threatening even when their facial expression is neutral.[18] This means that when we conduct a traditional ethics consult, they may see us as threatening. This may occur even when we are trying to help them, for example, in presenting a new option that may not be what they want.

When we encounter this kind of fearful or angry response, consciously or unconsciously, we may reciprocate. In turn, this may cause patients and family members to respond even more adversely, triggering an ever-increasing negative cycle that neither party understands nor can stop. Feelings that are this strong—especially fear and anger—may so wholly occupy our awareness that they cut off our capacity to think rationally, and even to compromise. As a result of this kind of cycle, clinicians may call child protection agencies, and families may surround a loved one's bed to shield a patient from staff.

Mediation approaches may help to prevent this. Absolute insistence that patients and family members have an equal voice in these interactions, as aforementioned, provides a structure in which such tragic outcomes are much less likely to occur. Our nonverbal expressions of emotions, and what we say, are more likely to stay within these same lines. Mediation approaches may be beneficial when we interact with people who are more likely to misperceive our intended neutrality. These people are worse-off than other patients and family members, due to their proclivity for misperceiving. By using these mediation approaches, we may be doing more to help this worse-off group.

When conflicts arise but aren't resolved, the rest of us may be worse-off, too. We may feel burned out and in time may even change profession. To the extent that these approaches enable medical staff to do better, they will benefit too. But there are three important questions to be considered before using these approaches: when to use them, what to say, and how much should be compromised.

When to Use Mediation Approaches?

Overall, mediation approaches are particularly helpful when patients and family members are distressed due to an ethical conflict, and the conflict is unlikely to resolve itself with the passing of time. This is because these mediation approaches tend to be successful in reducing the distress experienced by the parties in conflict. As Morreim states, these approaches seek to build trust "at every turn." They seek resolutions not "from experts," but "by those who are most deeply affected." Participation in mediation is "voluntary throughout," from the "first conversation." In some contexts, the need to consider using these approaches is urgent and more obvious. In the case that Morreim reports, the security guards were posted at Henry's door and his pediatrician was about to call child protective services.

Such an intervention—calling in protective services—sometimes is necessary. In other cases, though, it can do inordinate harm. For this reason, clinicians often choose to continue to see such families in the hope of resolving the problem, rather than making this call. Thus Morreim's case example does more than depict mediation approaches; it illustrates why clinicians might well use these approaches when they can. In other cases, such potential gains are obvious. Articles in *JCE* have described, for example, a family surrounding a patient's bed to protect him from clinicians, like a herd in the wild protecting its young. They have described a grandmother who threw herself over her grandson as he lay in his bed, for the same reason.

In addition, mediation approaches may be most beneficial in less obvious cases, for example, whenever people are distressed. Their distress may be the first sign that an ominous cycle, as described above, is beginning. Mediation approaches may prevent initial hostility from worsening.

Clinicians may want to consider using these approaches particularly when a patient has, to any degree, damage to the brain: from an injury, a previous coma, or early dementia. Patients with damage to their brain may, more than others, overrespond to what they see as threats. Further, those whom the patients feel they can trust may often be able to relieve the patients' angst more rapidly and effectively than for patients without brain damage.

For example, a patient who had some damage came to see me in a rage, because he had called his physician the day before and the physician hadn't called him back. The patient said he planned, after he saw me, to storm into his doctor's office and just lace into him. Suddenly interrupting his own fit of fury, he asked me, "What do *you* think?" I said, "I'd call him first and ask what happened." He said "Oh!" and his face softened. "Then I will." Clinicians who use these approaches may gain patients' trust much more than others using different approaches. Thus, they should especially consider using mediation approaches with these patients.

What to Say?

Morreim notes that mediations can be court ordered. In these contexts, if the conflict isn't resolved,

the outcome may seem like the sword of Damocles, hanging over the heads of the patient and family—not an improvement. What happens next may be out of their hands, as decisions will be made for them, by others. As Morreim notes, one cannot say at the outset of a mediation, "I'm not here to tell anyone what they should do," and then later be directive. The importance of making the best possible first step, then, can't be overstated.

We should accept the profound importance that others may place on whatever it is that they feel, whether this makes sense from an objective perspective or not. Some people may respond profoundly to what others see as only trivial or slight losses. Thus patients may make choices that make little sense to others. A patient may feel, for example, that she or he would rather die than lose a toe, or prefer to be constrained and carried out of a hospital when he or she no longer needs care than to leave on his or her own. Likewise, some patients may feel that they want to live longer, even with the amount of time gained may be only a few minutes.

Clinicians must initially indicate, nonverbally as well as verbally, that they recognize these feelings, and respect them, regardless of what they believe from their own medical perspective. In might be optimal to acknowledge the importance of a patient's feelings in our first words to the patient or family. For instance: "I'm sorry, I can't give you what I know is what you want . . . for your loved one to live. . . ." After communicating we have this understanding, we can say what we *can* offer and what will be likely to happen, if, using mediation-based approaches, a resolution isn't reached: namely, that others may make the decisions.

It may be best to clarify that it is possible to take this statement in two different ways. The first way is what is intended: to describe what can be gained by meeting. The second way may seem like a threat, even though it isn't intended to be. If it is clear that the clinician is the ally of the patient and family, the reality, the sword that hangs over their heads, may provide the greatest incentive to accept some outcome other than what they initially most wanted. Clinicians may be explicit. They can say that they wholly understand why the parties in conflict may have no interest in meeting, but the parties may come out better through mediation than they would if they can't agree—which would be that other people will decide what happens next. This is a core intervention I will discuss later. Clinicians should always tell patients and families *why* they will do what they will do, and then ask, "Would you be willing to participate?" Asking and then listening are essential.

How Much to Compromise?

If mediation approaches are to succeed, medical staff, like patients and families, may have to accept an outcome that differs from what they most hope for and want. If they can accept this in advance, they may be better prepared and so be more able to respond in a way that is conducive to compromise. The most difficult compromise for staff may be agreeing to give a patient suboptimal medical care. Patients can make this choice in other contexts, so long as they are competent. Greater problems may arise when they are not competent. Even then, using mediation approaches may be more important. When patients and families trust the staff, they may assent more readily to what they most need.

An example is a situation alluded to earlier, of a woman who had a gangrenous toe due to diabetes who refused an amputation. She also had early dementia. Some staff wanted her to be declared incompetent, and then, with her surrogate's concordance, they would cut off her toe without her permission. Staff feared that if they waited, her toe would become infected and the infection would spread throughout her body, possibly ending her life. Other staff believed that this risk, although real, was remote. Her toe, they thought, might possibly fall off on its own. Fortunately, one of the staff used a mediation-based approach. She found that the rest of the staff, even with their misgivings, were willing to give the patient more time. In time the patient accepted the surgery. But initially she had wanted to keep her toe more than her life.[19]

Sometimes a hospital's interests or rules need to be compromised. Staff may not have the authority to make that kind of decision. A third party may need to be brought in who can—for example, an administrator. An example of possibly supporting a compromise that goes against a hospital's interest is when a patient refuses to leave the hospital when he or she no longer needs hospital care. It is possible that, in time, the hospital may have to use force, invoking the law and physically forcing the patient to leave against his or her protests.[20] This is another instance when clinicians who use mediation approaches may do better. For example, they could bargain for time. They could indicate that they truly do appreciate the degree of the patient's fear about leaving the hospital, and they recognize their inability to reduce the patient's fear quickly or on their own. As a next step, they may be able to get a patient to agree to meet with a clinician who would be the best person to provide follow-up care for the patient after release from the hospital. What may be key is what is said to the patient as to why. A clini-

cian can explain that the meeting may not influence the patient's decision, but will give him or her "additional information." The clinician can add that, based on his or her own experience and expertise, more information is generally better than less information. (I will say more about clinicians' acknowledging expertise shortly.) In such instances, a clinician may be negligent in serving the patient if the clinician does less. The clinician can also explain this, and the patient will almost certainly agree.

Patients who are fearful may benefit a great deal from any additional knowledge we can give them that helps them decide what it is they want most. Making an early intervention such as this may make an immense difference in what subsequently occurs.

Another example is that of hospitalized psychiatric patients who usually benefit from timely follow-up care, after they are released. Early person-to-person conversations with these patients, while still in the hospital, may make the difference in whether or not they participate in follow-up care. The case of the woman with the gangrenous toe illustrates how mediation approaches may be likely to succeed if greater amounts of time are allowed, although this may require clinicians to agree to a compromise they don't want to make. Meeting with psychiatric patients before they leave the hospital must be arranged in such a way that the patients don't feel they are coerced. In reality, they aren't, as they can refuse follow-up care, and clinicians should try to insure they know it. Clinicians should ask whether they know it. When a clinician takes the time to assure a patient that the clinician accepts how the patient feels, and, still more importantly, acknowledges the patient may not be able to change how he or she feels, the patient may be more willing to accept noncoercive interventions that, based on the clinician's expertise and experience, the clinician would be negligent not to suggest.

Compromising a Hospital Rule

A final compromise that clinicians might want to consider is going against hospital rules. An example is when a patient's loved one wants to stay with the patient while he or she is dying. The effect of not staying with the patient if she or he dies during the night hardly needs to be stated. This is a strong reason for clinicians, and others, to make an exception to a rule against a loved one staying the night. Loved ones who are shocked by a patient's sudden death may not recover for an exceptionally long time.[21] This may especially be the case when the loved one wasn't with the patient at death, whether this makes logical sense or not. This again indicates the importance of subjective feelings. Often hospitals can make exceptions to the rules. An instance that moved me was a palliative clinician at a major institution who arranged for a patient's dog to join the patient in her ICU bed for a short time. This may be more common in some hospitals now.

Another consideration in conducting a mediation is being pro-active. In a previous issue of *JCE,* Edward J. Bergman gives an example of how to conduct a successful mediation.[22] He recommends calling in a third party to negotiate, if necessary. This represents not only compromise, but a willingness to be pro-active in asking others to compromise. When clinicians take initiative to further the interests of patients and family, it may add to their feelings of trust. Acquiring the trust of patients and family as early as possible, and then maintaining it, is a priority clinicians should strive for above all else. Clinicians should seek to maintain this trust even if a mediation fails—should it fail.

When in the hospital, patients and their family members may be afraid to say what they feel. Family may be especially afraid to ask if they can spend the night with a dying patient if they know it is "against the rules," and they may be afraid to "appeal" a decision if their request is denied. Clinicians may help them to overcome their reluctance to make a request by taking the initiative—often—to ask patients and family members, in an open-ended way, if there is anything else they feel they might want. When clinicians take this initiative and then pause, to further convey that they really want to hear what patients and family members want, it may enable patients and family members to newly express themselves in a number a situations, ranging from asking to stay with a loved one who is dying, to whether they can have more people with them during meetings. Clinicians may help further by supporting requests made by patients and family members after they voice one. For example, should they request something that hospital policy usually does not allow, a clinician may say something like, "Yes, it makes a lot of sense to me that you want to be with the patient tonight. Let's see."

Structuring Meetings

Morreim considers several decisions to be made about how to best structure mediation sessions. These decisions include, for example, how many should be present, and whether clinicians should meet with one of the parties privately.

As an aside here, I would like to consider private meetings. Sometimes when a patient's family members are "difficult," the medical staff arrange

for the family to meet with only one staff member, who explains what is going on with the patient. This limitation is frequently recommended by clinicians to minimize "splitting," a term used to describe how some individuals deal with emotional conflict and stress: they may fail to see other persons as having both positive and negative qualities, and see others as being "all good" or "all bad." For example, a family member who wants to know how the patient is doing may talk to the doctor on night duty and then the doctor on morning duty, and receive different information from each. The family may come to see the one doctor as "good," and the other doctor as "terrible." If only one doctor talks with the family, the hope is that such splitting may be avoided.

But when staff "lay down the law" and tell family members that they will be limited to communicating with only one staff member, this may be perceived by the family as being told that they "can't handle" talking with more than one staff member. Their perception may be that their ability to talk with other staff, who may have different views, has been taken away. Thus the pathology of splitting may be exacerbated by limiting contact with staff, and become instead an iatrogenic harm to the family.

Returning to the question of how many should be present during a mediation session, Morreim suggests the possible desirability of limiting the number of participants. I would add that perhaps the most important consideration is how many people the patient and family want with them who are "in their camp." This decision is one they can only make for themselves. It may be that just one person is enough. With this one person, they may feel they have sufficient support to fully express and defend their interests against others. This person may be their clinician, which is another example of how important it is for clinicians to acquire trust.[23]

During a mediation (and at other times, as well), clinicians should carefully attend to where they sit. They should sit next to patients and family members, indicating by this arrangement that they do not plan, in any way, to abandon them. Clinicians should still ask, "Who would you want to be with you?" Clinicians can normalize all the possible responses they may receive before asking, which may make it easier for patients and family members to say what they really want, for example, "Some people want more people they know well with them besides just me. Who do you want to be with you?"

Morreim advocates meeting with one party privately, when this is necessary, to help enable the person to speak more freely. How this is done may make a difference. It may be helpful to discuss the pros and cons regarding this, and then let the parties decide. Some persons may be able to speak more freely when speaking privately, but those who are excluded may have new fears; for example, What has a loved one said in meeting privately with a clinician that the loved one feels he or she can't say to the whole group, and why?

The possibility that a loved one will feel excluded, or that another is being treated as exceptional, may be substantial and may cause personal friction later. The mediator can inform the parties of these risks, which may reduce the risks this will occur later, and may help the parties decide about whether a private meeting is warranted. After a private meeting, the mediator can ask all of the parties involved whether they have new concerns, before resuming the mediation. This dialogue introduces a "mini-mediation" about the advisability of any one person meeting with the mediator privately. The time and possible discomfort this involves may be more than worth it. The outcomes may not be the most important aspect of the private meeting; that the parties involved have an opportunity make decisions for themselves may mean the most to them. This approach treats them with greater equality.

Clinicians may encounter patients or families with whom they feel friction. The patient or family member may engage in "splitting," as mentioned above.[24] To reduce the risk of splitting, some experts recommend that patients and family meet with only one member of the staff, who will update them on how the patient is doing. Experts believe this helps prevent patients and families from being as able to engage in the divisive and demoralizing splitting process. But this strategy, in itself, can be complex. Some staff speak with a disengaged tone or glare without knowing it, or may be seen as off-putting. Morreim notes that some clinicians sound like they are reading from a textbook. Families may perceive this consciously or unconsciously and react.

I noted above how some people may perceive a threat even when another person has a neutral facial expression. These people may pick up on subtle differences and responses and magnify what they may imply. Given this, clinicians who want to resolve conflict may undermine their goal if they push too hard. Should a patient or family member take offense at some aspect of the mediation, clinicians should attempt to address it, and ask, "Did I do or say something that made you feel angry?" If other party says "yes" and gives a reason, clinicians can try to discern whether they understand that concern, validate what the other party has said, and then say, "I'm sorry."

Further Interventions

There are numerous ways in which clinicians can seek to gain and maintain the trust of patients and family members. How they do this may be most important. Everything they do must be genuine. In this last section I will discuss some ways to be both genuine and effective. Morreim provides an example: she and one of baby Henry's parents sat side by side as they reviewed a video clip of one of Henry's test results. Such positioning, intended or not, implies an alliance. I still appreciate having this same opportunity with a patient: she wanted to become pregnant, and wondered whether, if she did, she should continue to take antidepressants. That's a complex question, so we sat side by side looking through a text for answers. These examples illustrate that clinicians should consider more than what they say when they meet with patients and family members. Clinicians should generally not sit opposite or on the other side of a desk when they meet with others. Here are similar key points clinicians may want to incorporate into their practice.

We should say why we are doing what we do, before we do it. This is optimal, as it helps patients and families gain more from mediation and shows greater respect. It is particularly important because it treats the parties as equals. Early on, we should explain the reason for the mediation: the parties are in conflict without a clear path before them, and mediation is the best effort to try to come together on a "solution." If someone else makes the decisions, the outcome will be more uncertain. Explaining *why* enhances the autonomy of the parties, as does offering to provide additional information. We should share all of the medical, legal, and even ethical information we have during a mediation, whenever possible. We may be negligent if we don't.

Before proceeding in any activity that involves patients and family members, it is probably best to first ask them if proceeding would be okay with them. In the last issue of *JCE,* I gave the example a clinician who, prior to conducting a mediation, asked a patient if he could sit down beside the patient.[25] Morreim provides a second example: she asks a parent whether it would okay if she jots down some notes. She even explains to the parent why she does this—so she won't miss anything.

A risk of asking is that patients and family may experience it as excessive, and wonder whether it is disingenuous: "Why would Haavi ask whether it is okay to jot down notes? Of course it's okay!" One answer to "Why?" and a justification for asking may be counter-intuitive: people may wonder about being asked, but, at the same time, feel respected by being asked. Our feelings are likely to be much stronger than our thoughts in these situations. This is especially likely when we feel vulnerable, as when we or a loved one is ill. Feeling that a clinician respects us is more important than ever. Tone of voice is also critical. If it is perceived as perfunctory, patients and family may feel patronized. For example, when Morreim asked about taking notes, she conveyed that, in some contexts, it can be distancing.

Some approaches used in mediation may seem manipulative. One approach is "priming," which is mentioning a possibility to a person, with the hope that it will linger in the person's mind and will reoccur later, as a new idea. For example, a clinician might "share a thought" with a family member as a surreptitious way to later move that person to support a choice for the patient that the clinician prefers, without the family member fully realizing later why that choice seems appealing. Another approach is "parroting," repeating the last words another says, to indicate paying attention. In an article on mediation in the last issue of *JCE,* Autumn Fiester suggests that repeating another person's words solely for the purpose of gaining the person's trust is disingenuous, and might rightly be viewed by the other person as an expression of condescension.[26]

There are, however, ways to employ these techniques that will help patients and family. For example, Morreim reports that she primed Henry's parents early on, when she mentioned it might be possible for him to receive a treatment on a trial basis, on the condition it be discontinued without argument if it became clear that it didn't help him.

Clinicians also can share early on in a mediation, as Morreim did, that they won't favor one or another position, but if they have an idea that no one has thought of, they will share it, and that, if they didn't do so, they would be letting the patient and family down. This allows clinicians who have ethics expertise the opportunity to share it. But, should they share their expertise, they must distinguish, ever so carefully, between an insight that others hadn't considered and their own moral views. Morreim's suggestion of a time-limited trial of treatment became the key to finding a good outcome for baby Henry. She would have failed him if she had thought of it, but did not mention it.

CONCLUSION

In her article, Guidry-Grimes may quite radically alter previous ethical thinking. She predominantly uses logic to do this, but she models two other strategies. First, she notes that Ms D's partner's feelings

are strong and deeply intimate, and thus exceptionally important "as is." If other clinicians similarly recognize when the strong and deep feelings of patients and families warrant moral weight, in and of themselves, they will be following Guidry-Grimes's courageous example. Second, Guidry-Grimes saw how Ms D's partner may have differed from all others who made the same request. Seeing this, she considered what about him and his request was distinct from all of the others. Clinicians can likewise use her analysis to consider their own cases.

In her article, Morreim spells out several mediation-based approaches clinicians can use. The commitment she brings to these efforts mustn't be missed, since it may be essential in using the approaches successfully. Morreim illustrates this commitment when she comments that she will write in the first rather than third person. She does this, she says, because she fears that the latter is too "stiff and artificial." She also illustrates this with baby Henry's parents. She initially asks them if they feel they have been heard, and indicates why she is asking: because families often report they do not feel they have been heard. She implicitly indicates her alliance with Henry's parents by asking about this. Emphatically yes, they reply. No wonder.

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NOTES

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6. Ibid., 53.

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Features

The Effectiveness of Standardized Patient Simulation in Training Hospital Ethics Committees

David Y. Harari and Robert C. Macauley

ABSTRACT

Clinical simulation using standardized patients has become standard in medical education—and is now being incorporated into some graduate programs in bioethics—for both formative and summative evaluation. In most hospitals, though, clinical ethics consultation is done by the ethics committee (or a subset of it). This study is the first, to our knowledge, to examine the effectiveness of standardized patient simulation in training hospital ethics committees to deal with ethically complex and emotionally fraught clinical situations. Following a substantial revision of the institution's nonbeneficial treatment policy, ethics committee members underwent a simulation to determine whether a specific requested treatment should be withheld on the basis of futility. Pre- and post-intervention surveys showed improvement in all domains, although the small sample size limited the power of the study, with only one measure showing a statistically significant difference. An interesting incidental finding was that one-quarter of committee members voted against a determination of futility, even though the case clearly met the definition set forth in the policy. This highlights the emotional challenges in implementing an ethically rigorous, unanimously accepted policy that ultimately determines the timing and manner of a patient's death.

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INTRODUCTION

Clinical ethics consultants and committees are called upon to facilitate the resolution of complex moral dilemmas that arise within the hospital setting.[1] The very nature of clinical ethics thus requires consultants and committee members not only to be skilled in identifying, analyzing, and exploring moral and clinical issues in abstraction, but also equally adept at mediating, negotiating, and facilitating meaningful dialogue between all participants. As such, clinical ethics is a relational discipline that demands proficiency in interpersonal skills and effective means of communication. These interpersonal skills may include elements of active listening, providing clarity, and articulating competing viewpoints, as well as other forms of nonverbal communication. Such skills are now recognized as core competencies by major clinical ethics associations and governing bodies.[2]

One of the most challenging ethical issues—even among highly skilled communicators—is medical futility (alternately known as nonbeneficial treatment). Given that patients in these situations are often critically ill and treatments may carry signifi-

cant burden, the emotional stakes can be extremely high. As a result, toward the end of the 20th century, as Helft, Siegler, and Lantos put it, "the concept of 'medical futility' was debated in the medical community with a vehemence that few philosophical concepts elicit."[3] Eventually the debate waned in the face of competing definitions of "futility,"[4] whether or not a treatment was "futile," and who—physician, administrator, ethics committee member, or the court—was responsible for the determination.[5]

The concept of nonbeneficial treatment has recently returned to the fore out of growing concerns about healthcare expenses,[6] the development of accountable care organizations,[7] and increasing attention to "choosing wisely."[8] For those institutions with a policy on responding to requests for nonbeneficial treatment, the matter of how to institute that policy—and, specifically, how to attend to patients and family members for whom a declaration of futility might literally be a question of life or death—is central.

Simulation has increasingly been used to prepare learners for complex, high-pressure, real-life situations. This is especially true in medical education, in which every respondent in a recent survey of U.S. medical schools reported using simulation at some point in the educational process.[9] Standardized patients (that is, healthy individuals trained to portray the roles of patients, family members, and others in realistic ways[10]) are often used to evaluate the skills of learners in undergraduate and graduate medical education.[11] Beyond assessment, standardized patients (SPs) also offer learners an opportunity to practice communication and interpersonal skills in a controlled environment. This is particularly crucial with regard to complex and emotionally charged issues frequently faced by clinical ethicists, such as advance care planning, physician-assisted dying, and organ donation.[12]

Recently, select graduate programs in bioethics have begun to use simulation to educate their students.[13] While these efforts have been directed toward future clinical ethicists, the majority of U.S. hospitals utilize ethics committees—not all of which have formally trained ethicists—to provide ethics consultations.[14] To our knowledge, there are no published reports on the use of SPs—for all their ubiquity in medical education—in the training of ethics committee members. (The relevant literature is limited to role playing by ethics committee members to gain a better understanding of ethical conflicts engendered by different values and principles.[15]) Given the increasing availability of SPs at academic medical centers, utilizing their talents in training ethics committees at affiliated hospitals would be a logical next step. This article describes the implementation and outcomes of just such a program.

BACKGROUND

In 2013, the University of Vermont Medical Center (a 500-bed academic medical center then known as Fletcher Allen Health Care) approved a new policy regarding nonbeneficial treatment (NBT). The previous policy had only permitted unilateral withdrawing/withholding of requested treatment in situations of "physiologic futility" (that is, when the requested treatment had no chance of achieving the stated goal), and thus was rarely invoked. The need to revise the policy became apparent in the aftermath of an especially troubling case of a patient who spent the last several months of his life in the intensive care unit (ICU).

Long after it became apparent to the care team that the patient would never leave the hospital, the patient's spouse continued to demand maximal treatment based on "the value of one more day." Full treatment accordingly ensued in the form of tracheostomy, mechanical ventilation, and enteral tube feeding. When the patient's bowel function no longer permitted the latter, however, the team reluctantly instituted total parenteral nutrition, based on the patient's wife's demand and in the face of significant risk for infection. The patient's code status was, however, unilaterally changed to DNR (do not resuscitate), since CPR (cardiopulmonary resuscitation) was deemed "physiologically futile" in the face of such overwhelming illness.

The patient eventually experienced cardiac arrest and was pronounced dead. Fortunately, the patient's wife did not follow through with her "threat" to begin chest compressions herself in the absence of the medical team performing CPR. In fact, she subsequently expressed her gratitude for the extent and quality of care provided to her husband. Many staff members, however, were deeply troubled by what they perceived as the suffering endured by the patient in the course leading up to his death, prompting reconsideration of the institution's "futility" policy.

The revised policy broadens the definition of "nonbeneficial" to include treatments that have "no realistic chance of achieving the medical goal of returning the patient to the level of health that permits survival outside of the acute care setting." This revision shifts the paradigm from one of physiologic futility to probabilistic ("no realistic chance") futility, and establishes a minimally acceptable goal (that

is, "survival outside the acute care setting"). The ability to merely prolong life within the ICU no longer qualifies a treatment as beneficial.

The revised policy also delineates a clear procedure for responding to requests for potentially nonbeneficial treatment, including a second opinion; attempted transfer to the care of a willing physician; consultations with clinical ethics, palliative care, social work, and risk management; and attempted transfer of the patient to an institution willing to provide the requested treatment. If these steps fail to overcome the impasse, the final step is a meeting with a five-member *ad hoc* subcommittee of the ethics committee, which will determine whether the requested treatment can be considered "nonbeneficial." If the consensus of the subcommittee is that the treatment is potentially beneficial, clinicians will be required to provide continued treatment. However, if the subcommittee determines that the treatment is nonbeneficial, no clinician in the institution will be permitted to provide that treatment.[16]

Recognizing that the revised policy represents a paradigm shift for the institution—as well as a new responsibility for the ethics committee, which previously has not been involved in NBT discussions—the ethics committee felt it was important to "pilot" the new policy in a context that would allow for personal feedback and fine-tuning of the policy, while also protecting distraught patients and family members from being exposed to a process of trial and error. For these reasons, the decision was made to simulate the process using SPs.

METHODS

A de-identified version of this case was the natural choice to simulate the new NBT policy for the ethics committee. Simulation was provided by the staff of the Clinical Simulation Laboratory, a collaborative effort of the University of Vermont College of Medicine, the University of Vermont College of Nursing and Health Sciences, and the University of Vermont Medical Center. The SPs employed by the Clinical Simulation Laboratory had extensive experience working with learners at several levels (from undergraduate medical and nursing students to attending physicians), but they had never before worked with the University of Vermont Medical Center Ethics Committee. Multiple meetings were required to brief the SPs on the context of the meeting and the respective roles they would be playing (that is, an ICU nurse, a respiratory therapist, and the patient's spouse and sister). A physician who had been involved in treating the patient on whom the scenario was based was enlisted to play that role in the simulation, given the degree of clinical knowledge required.

The ethics committee is made up of 24 members (one-third of whom must be members of the medical staff), divided into preventive and consultative subcommittees. Identical simulations were offered to members of both subcommittees. Members were provided a copy of the revised NBT policy (previously drafted and approved by their committee) as well as a summary of the clinical case. Prior to the simulation, they were also invited to take an anonymous survey of their knowledge of and comfort regarding the procedure of determining whether a treatment was nonbeneficial. (As the survey was anonymous and its primary purpose was to improve the quality of the NBT procedure, the study was determined to be "nonregulated activity" by the University of Vermont Medical Center Institutional Review Board.)

As delineated in the policy, the parties involved in the case (that is, one physician and four SPs) were ushered into the room as soon as the subcommittee members arrived. At the outset of the meeting, the physician reviewed the medical situation, clearly stating that there was "zero chance" that the patient would ever leave the hospital (thus fulfilling the policy definition of "nonbeneficial treatment"). The chair of each ethics subcommittee facilitated further discussion, seeking out the opinions of each of the SPs and allowing for dialogue and additional questions. Over the course of the discussion, it became apparent that some of the nonclinicians were struggling to apply the definitions of the policy to the case at hand, given the emotional anguish clearly communicated by the SPs who were playing the patient's spouse and sister. "One more day with him is enough for me," the SP playing the spouse said.

Some of the subcommittee members who were clinical ethics consultants also struggled with their modified role. For example, one consultant explicitly reassured the patient's spouse that "we're not here to tell you that you can't have these treatments"—a standard statement in the "ethics facilitation model" of ethics consultation[17]—whereas, in point of fact, that was exactly what the committee was tasked with determining. At the conclusion of the conversation, the physician and the SPs left the room to allow the subcommittee to confer and render a decision, as outlined in the policy.

In the week following the simulation, all participants were emailed an anonymous follow-up survey, which included the same seven questions of the pre-survey, as well as additional questions

regarding the quality/impact of the simulation. Free-text comments were also invited.

RESULTS

A total of 17 ethics committee members attended one of the simulations. Interestingly, despite the attending physician's explicit statement regarding zero potential for discharge, approximately three-quarters of the members (in each subcommittee) voted in favor of deeming continued intensive care as "nonbeneficial." The minority who supported continued treatment acknowledged that the treatment met the definition of "nonbeneficial," as stated in the policy (which they had approved in prior committee discussions); however, they questioned whether invoking the policy in this particular instance was worthwhile, given the entreaties of the patient's wife. One committee member went so far as to question whether committee review was even necessary, given the explicit definition put forth in the policy and the risk of raising the family's hopes that their request might yet be granted.

Of the 17 ethics committee members who attended one simulation, 15 completed a pre-survey and eight completed a post-survey. The survey responses were compared using independent samples *t*-tests with IBM SPSS Statistics version 22. Paired *t*-tests were not possible because of the anonymous nature of the surveys. The results are presented in table 1.

The post-survey included additional questions. Given the highly clinical nature of the discussion, participants were asked if having a clinical background made it easier to navigate through the dilemma (and, conversely, if not having a clinical background made it harder). Of note, all six clinicians felt their background made it easier, while neither of the nonclinicians responding to the post-survey felt their lack of clinical background made it harder.

The post-survey also asked about the most valuable learning points of the experience. Responses tended to focus on the verisimilitude of the simulation and the skills of the SPs. Representative survey responses included "EXCELLENT acting which brought the intangible feelings of the families into a reality," and "very excellent depiction of strongly held emotional positions." Capturing this sentiment, the physician playing the role of the attending exclaimed immediately upon conclusion of the first simulation: "That woman playing the patient's wife? She was Linda!" (Referring to the name of the actual patient's wife, changed here to protect her privacy.)

The final survey question sought input as to how to improve the educational experience. Suggestions included additional preparatory time to review the process as outlined in the policy, as well as additional time after the simulation to debrief. One participant, noting the importance of skillful facilitation, suggested enlisting an independent party to play this role in an actual meeting so as to allow

TABLE 1. Responses to pre- and post-simulation surveys (*N*=15), on a 7-point Likert scale, from strongly disagree to strongly agree

Statement	Pre-survey average	Post-survey average	*p* value
I have a thorough understanding of the definition of "nonbeneficial treatment."	5.67	6.00	0.50
I have a thorough understanding of the institutional procedures related to determining whether a treatment is nonbeneficial.	4.93	6.25	0.03
I have a deep appreciation for the emotional struggles patients and families face when a treatment they've requested may not be offered.	6.27	6.88	0.15
I have a deep appreciation for the challenges patients and families face in understanding the risks and benefits of certain medical treatments.	6.27	6.75	0.10
I have a strong sense of what the role of the ethics committee is in meeting with families and staff regarding nonbeneficial treatment.	5.60	5.75	0.79
I believe that the process laid out in the new policy is an appropriate and effective way to address requests for potentially nonbeneficial treatment.	5.93	6.00	0.88
I feel equipped to be a member of the *ad hoc* ethics subcommittee tasked with determining whether or not a requested treatment is nonbeneficial.	5.40	6.00	0.29

ethics committee members to focus on the question at hand.

DISCUSSION

The futility movement may have faded in the face of definitional and logistical challenges,[18] but concern regarding nonbeneficial treatment remains, often based on concerns of increased morbidity[19] as well as increased costs.[20] In response to these concerns, the University of Vermont Medical Caner revised its NBT policy, both in terms of definitions and procedures. To identify weaknesses in the process and to prepare the ethics committee for real-life application of the policy, SPs were used to simulate a determination of whether requested treatment could be considered nonbeneficial.

Ethics committee members' understanding, appreciation, and confidence trended upward in every measured domain as a result of the simulation, a finding that was corroborated by the overwhelmingly positive free-text comments (see table 1). The small sample size limited the power of the study, and thus only one element ("I have a thorough understanding of the institutional procedures related to determining whether a treatment is nonbeneficial") demonstrated statistically significant improvement. The very high pre-survey scores on most of the other elements also limited the range of potential improvement, which may help explain the lack of statistical significance for those questions.

The surveys also identified areas of potential improvement. The simulation format was new to many participants, and the verisimilitude of the simulation might have been intimidating compared to traditional round table discussions. This would explain the requests for additional opportunity to prepare and debrief, which in this case were limited by scheduling constraints. Given the complexity of the clinical context and the emotional angst displayed by the SPs, one respondent aptly identified the need for a skillful facilitator, especially one who was not involved in the committee deliberation. This idea had not arisen in the extensive discussions of the policy revision, but will be seriously considered when the policy is re-evaluated.

The fact that clinicians felt their background was helpful and nonclinicians did not feel at a disadvantage may reflect the thoroughness of preparation for the discussion and the understandability of the clinical summary provided by the physician at the outset. One might also wonder whether the aspects of their background that the clinicians felt were helpful might not be unique to physicians and nurses. Perhaps it was their experience grappling with challenging issues or managing complex emotions that was most helpful, and the nonclinicians in the group (social workers and patient advocates among them) were equally familiar with these experiences, albeit from a different vantage point. Alternatively, one might also wonder if denial or rationalization played some role, especially given the complexity of the clinical case and that the fact that the ethics committee's charter requires that one-third of the members belong to the hospital medical staff.

Perhaps the most interesting finding of the study was that after extensive discussion by the ethics committee of the proposed (and, subsequently, adopted) policy revision—as well as thorough preparation of the ethics committee for the simulation—one-quarter of the participants were unwilling to categorize the treatment in question as "nonbeneficial," even though it clearly met the definition as put forth in the policy. (And, thus, from a technical perspective, the question before the ethics committee was rather simple to answer.) Some might therefore criticize the case chosen for the exercise as being too cut and dry, given that it so explicitly fulfilled the policy's definition of "nonbeneficial treatment." However, that was the primary reason this case was chosen, not merely because it was the paradigmatic real-life case that led to the reformulation of the policy itself. Committee members need to not only thoughtfully listen to the concerns of family members and staff, but also be willing—should the circumstances justify it—to make the extremely difficult decision to refuse to provide a requested treatment. Members would likely benefit from a subsequent simulation that directly addresses the question of whether a treatment meets the definition of "nonbeneficial," but the initial session focused on whether they were prepared—in the face of profound personal and emotional implications for the patient and his family—to authorize withholding life-sustaining treatment.

That one-quarter of the ethics committee members voted against withholding treatment that they freely admitted met the definition of "nonbeneficial" highlights the profoundly human aspect of the deliberations. This is reminiscent of the opening scene in the movie *WarGames,*[21] in which a pair of U.S. Air Force officers receive a properly formatted order to launch a missile armed with a thermonuclear device. While the lieutenant is willing to "turn the key" to launch the missile, the captain is hesitant to do so in the face of such loss of life, demanding additional evidence that a mistake hasn't been made. An impassioned discussion follows about the need to follow pre-established procedures, prompting the

captain to explain, "Screw the procedure, I want somebody on the g*****n phone before I kill 20 million people!"

The scene concludes with the lieutenant pointing a gun at his superior and speaking in a clearly threatening tone: "Turn your key, sir."

The scene reflects the underlying truth that it is one thing to ratify a policy that could conceivably lead to even one human death (let alone 20 million); it is quite another to put that policy into practice, especially when confronted with the actual people your decision will affect. The simulated case underscores the human element that is inherent in a determination of whether a treatment is nonbeneficial, which plays just as important a role as a thoughtfully crafted definition. (And which may be another reason for the "fall of the futility movement,"[22] for all its rational analysis.) Certainly, one could sensibly disagree on ethical grounds with the revised policy, but the fact that the same people who voted against applying the policy had earlier participated in crafting it—and had voted unanimously to adopt it—suggests that the basis of the disagreement was primarily emotional, rather than ethical.

This, in turn, raises the deeper question of the necessity—or even utility—of involving an ethics committee in the process. At least for the simulated case, the outcome should have been clear prior to any deliberations, based on the medical opinions of the attending physician and consultant and the definition of "nonbeneficial" outlined in the policy. One might reasonably argue that a checklist composed of required steps would be more efficient in adjudicating a determination of "nonbeneficial treatment," in much the same way that the U.S. Air Force, in the movie *WarGames*, fully automated its missile silos after noting the extent of human hesitation to initiate thermonuclear war.

On the other hand, human involvement may provide an essential check on the use of the "nonbeneficial" checklist, which otherwise might become a one-size-fits-all process. Just because a treatment is deemed "nonbeneficial" doesn't mean it is in the best interest of the patient, family, or medical team to limit it. In *WarGames,* the Air Force opts to automate missile launch to prevent any possible human interference; but later, when the controlling software is hacked, the program comes terrifyingly close to automatically initiating nuclear war. Amid the complexities of the futility debate, we should never lose sight of the injunction, "first, do no harm."

The final point to be made has to do with the feedback loop between education and training on the one hand, and quality improvement on the other. While the primary purpose of this simulation was to prepare ethics committee members to effectively implement the new NBT policy, the results of the study identified areas in which the policy itself could be improved. Specifically, additional time for preparation and debriefing should be built into the process, and consideration should be given to using an independent, skilled facilitator. This would allow every ethics committee member to focus on the deliberations—rather than the designated chair having to attend to group process—and also ensure that the meeting fully attends to the needs of any family members who are present. The findings of the study suggest not only additional factors in implementation of the policy, but also the potential for improvement of the policy itself through thoughtful modification.

The limitations of this study include its power, since the respondents by definition had to be members of the ethics committee. Consequently, while all seven questions showed increasing trends following the simulation, only one was statistically significant. In addition, the generalizability of the study is limited because it involved the ethics committee of only one institution, applying a very particular policy that may not reflect the culture or philosophy of other institutions.

Nevertheless, this study suggests that the novel use of standardized patients in the education of ethics committees can be practical and beneficial. With the increased utilization of SPs in both undergraduate and graduate medical education, ethics committees will increasingly have access to this unique educational resource. Further investigation is necessary to evaluate the generalizability of this method to other institutions and settings, and to identify areas beyond questions of nonbeneficial treatment (such as families who refuse to accept a diagnosis of brain death, or cling tenaciously to the possibility of a miracle), in which clinical simulation might prove valuable.

MASKING OF THE CASE

Details of this case have been altered to protect the patient and family.

NOTES

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16. There are several reasons for this institutional prohibition on another clinician providing the requested treatment. First, transfer of care to another physician is a much smoother and less contentious solution to the clinical impasse, and should have occurred long before an ethics committee review. (Indeed, the stepwise process requires prior thorough exploration of transfer to another clinician, and thus the question of whether such a transfer is even possible should be moot by the time the ethics committee becomes involved.) Second, failure to extend the restriction on providing treatment deemed after such extensive review to be nonbeneficial risks indefinitely prolonging the process by not providing definitive closure, thus rendering a futility policy itself "futile." Lastly, there are established precedents for such an institution-wide restriction. "Model policy on non-beneficial treatment," *http://www.thaddeuspope.com/images/Model_Policy_ on_Non-beneficial_Treatment_San_Diego_County_Medical_Society.pdf.*

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Clinical Recommendations in Medical Practice: A Proposed Framework to Reduce Bias and Improve the Quality of Medical Decisions

David Alfandre

ABSTRACT

Patients rely on, benefit from, and are strongly influenced by physicians' recommendations. In spite of the centrality and importance of physicians' recommendations to clinical care, there is only a scant literature describing the conceptual process of forming a clinical recommendation, and no discrete professional standards for making individual clinical recommendations. Evidence-based medicine and shared decision making together are intended to improve medical decision making, but there has been limited attention to how a recommendation is discretely formulated from either of those processes or how patients' preferences ought to be considered and how much weight they should hold. Moreover, physicians' bias has been reported to strongly influence how a recommendation is derived, thereby undermining the quality of healthcare decisions and patients' trust. To demonstrate a potential for improving the quality of decisions, this article proposes a conceptual framework for how physicians should reach a clinical recommendation and apply the process in practice. For preference-sensitive clinical decisions—that is, clinical decisions when patients' values and preferences are relevant—the process for reaching a recommendation should be transparent to patients and should be based solely on the medical evidence and patients' values and preferences. When patients' preferences for care do not prioritize health, physicians decide whether their recommendation will prioritize a welfare-enhancing versus an autonomy-enhancing approach. When there are gaps in understanding how physicians derive their clinical recommendations and how to further improve the quality of the decisions, the author calls for further empiric research.

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INTRODUCTION

Consider two clinically similar patients under your care. Both are 78 years old with New York Heart Association Class IV congestive heart failure (CHF). Both are medically well managed, not depressed, and live with supportive families. Their physical exams, lab work, medications, and prognoses are similar. One tells you she wishes for continued medical treatment and hospitalization, as needed. She also wonders if an automated implanted cardiac defibrillator is appropriate for her. The other patient finds her quality of life to be poor and wishes to have symptomatic management of her shortness of breath, but she does not wish to return to the hospital for further management of her CHF exacerbations; she wants to spend the rest of her limited time comfortable and with her family. Both patients ask for your recommendation about their care. What factors are relevant to making a recommendation? Should your

recommendations be different because the patients' preferences are different? And if patients' preferences are the determining factor in this case, when should they be determining factors in making clinical recommendations?

A physician's clinical recommendation is central to medical practice and to the physician-patient relationship. Patients expect and depend on a physician's guidance and recommendations to help them to understand their medical issues and make good choices about their care.[1] When patients are faced with medical complexity and multiple options, recommendations can help them manage uncertainty. In some cases, patients' cognitive biases can lead them to ask for or to decline a recommended treatment that isn't consistent with their values.[2] A physician's recommendation can strongly counteract this by influencing patients to consider other options.[3] It has long been held in medicine and ethics that simply leaving a patient to choose from a list of medical options without a recommendation or guidance is a relinquishment of a physician's obligation of non-abandonment.[4] While there is no widely accepted definition of a clinical recommendation in the literature, it will be defined here as the part of a clinical encounter that responds to a specific clinical question and is an explicit statement[5] by a healthcare professional about which course of action should be taken, why it is beneficial, and the reasons that support it.

In spite of the centrality and importance of recommendations to clinical care and their ability to strongly influence patients, there are no clear professional standards on making clinical recommendations and only scant literature describing the specific conceptual process of coming to a clinical recommendation.[6] How a recommendation would fit into a model of "decision quality," which is defined as how well a healthcare decision is informed and how well it reflects a patient's preferences and values,[7] has not been elucidated. Evidence-based medicine and shared decision making together are intended to improve medical decision making, but there has been limited attention on how a recommendation is discretely formulated from either of those processes or how patients' preferences ought to be considered, and how much weight they should be accorded. These considerations are particularly important given the known sources of physicians' bias, that can influence their recommendations and that have the potential to undermine patients' trust in the healthcare system and in the quality of the services it provides. Although financial conflicts of interest have long been recognized as having a potentially problematic biasing effect on physicians' recommendations,[8] other nonclinical factors—including physicians' personal values,[9] medical specialty,[10] patients' race,[11] geographic area,[12] and undue consideration of socio-economic factors[13]—have all been reported to adversely affect physicians' recommendations.[14]

In this article I propose a conceptual framework for how physicians formulate clinical recommendations and apply them in practice. Having a framework for recommendations permits basic standardization to inform further research to describe and analyze this aspect of care, as well as to guide education and training efforts. I propose that for preference-sensitive clinical decisions—that is, decisions about treatment options when patients' values and preferences are relevant—the process for reaching a clinical recommendation should be transparent to patients, and the recommendation should be based solely on a combination of medical evidence, clinical experience, and patients' values and preferences. This article will apply this clinical recommendation model to a variety of clinical scenarios to illustrate its potential value for improving the quality of physicians' decisions.

SHARED DECISION MAKING

The process by which patients and physicians discuss healthcare decisions has changed considerably in the last 50 years, moving towards the empowerment of patients and patient-centeredness and away from paternalism. Patient-centered care has been described in a report by the Institute of Medicine, *Crossing the Quality Chasm,* as one of six crucial elements to ensure the overall quality of healthcare. "Quality" is defined as "providing care that respects and recognizes patients' values and preferences and ensures that those preferences guide all decision making,"[15] to be accomplished through a process of shared decision making (SDM).[16] This practice, for which there is widespread ethical and professional consensus, is the process of physicians and patients making healthcare decisions together by combining the physicians' experience, expertise, and knowledge of medical evidence with patients' values, needs, and preferences for care. Although SDM is used as a catch-all term for decisions about patients' care that are preference-sensitive,[17] there are a variety of ways that patients' individual preferences can affect a recommendation, even for the same clinical decision. For example, for many patients, the choice of delivering general anesthesia by endotracheal tube intubation versus laryngeal

mask airway may not be relevant or important. To a professional opera singer who values reducing her risk of laryngeal side-effects and complications, however, such a decision is likely to be preference-sensitive, that is, it is not value-neutral, and a decision that would benefit from SDM.

For preference-sensitive decisions, patients and physicians should engage in SDM discussions that identify the specific clinical problem, gauge patients' preferences for involvement in the decision-making process, elicit patients' values and preferences for care, and then identify a range of medically appropriate options for management of that clinical problem. Together, physicians and patients decide which of those medically appropriate options might be best, based on the medical evidence in the context of the patients' articulated values. Ideally, this process promotes patients' trust by making explicit how decisions are made and can therefore provide the basis for improving the quality of the decisions made.

On what, then, should a clinical recommendation be explicitly based? The process of SDM that leads to a recommendation draws from two critical sources: (1) the medical facts and evidence base, and (2) patients' values and preferences for care. While there is widespread consensus that both are important to SDM, there is limited clarity on how to incorporate both of them into a recommendation and how to weight each element, particularly when patients' values and preferences regarding care are in conflict with best medical practice.

CONCEPTUALIZING THE RECOMMENDATION

Forming a recommendation based solely on the medical evidence without attention to patients' preferences risks not promoting an individualized treatment plan,[18] may prioritize physicians' values of promoting health, and may be considered a medical error.[19] The general recommendations provided by clinical and professional societies are guideline statements that do not necessarily incorporate patients' preferences in their development,[20] and physicians who make recommendations that are concurrent with guidelines but do not individualize treatment to the patient are at risk of not appropriately contextualizing care.[21]

Care that is individualized to patients' values and needs is associated with improved outcomes and better patient-centered care.[22] For example, with multiple medication options, the same specific medication recommendation for all patients without regard for their individual preferences regarding effectiveness, risk/benefit profile, side-effects, cost, oral regimen, and timing, does not individualize care because patients' preferences surrounding these factors vary.[23] Patient-centered care considers patients' other articulated priorities and life goals, which can only be done if those values and preferences are elicited and there is an attempt to incorporate them into the medical recommendation.

Alternatively, when patients' preferences and values are the only elements used to form a clinical recommendation, medical expertise and clinical experience are unreasonably and unprofessionally marginalized. Professional commitments to provide care in accord with generally accepted standards of medical practice cannot be routinely abandoned in an attempt to single-mindedly adhere to patients' preferences. Physicians provide the specific medical knowledge and expertise that patients both lack and need. To provide treatment that is consistent with professional standards, patients' preferences cannot be the only considerations in forming a clinical recommendation.

The application of the SDM framework to common clinical decisions is already recognized as a way to promote patient-centered care. For example, for a 46-year-old woman without breast cancer risk factors, a clinical recommendation to have an annual mammogram will depend on both the clinical practice guidelines and the patient's preferences and values about the various risks and benefits of either having or forgoing screening. In these clinical decisions, there is reasonable medical debate about which option is best for an individual patient. When patients have varying levels of risk tolerance with regards to missing a cancer or potentially unnecessary exposure to radiation, the recommendation will depend in part on eliciting and understanding the patients' values and preferences. The same principles are operative in recommending prostate-specific antigen (PSA) screening, in that there is reasonable clinical uncertainty about the appropriate choice, because any recommendation should depend, in part, on patients' values and preferences, so the recommendation should reflect, among other medical details, patients' preferences for either detecting cancer early or avoiding potential diagnostic and treatment morbidity.

The benefit and relevance of making clinical recommendations as a part of SDM do not just apply in situations of clinical uncertainty, that is, when there are medically equal alternatives. Recommendations are useful when a clinical decision must be sensitive to patients' preferences and values. How should physicians make recommendations when the

medical options that are available to patients are not medically equivalent?

When promoting health is the primary goal for the physician and patient, recommendations are less likely to be in conflict. For example, recommending an appendectomy for life-threatening acute appendicitis is usually a straightforward decision, because the physician and patient implicitly agree that lifesaving therapy is desired, and the patient values health promotion to the same degree as the physician. But when promoting health and promoting a patient's other identified goals do not overlap, the physician faces a dilemma. Should the physician base a recommendation strictly on what is in the patient's medical best interests (that is, what promotes the patient's health)? Or should a physician tailor the recommendations to the patient's preferences, even when those preferences result in a medical option that does not maximally promote health? Fundamentally, this illustrates an ethical dilemma about the appropriate goals of medicine, a topic that is beyond the scope of this article. The remaining challenge for physicians is to recognize that, in such circumstances, whatever recommendation is provided, it will either prioritize the patient's welfare or enhance the patient's autonomy to pursue his or her own identified goals. How physicians navigate such decisions has not been assessed empirically, nor have patients' perspectives been evaluated.

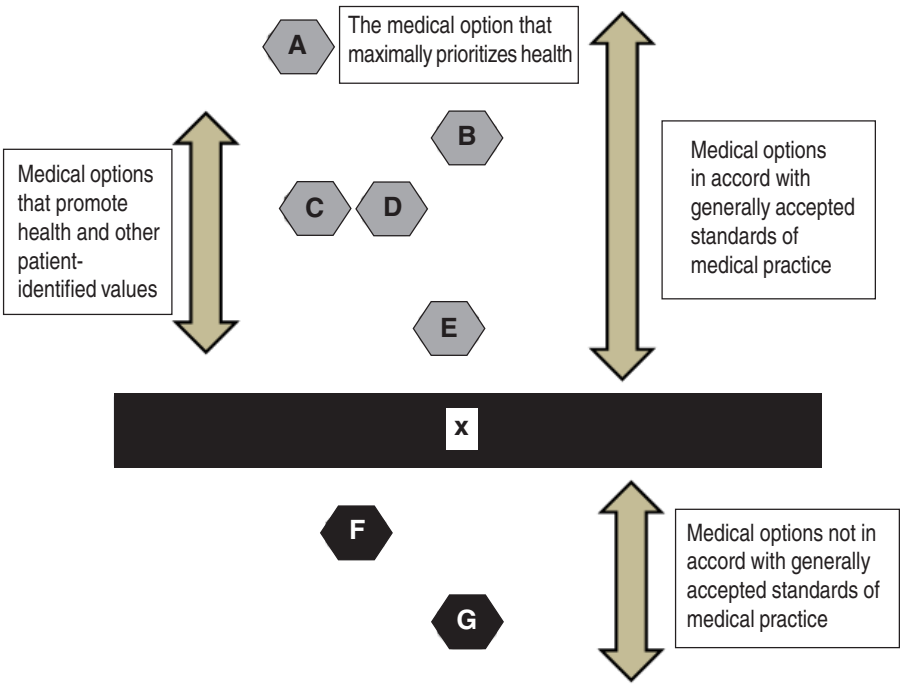
Figure 1 graphically represents the options available to physicians when making recommendations. In the figure, all of the acceptable medical options that are in accord with generally accepted standards of medical practice are placed above a theoretical "bar," labeled X. Note that there is not simply one option above the bar but many, as good medical care is rarely limited to a single choice.[24] This bar is also the "floor" beneath which a physician would be justified in not offering a certain treatment or procedure as an option (points F and G), as they are considered inconsistent with generally accepted medical standards, and would not be recommended by a physician regardless of a patient's values and preferences for care; for example, surgery without sufficient anesthesia, or treatment with warfarin without any expectation of subsequent monitoring.

As part of SDM, physicians elicit patients' relevant preferences and values about care. Assuming that the physician accurately elicits a patient's preferences, a patient might choose to make reasonable trade-offs between maximizing a health outcome and pursuing another identified life goal or value. If a patient's values translate to medical options that have been determined by the physician to be above the bar (points B through E) but not the highest point (point A), the physician can provide the medical options as being acceptable options.

While all of the options above the bar may be medically acceptable, they are not all equal, because the option at the highest point (A) prioritizes health more than any other option above the bar. It may be that two alternatives are medically equal, which would be depicted in the model as being at the same level above the bar (points C and D). Physicians could choose to recommend any medical option that is above the bar, because they are all medically acceptable, even if not medically ideal (that is, they may promote the patient's health to varying degrees).

Here is another clinical example to illustrate this process. As a physician, you are caring for a 54-year-old woman with hypertension who was admitted to

Figure 1. The range of medical options for clinical recommedations.



the hospital for unilobar pneumonia three days ago. On your morning rounds, she is afebrile, but her respiratory rate is 20 and her pulse oximetry is 91 percent on room air. Based on your assessment, you suggest that an additional day of hospitalization is medically ideal to safely monitor her respiratory status and prevent readmission. A longer discussion ensues when the patient reports that she is feeling much better since admission, and that she has to attend to a series of important work and personal obligations. She says that if her immediate health is a concern, she is willing to follow up promptly as an outpatient with her primary care physician. The patient knows she has the right to leave the hospital, but she asks for your recommendation.

Applying the model in figure 1 helps avoid conceptualizing this decision as a simple dichotomous choice by the patient between acceptable and unacceptable care, and which does not facilitate SDM. The recommendation derived from the SDM process is the one based on the patient's values and preferences that is also within the range of acceptable medical options. In this case, the patient initiated a negotiation for an expanded number of potentially medically acceptable options (points B through E) by suggesting she leave the hospital, but with close outpatient follow up. This option promotes her interests in pursuing her work and personal obligations and promotes her health, albeit to a lesser degree. Should you consider this option medically reasonable (an option above point X), even if not medically optimal, your recommendation would depend on whether you decide to prioritize the patient's autonomy or welfare.

How physicians make these distinctions, on what criteria, or how they deem a patient's treatment goals as legitimate or not has not been systematically studied. When physicians believe that their recommendations are tacit endorsements of patients' unhealthy behavior and choices, they may be unwilling to recommend a care plan that does anything less than prioritize the promotion of health (that is, any point below A in the model).

This highlights similar clinical challenges that are seen when advocating for harm reduction in substance use, such as promoting clean needles for an intravenous (IV) drug user. While recommending that a substance-abusing patient stop using all IV drugs is often the most medically ideal option, physicians may recognize the benefit of providing clean needles to patients who are unable or unwilling to stop using IV drugs, and who will not conclude that this option is an endorsement of illegal drug use.[25] Although the outcome data indicate that, in general, harm-reduction programs are more effective than abstinence-only programs for reducing the harmful health effects of substance-use-related behaviors,[26] reluctance or opposition to harm reduction as a medically appropriate approach still persists (although it varies by the specific harm-reduction strategy employed and the type of service provided).[27] How physicians view the principles of harm reduction for other medical decisions and behaviors and their potential impact on clinical recommendations has not been systematically studied.

To demonstrate the potentially definitive role of patients' preferences, it is instructive to return to the patient described in the introduction who does not wish to pursue further curative therapy. She understands this option as hospice care and that choosing it may hasten her death. Because both standard and hospice care are medically acceptable (that is, above point X in the model), the final decision to pursue either one of the options would rest on the patient's articulated preferences. This example demonstrates when a patient's preferences are determinative for a recommendation. In this case, her preferences, even though they do not prioritize health and longevity, would still be considered to be legitimate, primarily because hospice care is considered to be an appropriate goal of medicine.

Implementing this SDM process with discrete recommendations may be perceived by some as impractical for every clinical decision. Decision aids have been designed to practically assist with SDM, but, in addition, transparency can streamline this process. Once a patient's general values and preferences are known for care and there is a relatively consistent history of past decisions conforming to them, physicians can use them as a template for making subsequent recommendations. Of course, these assumptions may need to be challenged as conditions change, but the basis for them remains the same.

CONCLUSIONS

Patients rely on and benefit from physicians' recommendations. Promoting a transparent process for making clinical recommendations has the potential to improve the quality of healthcare. For preference-sensitive decisions as a part of SDM, physicians' recommendations should be based on patients' values and preferences, as well as on the medical evidence. When patients' preferences for care do not prioritize health, physicians decide whether their recommendation will prioritize a welfare-enhancing versus an autonomy-enhancing approach. Although this

article has outlined the conceptual basis for understanding how recommendations are made, further research examining the empiric elements of recommendations is needed to further improve the quality of healthcare decision making.

DISCLOSURES

The views expressed in this article are those of the author and do not necessarily reflect the U.S. Department of Veterans Affairs or the Veterans Health Administration National Center for Ethics in Health Care. The author has no conflicts of interest to disclose.

NOTES

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The Role of Communication and Interpersonal Skills in Clinical Ethics Consultation: The Need for a Competency in Advanced Ethics Facilitation

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ABSTRACT

Clinical ethics consultants (CECs) often face some of the most difficult communication and interpersonal challenges that occur in hospitals, involving stressed stakeholders who express, with strong emotions, their preferences and concerns in situations of personal crisis and loss. In this article we will give examples of how much of the important work that ethics consultants perform in addressing clinical ethics conflicts is incompletely conceived and explained in the American Society of Bioethics and Humanities *Core Competencies for Healthcare Ethics Consultation* and the clinical ethics literature.

The work to which we refer is best conceptualized as a specialized type of interviewing, in which the emotional barriers of patients and their families or surrogates can be identified and addressed in light of relevant ethical obligations and values within the context of ethics facilitation.

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INTRODUCTION

Clinical ethics consultants (CECs) often face some of the most difficult communication and interpersonal challenges that occur in hospitals, that involve stressed stakeholders who express, with strong emotions, their preferences and concerns in situations of personal crisis and loss. As Ford and Dudzinski write in their book, *Complex Ethics Consultations: Cases that Haunt Us,* "To be effective, consultants invest themselves in the devastating circumstances of others and attempt to assuage suffering by facilitating critical reflection. Emotions and facts are important to the dynamics of ethics consultation."[1] Much of the work done by clinical ethics consultants in performing a consultation requires becoming deeply involved in the cases as a facilitator and in helping the patient—and more often the patient's surrogate—come to terms with the grief and emotional barriers that impede them in making treatment decisions.[2]

There is plenty of evidence to indicate the frequency and relevance of such concerns. A number

of authors have examined the emotional and moral distress that surrogates and family members experience when they face difficult end-of-life decisions, particularly in the intensive care unit (ICU), which may often result in mental health problems such as anxiety and depression. A survey of 920 family members of ICU patients found that more than two-thirds suffered from anxiety and depression significant enough to potentially affect their capacity to make decisions.[3] Recent research suggests that more than 80 percent of patients' family members who are involved in making decisions for a patient who eventually died in the ICU had a post-traumatic stress type of reaction.[4]

Other empirical studies have found that poor communication skills and a lack of empathy from physicians, particularly in family meetings, can amplify traumatic circumstances and intensify surrogates' psychological disturbance. Curtis and colleagues studied family conferences to identify missed communication and interpersonal opportunities to discuss critically ill intensive-care patients. These missed opportunities fell into three primary categories. The first deficit they identified was not listening and responding to family members. The second lapse was to not acknowledge and address emotions. The third was not pursuing chances to explain key principles of medical ethics and palliative care.[5] The most commonly missed opportunities involved the lack of empathic listening and responsiveness—the psychotherapeutic aspects of clinical ethics facilitation that are necessary to help resolve ethical issues and thereby prevent or lessen the psychosocial burdens that surrogates and family members bear.

These studies support our contention that, in many ethics consultations, strong emotional barriers are present that must often be overcome before value conflicts can be analyzed and resolved. We conjecture that what makes an ethics consultation occasionally "haunt us" is less that the consultant lacked the applicable ethics knowledge, or even adequate process skills to handle the ethical issues, but more that the consultant lacked the ability to deploy the advanced facilitation competencies needed to recognize and manage psychological reactions and coping patterns that interfere with the ability of surrogates to make reasoned choices.

It is concerning that among all of the health professions—nurses, chaplains, and physicians—involved in the care of patients with life-limiting illness and their distraught families and surrogates, ethics consultants alone are not required to receive any clinical training in basic counseling concepts and skills such as active listening, open-ended questioning, empathy, and reflection—among others. Increasingly, the accrediting organizations of the major care professions have established interpersonal and communication skills and professionalism as core competencies that every trainee must satisfactorily demonstrate to graduate from a training program.[6]

It seems self-evident that similar clinical education should not only be available, but be required in ethics consultation training. Curricula should be developed that utilize the evidence-based teaching methods that other healthcare training programs employ to develop these competencies, such as clinical supervision, videotaping and the use of simulated patients, and objective structured clinical examinations to evaluate consultants' ability to relate to patients.[7] While a few innovative clinical ethics programs employ these methods, they should become as foundational as courses in ethical theory and health law are in clinical ethics masters and especially fellowship training.

In this article we will give examples of how much of the important work that ethics consultants perform in addressing clinical ethics conflict is incompletely conceived and explained in the second edition of the American Society for Bioethics and Humanities Task Force's *Core Competencies for Healthcare Ethics Consultation* (hereafter, the ASBH *Core Competencies*)[8] and the clinical ethics literature. The work to which we refer is best conceptualized as a specialized type of interviewing, in which the emotional barriers of patients and families—or surrogates—can be identified and addressed in light of relevant ethical obligations and values within the context of ethics facilitation. Although the ethics consultant need not delve deeply into the precise nature or origin of these psychological barriers, having the advanced skills that are needed to recognize and appreciate the general features of the psychosocial dynamics and coping patterns in particular cases enhances a consultant's ability to manage discussions with greater compassion and insight.

As a way to describe the general outlines of these emotional barriers, we will develop and analyze three model case scenarios. One case involves interactions with patients who have decision-making capacity; two cases involve interactions with surrogates who are acting for patients who lack decision-making capacity. In these cases, we will summarize how specific, advanced ethics facilitation skills and strategies that are based in behavioral health approaches can be employed to help CECs interact helpfully with individuals who are expressing strong

emotions in these situations. Finally, we will describe how our analyses of these cases clarify our conception of advance facilitation in clinical ethics consultation. As a first step, it is necessary to describe more clearly how intertwined values and emotions are in expressing a clinical ethics dilemma.

CLINICAL ETHICAL DILEMMAS AS EXPRESSIONS OF VALUES AND EMOTIONS

A pluralistic setting, of diverse values and moral conflict that are expressed through strong emotional reactions, is a basic feature of contemporary healthcare in the United States. As John Lantos observes, in relation to a difficult ethics case from the neonatal intensive care unit (NICU), "everyone started with a moral intuition, a gut feeling, a sense of what was right and wrong."[9] Although Lantos was referring to the divergence of moral views of healthcare workers, the same is true of all of the participants in a clinical ethics case. Rarely do disputants in a moral conflict have a change of heart or mind by hearing opposing moral positions and arguments.[10]

With no universal basis of moral authority to which to appeal for substantive moral answers,[11] caregivers and patients and their surrogates are left with the tools of communication and negotiation to find common ground in defining treatment goals and making appropriate decisions in individual cases, in light of well-established ethical and legal principles. Such tools reflect both the rise of democratic pluralism and the need for ethics facilitation as the most appropriate approach to ethics consultation,[12] which has been defined as the process skill that helps to resolve "value uncertainty and conflict."[13]

Yet we believe the description of ethics facilitation, as presented in the current professional literature and the ASBH *Core Competencies,* fails to fully capture much of the nature of the interpersonal competencies that are required to deal with the emotional responses at the level of "advanced ethics facilitation."[14] It is not enough to simply understand the process of facilitation; an ethics consultant at the advanced level must possess advanced interpersonal skills in order to engage participants and perform the work of facilitation. Clinical ethics must be seen as an active engagement in patient care by the CEC who performs the work of facilitation in "an interpretive interaction with others in the case."[15]

The specific skills that are most relevant to the focus of this article—that is, addressing the emotional reaction related to a value position in an ethical conflict—are listed under "Interpersonal Skills" in the ASBH *Core Competencies,* and include "listening," "clarifying values," "facilitating understanding of factual information," "identifying and supporting the decision maker," and/or "applying mediation or conflict resolution techniques."[16] Missing from this list is any mention of the core consultation skills that are used to discern and understand, in any depth, the basic psychosocial processes and coping patterns involved in the "doing" of clinical ethics consultations, namely, providing support for and constructively interacting with stressed and distressed participants in the common types of clinical ethics conflicts that involve patients, and more often their families and surrogates, who struggle to make an emotionally difficult, value-laden decision on behalf of the patient.

The emotional difficulty these individuals experience may relate to their perceived personal shortcomings, failed family expectations, troubled relationships, and a myriad of family-system dysfunctions and other emotional influences. In these situations, a CEC must facilitate a decision-making process in which the values and emotions that are expressed are intertwined such that an ethical decision cannot be made apart from, and often not until, the participants' emotional responses to the situation have been given an opportunity to be expressed in active interpersonal interaction. This basic feature of clinical ethics consultation receives no focused attention in the ASBH *Core Competencies,* and, at best, remains implicit and undeveloped in the clinical ethics literature.

For example, Tarzian and colleagues, in an important update on the *Core Competencies,* cite three articles to demonstrate how a distinction between basic and advanced skills means that some ethics consultations "require more expertise in one domain or another."[17] The first article cited by Tarzian and colleagues, written by Autumn Feister, describes the use of an overly simplified approach to ethical problem solving that Feister calls the "principlist paradigm." This paradigm provides only a partial grasp of the ethical issues before a normative assessment is made and a recommendation is presumptively formulated, based on a "set of reductive ethical concerns."[18]

In the case provided by Feister, a young patient who has strong feelings of powerlessness and a sense of being wronged refuses to consent to a have a central venous catheter. The catheter is necessary to provide a lifesaving blood transfusion, that follows several botched attempts to place an intravenous angiocath peripherally. The reductionistic, simplistic ethical answer the ethics consultant gives is that

this patient's autonomy cannot be violated, and he has a right to refuse treatment. Of course that is true. But a CEC who has advanced ethics facilitation skills would attempt to get to the core of the conflict. Instead of simply trying to cajole and convince this patient to consent, the CEC would execute something like what Feister recommends, which includes apologizing for the failed attempts, acknowledging the patient's pain, and trying make amends.

But Feister's thoughtful recommendations are stated in terms of knowledge and process skills only. It is not enough to know what to *do.* The clinical caregiver, whether a CEC or a physician, must be able to know why these recommendations make sense as ways to address a strong emotional reaction and facilitate a beneficial outcome in an interpersonal interaction with the patient. This interaction would be necessary to bring to light the patient's strong emotional reaction, which is a barrier to his accepting lifesaving treatment. If done successfully, advanced ethics facilitation may allow the patient to pursue what seems to be his genuine goal, which is to get better and live. In contrast, when approached from the vantage point of the principlist paradigm, without adequate advanced ethics facilitation, the patient will likely die because of a superficial application of respect for his autonomy. This whole level of skill analysis in discussing advanced ethics facilitation is at best implicit, even in this sophisticated article.

The second example cited by Tarzian and colleagues is from a article by David Adams, which involves a 70-year-old patient who suffered a brain stem infarct following a coronary bypass graft (CABGx6). The thrust of the article is to show how ethics facilitation failed to adequately resolve the conflict between the physician and the medical team, who want to continue treatment, and the patient's family members, who are convinced the patient would not want to be on life supports and endure a diminished quality of life. The author, who was the ethics consultant called to consult on the case, focuses on the lack of defined constraints that would clarify how to balance the competing claims. Yet it is on this basis that Adams claims that the ethics facilitation process failed, and he resorted to encouraging the family to agree to a court-appointed conservator.

But, at the same time, astonishingly, Adams states, "No real effort was made to conduct a meaningful dialogue among the involved parties."[19] Clearly, Adams does not view ethics facilitation as involving a CEC who directly engages the participants in discussion in order to clarify more fully the medical facts of the case, particularly the patient's prognosis, and how they fit with the known wishes of the patient. This is a competency that we would consider basic for a CEC.

Tellingly, the case ended when a wiser physician, who was covering for the physician in charge while he was on holiday, held several family meetings and finally respected the request of the family to extubate the patient, allowing the patient to die. In this article there is no mention of the fact that a CEC with advanced ethics facilitation skills—most crucially the developed interpersonal skills of listening to and acknowledging a family's strong emotional concerns and considering them in relation to the patient's medical condition and prognosis—is what is missing in this case. There is no mention of the fact that when these skills were brought to bear by the second physician, a negotiated resolution to the conflict was reached.

The final case that Tarzian and colleagues reference is presented in an article written by Joseph Kaufert and Thomas Koch.[20] These authors discuss a case that is presented by "two clinicians" to an audience that includes disability advocates. The intent of the article was to show how the case of a patient with ALS (amyotrophic lateral sclerosis), who wanted to be withdrawn from mechanical ventilation and die, was successfully handled. After discussions between the two clinicians (presumably at least one of whom was a physician) and the patient, an agreement was reached to respect the patient's wishes.

The disability advocates attending the conference reacted quite negatively, much to the presenters' surprise. The single case narrative failed to convince the audience that the patient's decision to forgo continued life support and die stemmed from a rich and informed dialogue that was "thick" in terms of demonstrating the patient's authentic goals and wishes. Of course, to accomplish this level of narrative, it was necessary for the clinicians to share the particularities, not just of the clinical reality, but also of the nature of their interpersonal encounter with the patient—which they did not do. For that encounter to truly be successfully completed, the skills of advanced ethics facilitation would be essential. The article instead focused on the conceptual aspects of the case narrative, leaving to one side any discussion of the actual interpersonal interaction that would have been necessary to adequately resolve the case.

In all three articles, there were patients and families who required a CEC (or clinician) with advanced communication and interpersonal skills to interact

with the patient or surrogate about their strong emotional state or reaction, in order to process the pertinent ethical issues—getting valid consent to receive lifesaving treatment in the first case, and finding an ethical basis to withdraw lifesaving treatment in the next two cases. In none of these three examples do we see the importance of advance facilitation skills and competencies adequately defined and demonstrated. Rather, these skills and competencies are the subtext of the articles, and what is discussed are the more abstract, intellectual topics related to facilitation, such as the narrow interpretation of principles, moral constraints, and "thick" versus "thin" patient narratives.

Never do the discussions get to what happened—or what should happen—at the "ground zero" clinical level of direct, interpersonal interaction between a CEC or clinician and patient. Thus, the skills necessary to do advanced ethics facilitation do not receive the attention they deserve. A fundamental characteristic of advanced ethics facilitation, which we develop in this article, is that before a CEC or clinician engages a patient or surrogate in a discussion about value-laden conflict related to medical goals and treatment decisions, it is first necessary to interact at a meaningful level with a patient or surrogate about emotional reactions and concerns.

EXPANDING OUR UNDERSTANDING OF WHAT WE DO IN CLINICAL ETHICS CONSULTATION

Although most experienced ethics consultants would readily acknowledge that such fully integrated core skills pertaining to ethics facilitation are essential to perform consultations, we reiterate that, in our judgment, these skills have not been adequately discussed and developed as advanced ethics facilitation skills within the field of clinical ethics education and practice. One possible exception is the work of George Agich on the role of defense mechanisms in ethics consultation, from which we draw in our own formulation.[21] Agich recognized that a hallmark of challenging cases is not infrequently a characteristic psychological dynamic of the individual patient or surrogate, often embedded in a family dysfunction. This dynamic, which Agich refers to as a defense mechanism, may be an emotional barrier that is limiting the individual's ability to see the ethical issues at stake in the present situation.[22]

Part of the barrier to adequately addressing this area of clinical ethics consultation relates to our tradition of modern dualism, which divides the intellectual activity of ethical analysis from the emotional realities to which those analyses relate.[23] The result has been a division between the theoretical and abstract ways of thinking in relation to the core elements of interpersonal and communication skills.[24] In the field of clinical ethics consultation, skills involving knowledge, analytic reasoning, and process are tacitly prioritized over skills relating to interpersonal communication and interaction with human beings who are expressing strong emotions. While the emerging field of clinical ethics consultation debates the need for cognitive certification examinations,[25] there appears to be less concern that the CECs who are currently performing consultations have skills in what we refer to as advanced facilitation. We contend that deficits in these crucial areas of human interaction are much more likely to negatively affect the outcome of an ethics consultation—and even potentially harm the participants—than gaps in knowledge areas that are often emphasized in the education of CECs, such as ethical theory and philosophical argumentation.

Thus, we need an expanded vocabulary and new sensibilities in clinical ethics consultation that better capture all of what we do. It is crucial for CECs to have an appropriate conceptual understanding of how strong emotional responses function in patients, surrogates, families, and careproviders, and how they affect, and sometimes create, a barrier to decision making that can lead to ethical conflict. It is equally crucial for CECs to be competent in using those skills to actively engage participants in a beneficial dialogue in the clinical setting.

CONNECTING BEHAVIORAL HEALTH THEORY TO CLINICAL ETHICS CONSULTATION

For CECs to acquire these interpersonal skills and the required knowledge base, we propose that CECs must first be familiar with the basics of behavioral health theory and psychological constructs in order to enhance and complement the ASBH *Core Competencies*—specifically, to develop advanced-level ethics facilitation skills.

Although it is clear that CECs play a significant role in how participants in ethics consultation process, express, and act on their emotions in relation to ethical decision making, there is much we need to learn about how the core skills related to ethics facilitation are used to help participants deal with their strong emotions in reaching an acceptable ethical resolution. The skills listed in the ASBH *Core Competencies* notwithstanding, the field of clinical ethics consultation needs a robust explication of how these specialized, core communication and interpersonal skills might be attained at an advanced level,

with input from behavioral health approaches and psychological constructs to guide such preparation. Just as academic philosophy shared its tools with healthcare to help establish theoretical frameworks for approaching challenging healthcare dilemmas, we propose that the field of clinical ethics consultation should draw from behavioral health approaches and psychological concepts to develop a more complete theoretical understanding of interpersonal skills in clinical ethics consultation practice.

Common approaches that seem to be the most clearly related to the day-to-day work of clinical ethics consultation include a blend of (1) solution-focused strategies, (2) crisis intervention, and (3) family-systems theory.[26] Each of these selected approaches will now be briefly summarized. These three approaches have been chosen over more well-known types of formal counseling, such as cognitive-behavioral or psychodynamic, for several reasons. First, they do not require an CEC to subscribe to any particular theoretical understanding of human functioning or the origin of psychosocial dysfunction that could potentially distract or distort the fundamental orientation of a CEC as one of facilitation, not therapy.

Second, these approaches do not require the long periods of training and supervision required for the competent practice of cognitive or psychodynamic psychotherapy; as with the other helping professions discussed below, these three approaches could be taught and learned with a reasonable amount of effort and time.

Third, and most importantly, these three approaches include ideas and techniques that are foundational for all of the helping professions; practitioners in these professions are required to master them because they must deal with distressed human beings. The strategies utilized in these approaches are directed toward elucidating and shifting behaviors or dispositions in particular, short-term clinical situations, rather than altering personality structures or patterns of thought over time. The goal of these approaches is to train a CEC to sit compassionately with a distressed individual or family as a supportive presence for the venting of strong emotions, or the telling of past narratives to the extent that they are impeding the ethical decision-making process in the here and now. These are teachable techniques that are essentially mature relational responses, not complicated psychotherapeutic interventions.

Fourth, each of these approaches is patient-centered, as they foster empathic listening, respectful validation, and a generally hopeful orientation, overall. They help those involved to mobilize internal resources and external supports to resolve the dilemma.

We believe that the most successful CECs either have acquired these abilities through one of three ways: (1) other forms of training such as social work or chaplaincy, (2) informal trial and error, or (3) being simply temperamentally adept at interpersonal interaction. It will be instructive now to provide some initial evidence of how these three approaches might apply to typical clinical ethics cases.

TYPES OF CASES WITH STRONG EMOTIONS

Patients With Decision-Making Capacity

Patients who have decision-making capacity may become the center of an ethics case when they do not make decisions in a manner that is consistent with what appears to be their own prior known wishes or best interests. Once patients demonstrate that they have the capacity to make their own healthcare decisions, the principle of respect for patients' autonomy requires that their preferences be honored—in most cases. This is certainly true in the context of a capacitated patient's right to refuse any and all treatment: this negative right to be left alone is perhaps the closest thing there is to an absolute rule in clinical ethics.

But even in these instances, physicians and other caregivers, including CECs, may not disregard their beneficence-based obligations to interact with patients when a treatment is likely to produce what seems to be a beneficial effect. It is possible that, through sustained conversation, a CEC who utilizes the above approaches can move, or even remove, a powerful emotional obstacle that may be blocking a patient from coming to a new realization about the benefits of the proposed treatment.

Case Scenario 1: Asserting the Right to Make an Unsafe Choice

An 85-year-old patient at high risk for falling due to the progression of Parkinson's disease wants to return to her apartment against medical advice. Her strong preference to return home has created an impasse for her care team, who believe it is dangerous for her to continue to live alone. She has the option of going either to a long-term care facility or of moving in with her adult son, but she insists on returning to her apartment in order to maintain her independence.

Solution-Focused Intervention

The utility of a solution-focused intervention in this case is that the patient may be encouraged to

consider what is possible for her, in a future-oriented sense. Although the CEC should compassionately acknowledge the patient's grief about losing her independence due to disease, the CEC can use solution-focused techniques to help the patient realize that dwelling on what was once possible will not be the most productive response to the impending need to adapt to a new life situation. By redirecting the patient's energies toward the practical needs of the situation, the CEC may help resolve the ethical question. The CEC, by using a solution-focused intervention, can orient the patient toward the basic problems of living that she now faces, such as physical disability that requires additional assistance, and to think about what supports or adaptations can be offered to solve these problems in ways that permit her the most independence.

Crisis Theory

Understanding crisis theory may be helpful in this case because this patient is facing what she may perceive to be a very serious crisis. Losing her independence and moving her residence may represent critical changes that disrupt her emotional stasis in such a significant way that she may be unable to formulate plans or problem solve without assistance. The CEC can empathically engage the patient to move beyond the intense immediate feelings of sadness and anger to consider options that might preserve some of the autonomy and dignity the patient fears is being taken from her.

Family-Systems Theory

A family-systems perspective on the patient's situation may also be helpful. Such a perspective will consider how such changes in residence may especially affect the patient's son and the mother-son relationship, and also affect others who depend on, or are depended upon, by the patient. It is likely that the patient's dilemma is also concerning to her family and friends, for any number of reasons, and understanding how this crisis impacts others may help lead to a richer understanding of what an acceptable resolution should include for this patient. It may also uncover resources of which even the patient is not aware.

Surrogates: Individual Surrogates and Group/Family Surrogates

Many, perhaps most, difficult clinical ethics cases involve patients who lack the capacity to make their own decisions, and thus a CEC's primary interaction may be with surrogates and family members. The reactions of individual surrogates, especially when they are highly distressed over a difficult decision, often reflect dual and even conflicting role expectations. Surrogates are often grieving or in emotional pain because of the serious medical condition of a loved one, yet they are also expected to function as informed, rational decision makers. Thus, their emotional responses may be a function of the tension between their subjective reaction to—and a way to cope with—the patient's illness, versus their role responsibility to objectively act on behalf of the patient's wishes or best interests.

When a strongly felt, personal emotional response precludes a family member from acting appropriately in the role of surrogate, a barrier to decision making and a possibly value-laden conflict arises. When conflicts develop for family members or group surrogates, it is usually the result of differing opinions about the patient's wishes and values or the medical prognosis. Thus they are unable to reach consensus regarding the goals of care for the patient. These differences may pertain to many possible factors within the family-system framework and the individual psychological makeup of individual surrogates.

Case Scenario 2:
Surrogate with a Firm but Erroneous Understanding of the Medical Facts

The patient is a 16-year-old boy who was injured in an ATV (all terrain vehicle) accident and is currently on a ventilator in the ICU. His parents are told he has a very serious, irreversible brain injury and will never regain consciousness. Due to the injury, the patient is kept sedated to prevent a dangerous rise in blood pressure that could kill him. His mother insists that her son "is in there" and that he is trying to wake up. She pleads with the doctors to back off on the sedation to allow her son to show that he can respond to commands. The physicians say that if her request is followed, the patient will be at risk of suffering and even of dying.

Solution-Focused Intervention

In this case, it may be difficult even for a CEC to take a future-oriented stance until the clinical facts of the present situation are adequately understood. Once the patient's loved ones are able to accurately perceive the risks of honoring their request, small goals may be set to allow for some future-oriented thinking, when possible.

Crisis Intervention

The tragic events surrounding a serious and life-altering injury such as this certainly constitute a cri-

sis for the patient, and most urgently for his parents and other loved ones. Here, a crisis approach seems to require the CEC to express a compassionate appreciation of the emotional impact of this devastating situation for this particular family and to be willing to hear the story they tell about why they think their son is trying to wake up.

Family-Systems Theory

While most CECs readily appreciate the magnitude of such a traumatic event in any family, an understanding of family systems can prompt a more robust intervention to attend to the multiple persons affected. Does the patient have siblings? If yes, what is the nature of the relationships between the siblings, parents, and this child, respectively? Are their extended family members or close friends available and able to support the nuclear family? Sometimes during a consult we learn that families are already dealing with multiple crises that are compounded when a health event occurs, and they may require additional support. Such a realization can help a CEC to appreciate the intensity of the emotional reaction.

Even when there is a formally designated surrogate, the cultural pattern of many families is to include all of the key members of the family in making decisions about the patient's plan of care. This becomes problematic when family members see treatment options differently and are guided by strong feelings, usually grounded in their divergent relationships with the patient. These positions are often diametrically opposed, creating a dilemma when healthcare professionals expect that a single individual, for example the "surrogate decision maker," to speak for the patient. This situation is illustrated in the following case example.

Case Scenario 3:
Divisions Within a Family

The patient is Mr. C, a 70-year-old man with four children. His wife and the three children who live in the same city have provided daily care for Mr. C during a long chronic illness. The fourth son, who lives in a distant state and has not visited in years, wants to continue treatment for end-stage heart failure, while Mrs. C and the other siblings want to discontinue treatment according to the patient's wishes. The family is unable to agree on any course.

Unexpressed long-standing feelings of anger, guilt, and resentment among family members may be so powerful that a CEC cannot even have all parties in the same room, much less facilitate a consensus. CECs must be adept in conducting family meetings in such cases and allowing emotions to be vented and validated using the approaches outlined here, with the aim of reaching an ethically justifiable resolution within the consultation procedural process.

Solution-Focused Strategy

In this case, a solution-focused strategy might assist the family in clarifying their goals of care for Mr. C, as well as in clarifying individual goals with regard to the decision-making process. A CEC working from a solution-focused strategy would engage the family stakeholders to help them to see the importance of clarifying care goals and reaching a consensus that reflects the best interests of the patient. From the perspective of this approach, a CEC would engage the patient and family in the "now," rather than on what once was.

Crisis Theory

In this scenario, Mr. C's family experiences crisis on two levels: a medical crisis for the father, and an interpersonal crisis among the family members, because the current medical crisis is the occasion for an intense family disagreement. If the CEC using this approach can define the problem and provide support to the family while encouraging them to examine alternatives, some of the tension may be diffused, allowing the divided group to come together to make plans for the good of the patient.

Family-Systems Theory

It can be useful to have Mr. C's family members define Mr. C's role within the family as part of an ethics consultation, in order to understand the disequilibrium that has been created in the family structure with his present illness and threat of losing their father. By using this approach, the CEC can better understand how the patient fits into the fabric of his family's life, and can open a discussion of the changes that the loved ones are facing in this time of crisis.

It is crucial for a CEC to create a space in which family surrogates can speak and voice their deepest hopes and fears with someone who is able to listen empathically and nonjudgmentally and provide a supportive yet nondirective presence. Many cases can be resolved at this level of discussion once the emotional barriers have been identified and discussed. In all of the scenarios presented above, the CEC seeks resolution within the established ethics

consultation procedural process of finding a way for surrogates to reach agreement with physicians on establishing reasonable goals of care.

This is the initial and most fundamental competency of a CEC, but, in our framework, this is achieved through compassionate interaction and focused communication—what we call advanced facilitation—between the CEC and surrogates. In cases when agreement is not reached even through advanced facilitation, then the CEC must consider the facts of the case in light of well-established ethical principles. The CEC will then be able utilize more traditional ethics consultation competencies to determine how to frame a recommendation that is grounded in ethics knowledge to a physician regarding his or her obligations to the patient. And this may include supporting a physician in setting limits regarding which interventions will be provided.

A truly comprehensive ethics consultation will integrate all of the ASBH *Core Competencies* at a high level of proficiency. As the above scenarios suggest, a CEC's ability to utilize several different behavioral and psychosocial approaches can create a place in which all stakeholders can safely voice painful emotions. We posit that a CEC who can empathically hear these strong emotions and employ approaches like those briefly described here is in the best position to discern and resolve hidden value conflicts.

A SHORT-TERM, TASK-ORIENTED CONCEPTION OF ADVANCED FACILITATION IN CLINICAL ETHICS CONSULTATION

All of the above scenarios reflect common types of communication and interpersonal conflicts that CECs encounter. In such situations, CECs can actively engage individuals in one-on-one dialogue. In groups, CECs can support, assist, and, if possible, make easier the process of making difficult decisions that reflect principled ethical resolutions. Because of the delicate, complex, and extensive psychological and family issues that are encountered in these scenarios, and the CECs' time-limited exposure to them, we should reject the temptation to see CECs as a type of professional therapist or counselor, which would be a clear violation of boundaries. Nonetheless, CECs who deal with these most intractable and difficult ethical issues in the clinical setting, particularly at the end of life, must have advanced facilitation knowledge and skills rooted in established, relevant behavioral health theory.

We propose that we enhance and expand the ASBH *Core Competencies* of clinical ethics consultation in the domains of communication and interpersonal skills that are necessary to perform advanced facilitation by emphasizing the following claim: CECs engage the patient, family surrogate, or family as a whole in a short-term, active dialogue that is a type of task-oriented supportive interaction, and may incorporate the common elements of counseling that are similar to those used in almost all other helping professions in the service of patient-centered care.

In this sense, the work of CECs is continuous with the mission of the entire care team, which is to provide excellent patient care by clarifying and pursuing ethical, patient-centered goals of care. CECs who can use these enhanced communication and expanded interpersonal skills to engage all of the stakeholders in a dialogue, to the degree that they are able to talk about their emotions, may guide the parties involved to an awareness of how their emotions may be related to, or even interfere with, the charge of ethical decision making.

The specific task of the advanced facilitation we propose in this article is for CECs to be competent to support and guide patients and surrogates in parsing out the most salient values that are intertwined with, and often hidden or confused in, the overwhelming emotions that surround serious or life-threatening illness or injury. Once the emotions and values involved have risen to a conscious level and have been clarified in words as much as possible, patients and surrogates—often with the support of CECs—may be able to arrive at a reasonable decision that honors and validates the personal authenticity of the stakeholders' emotions while it accommodates the ethical responsibilities and medical realities at hand. At this point, it is often possible to reach a new consensus or agreement about the goals of care and options for treatment. Regardless, because CECs are able to delve more deeply into the emotions that underlie ethical dilemmas, they are in a stronger position to write an ethics recommendation that affirms the interests of all involved.

CONCLUSION

Value-laden conflicts that are addressed in clinical ethics consultation require CECs to use advanced communication and interpersonal skills to engage in active dialogue with patients—and even more frequently, their surrogates—who are experiencing strong emotions about a difficult clinical ethics decision. Most often it is necessary for CECs to support patients or surrogates in expressing their strong emotions before an ethical decision can be made.

We propose that the support and help provided by CECs in these settings be construed as an advanced ethics facilitation, be taken seriously as an area of inquiry in clinical ethics consultation, and developed as a core skill.

It is troubling that these most basic human skills have not been more widely discussed and identified in the professional and educational literature of a profession that was forged in the integration of ethics and the humanities into biomedicine. Not only must the field of clinical ethics consultation remedy this deficiency, it must also find ways to ensure that trainees are fully competent in these core skills. The first step is to define the range of challenges encountered in ethics facilitation when dealing with strong emotions. Next, we need to show how behavioral approaches can help the field better understand and define the core skills used in active dialogue with participants, and translate them into educational initiatives. This article represents a beginning in this effort and will be developed by the authors in their future work.

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A Case of Attempted Suicide in Huntington's Disease: Ethical and Moral Considerations

Kristin Furfari, Nichole Zehnder, and Jean Abbott

ABSTRACT

A 62-year-old female with Huntington's disease presented after a suicide attempt. Her advance directive stated that she did not want intubation or resuscitation, which her family acknowledged and supported. Despite these directives, she was resuscitated in the emergency department and continued to state that she would attempt suicide again. Her suicidality in the face of a chronic and advancing illness, and her prolonged consistency in her desire to take her own life, left careproviders wondering how to provide ethical, respectful care to this patient.

Tension between the ethical principles of autonomy and beneficence is central in this case. The patient's narrative demonstrated that her suicide was an autonomous decision, free from coercion or disordered thinking from mental illness. Beneficence then would seem to necessitate care aligned with the patient's desire to end her life, which created ethical uneasiness for her family and careproviders.

The case highlights several end-of-life ethical considerations that have received much recent attention. With ongoing discussions about the legalization of aid in dying across the country, caregivers are challenged to understand what beneficence means in people with terminal illnesses who want a say in their death. This case also highlights the profound moral distress of families and careproviders that arises in such ethically challenging scenarios.

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Mrs. J is a 62-year-old female with advanced Huntington's disease who was brought by ambulance after an apparent suicide attempt by overdose. Mrs. J's daughter and son-in-law called 911 when they found her approximately six hours after the overdose, still breathing. Upon arrival to the emergency department (ED), Mrs. J was noted to have decreased respirations and a Glasgow Coma Score of 6. Her daughter arrived shortly after and brought an advance directive (AD) dated five years earlier indicating that Mrs. J did not want intubation or resuscitation. Despite knowing about these directives and supporting them, her family called emergency medical services (EMS), in part because her son-in-law was in law enforcement and felt a duty to call 911.

Mrs. J was intubated, admitted to the intensive care unit, and then extubated after 24 hours of supportive care. Once extubated, psychiatry was consulted due to concern for her continued suicidality. She was placed on a mental health hold to allow

psychiatric assessment, given her high risk for self-harm. Psychiatry determined that she had decision-making capacity and she met criteria for major depression driven by both the biological and psychological impact of her Huntington's disease. Mrs. J declined antidepressant treatment and refused all psychiatric interventions including inpatient psychiatric hospitalization.

An ethics consult was requested based on the question: Should we commit this patient with persistent suicidal ideation against her will for inpatient psychiatric treatment, or do we need to honor her request for discharge despite ongoing suicidal intent?

Additional history, obtained by the primary care team and the ethics consultants, revealed that Mrs. J had been diagnosed with Huntington's disease seven years earlier and had tried various treatments, all of which she stopped due to side-effects. She had developed advanced chorea (involuntary movements) and was no longer able to eat without assistance, ambulate, or perform activities of daily living independently; she rarely left the house due to fear of falling. She had difficulty sleeping, restlessness, weight loss due to inability to swallow, low energy, poor concentration, and memory loss, all attributed to her Huntington's disease. Mrs. J had watched several family members including her father, two sisters, and several aunts suffer through the stages of Huntington's disease. She stated that she believed "it is time to exit stage left," while reporting tremendous grief because "I have lost who I once was and will never get it back." She had no history of previous suicide attempts or self-harm and asked careproviders for "compassion" by letting her leave the hospital to complete her suicide.

It was concluded that, given the chronicity of her suicidal ideation and the lack of any present or new active psychiatric conditions, an involuntary commitment for further evaluation was unlikely to change her thought process and would disrespect and disempower her further. Therefore, the 72-hour mental health hold was not renewed. She declined to remain for a palliative care consultation or to arrange for follow up with a primary physician or neurologist and left the hospital with her daughter.

Mrs. J's obituary was found in the newspaper several weeks later. The assumption that Mrs. J was ultimately successful in completing her suicide left all of the caregivers involved in the case wondering whether the care they had provided had been respectful and appropriate in this ethically challenging situation.

IMPORTANCE

Several ethical considerations are highlighted in this case. Should this patient with suicidal ideation be considered autonomous? What would "beneficence" by healthcare providers look like in the face of this life limiting but not imminently terminal disease that would be expected to cause extreme suffering in subsequent years? How could the healthcare providers reconcile their professional duties with the patient's request for assistance in dying to alleviate suffering? And how should we address our moral distress as caregivers in an ethically ambiguous situation such as this?

DISCUSSION

Prehospital personnel perform lifesaving interventions when summoned to the scene of a patient who is unstable or experiencing an altered mental state. Advance directive documents are advisory and may not be honored if they are unclear—EMS personnel will err on the side of life to resuscitate and stabilize a patient unless there is clear evidence that this is not wanted. Professional guidelines affirm the goal of preserving life, and legal caveats in several states (including Colorado, where this case played out) warn against abetting suicide or actively participating by honoring an advance directive in such an instance.[1] While many states have adopted prehospital do-not-resuscitate (DNR) policies or directives regarding cardiopulmonary resuscitation (CPR) that permit paramedics to withhold unwanted resuscitative measures in cardiac or respiratory arrest, these documents must be signed by a physician and are only indicated for seriously ill or terminal patients. Approximately 33 states also have legislated a physician orders for life-sustaining treatment (POLST-paradigm) order set, which is enacted in the face of a terminal illness expected to cause death within six months. EMS and other careproviders are required to honor state-specific POLST-paradigm orders, which often require that CPR not be initiated.[2]

In the face of a need for emergent action and a lack of knowledge of the details of the medical situation for Mrs. J, however, EMS and ED careproviders would not be expected to honor the wishes expressed in her AD. This is particularly true in the face of a suicide attempt, since the presumption is that suicide attempts are part of a mental illness that itself is potentially treatable.[3] Completed suicide is not that common after an attempt, with one study

indicating a 10 percent suicide completion rate in women following an attempt, in 37 years of follow up.[4] When it is unclear if a patient's decision is truly an autonomous decision, as in a suicide attempt, physicians reasonably argue that the patient's best interest is to restore the patient to a level of functioning in which it is possible to assess autonomy.[5] Mrs. J's scenario was particularly challenging and forced her careproviders to consider how to best care for a patient who "rationally" wished to hasten death, as opposed to a transient, mental illness-based suicidal ideation.

The tension between the ethical principles of beneficence and autonomy is central in this case of a patient whose suicide attempt could be considered and reasonable, given her situation. While beneficence would seem to justify resuscitation in the most common situation of depression and disordered thinking due to mental illness, the most beneficent approach to Mrs. J is more ambiguous, once her narrative is better understood.[6] Mrs. J was able to demonstrate the lack of coercion, lack of mental illness, and the reasoning that underlay her attempt—all aspects that compelled her careproviders to believe that she could express her autonomous values and wishes. For her medical careproviders, it was uncertain whether resuscitating her was beneficent or respectful for a woman who appeared to have documented as much as possible through her note and her AD that she wanted to control her death before she could no longer do so.

The ethical ambiguities and challenges in this case caused significant moral distress for Mrs. J's caregivers. (Ulrich, Hamric, and Grady define "moral distress" as "the inability of a moral agent to act according to his or her core values and perceived obligations due to internal and external constraints."[7]) This case caused moral distress for all involved. The medical careproviders understood that among the primary goals of medicine is relief of suffering and provision of comfort, and they found Mrs. J's narrative compelling. She faced several years of the progressive disability that she had seen in family members, without medical interventions that could alter its course. While it is dangerous for careproviders to judge the quality of life of a patient and to determine what is in her best interest, Mrs. J herself was the one who deemed her situation and her quality of life as unbearable. If she was autonomous and her decision making was not distorted by mental illness, she had the right to refuse unwanted medical interventions. Although this was not possible to determine emergently, agreeing to honor her wish to be discharged felt like abandonment. Mrs. J remained suicidal at discharge and would not accept a referral for primary care, neurology, or palliative care to manage her disease progression and accompany her on her disease course. For the hospital careproviders, this meant that they had not relieved, but rather had exacerbated and prolonged her suffering.

The moral distress also involved the patient and her family. For the patient, failing to control the end of her life as she desired was frustrating, and she expressed this through her anger at waking up in the hospital and her anxiety to leave the moment her 72-hour mental health hold was over. She had not taken enough medication to kill herself, since she was found six hours after her overdose still breathing and responsive to resuscitative measures. This overdose had been the culmination of years of planning, and Mrs. J feared that she was running out of time to physically accomplish her death on her own terms, given the progression of her disease. The family too, upon finding her following her overdose, was left with the difficult decision to call 911 despite knowing her wishes. We can only imagine how this "failed" suicide attempt felt for her daughter, who had participated in fulfilling her mother's "bucket list," and lived with her mother, watching her progressive disability, and knowing how she was suffering.

For the ethics consultants, getting to "doing right" for Mrs. J presented an unresolvable dilemma. To allow Mrs. J to leave when the clock said her mental health hold was over, without the ability to find her a careprovider, garner a support structure for her, or to support her family in their moral distress felt incomplete and inadequate. Balanced against the patient's autonomous and steadfast belief that the future was unacceptable was the inability of the healthcare team to change her future. Beneficence seemed to require some kind of longitudinal professional expertise, multidisciplinary support, and sharing of this painful end-of-life journey. Mrs. J would not accept this, leaving the moral distress of an incomplete resolution to the ethical dilemma.

CONCLUSIONS

Mrs. J deserved and needed a healthcare provider who would travel the road of Huntington's disease with her. She had no previous relationship with such a careprovider. During the several ED visits to stitch up lacerations from falls in the prior two to three years, the ED might have questioned how she was doing with her Huntington's disease and tried

to link her with a continuing care physician. Early palliative care involvement might have been able to support her through this difficult life trajectory and provide spiritual and psychosocial support, as well as symptom control. Physician assistance in dying is not legal in Colorado, but Mrs. J would have been a persuasive person to plead for that right, even though her life expectancy was still measured in years; had she been a resident of Oregon, she would not have qualified as having a "terminal disease" for purposes of their legislation.

In describing the goals of clinical medicine, Matlock and Mandrola recently described the role of careproviders as follows: "The essence of being a caring clinician is working with patients to help them achieve the life they want to lead. That's it. We are consultants in the service of people. We are the experts in medical science, and patients are the experts in what is important to them."[8] For some physicians, this role would extent to facilitating the kind of death that a patient like Mrs. J would want. We have compiled a list of lessons learned from this case, as table 1.

TABLE 1. Lessons learned

- Recognize that moral distress can occur in ethically challenging situations
- Acknowledge the moral distress and get support for families, staff, and caregivers
- Seek the patient's narrative within the disease
- Work with the patient and family to discern what beneficence looks like in their situation
- Explore resources to support the patient and family that are aligned with their goals

MASKING OF THE CASE

Details of this case were masked to protect the identity of the patient and family.

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Mediation

Story of a Mediation in the Clinical Setting

Haavi Morreim

ABSTRACT

Conflicts in the clinical setting can spiral downward with remarkable speed, as parties become ever more incensed and entrenched in their positions. Productive conversations seem unlikely at best. Nevertheless, such situations can sometimes be turned into collaborative problem solving with equally remarkable speed. For this to happen, those providing conflict-resolution services such as mediation need to bring, not just a set of skills, but also some key norms: the process must be voluntary for all; the mediator must abjure giving advice or taking sides, and must honor the privacy of privately offered thoughts.

This article describes a conflict that had reached the point of a hospital's requesting judicial coercion. However, a conflict-resolution process was then initiated that, in the end, led to amicable resolution and mended relationships, obviating the need for court orders. This article describes that conflict and the resolution process in detail, along the way annotating specific strategies that are often highly effective.

The following story is modified to protect privacy, but all the "moving parts" are preserved intact, just as they occurred.

Henry, now five months old, was born "floppy," with little to no muscle tone or reflexes. Although he did not have spinal muscular atrophy—which has a terrible prognosis—he had significant neurological deficits. Henry was gaining weight but he was thin, and although he could move, it was not like a normal child. Mom and Dad took him to their pediatrician, concerned about a somewhat persistent dry cough and also wanting Henry to receive physical therapy and speech therapy to improve his feeding. "Let's get a swallowing study," suggested the pediatrician, "to see how well Henry sends food to his stomach rather than his lungs." In a swallowing study, barium (a contrast agent) is mixed with various kinds of food—thin liquid, thickened liquid, pudding, *et cetera*—and radiographic imaging captures where the food goes as the baby eats.

Henry "failed" at every phase. Per the speech therapist, he had severe dysphagia (difficulty swallowing). Per the pediatrician, it was time to implant a gastrostomy tube (g-tube) surgically, so that Henry could be fed directly into his stomach. Mom, shocked, resisted the idea vigorously. "Maybe in the future, but no! He doesn't need it now!" An argument ensued in which the pediatrician intimated that maybe he would need to call DCS, the Department of Children's Services. The doctor was serious. Henry needed this.

The test had been performed in the hospital and now, several days later, Henry's inpatient care was overseen by a hospitalist—a physician specializing in the general care of hospitalized patients. As the situation spiraled downward with increasing intransigence on all sides, Mom and Dad proposed that they could simply leave AMA—against medical advice. "We'll sign whatever documents are necessary, and then the doctors are 'off the hook' and won't be liable if anything goes wrong."

"No way are you taking this baby out of here!" responded the risk manager, posting two hospital security officers outside Henry's hospital room. In response, Mom and Dad "fired" the hospitalist. That evening at 10:30 p.m. the risk manager phoned the chief of social work at home, asking her to initiate proceedings to obtain a court order for the g-tube.

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The next day I received a phone call from the social worker on Henry's floor.

What follows is a story of what I call "clinical-setting mediation." Not really bioethics mediation or even clinical ethics mediation,[1] but simply a mediation for a fairly commonplace clinical disagreement. As the mediator for this case, I tell the story in the first person because a more formal third-person narrative would seem stiff and artificial.

I like this story, not because it shows a mediator's brilliance, but because it does not. Virtually every move, as events unfolded, was Mediation 101. I think it shows well what mediators often teach: "design the process, then trust the process." As colleagues in clinical ethics reach further into the realm of conflict resolution and mediation, I hope it will be helpful to see what a fairly ordinary clinical mediation looks like, in detail. Here, the story as it developed will be will be offset by smaller type and blank lines, with intermittent discussions about process and method.

As the social worker described the situation to me over the phone, fairly quickly we gravitated toward some sort of conflict-resolution process. Only time would tell whether that would be just an informal conversation or two, or an everyone-at-the-table mediation, or something in between. I proposed that she first reach out to the physicians and then the family. Since the social worker was already familiar to everyone, she would briefly describe to them who I was and what I might offer, and inquire whether they were interested in chatting further with me. I coached the social worker a bit on how I preferred the idea to be presented—particularly, that my role was not to take sides or tell anyone what to do, but just to explore whether they might be interested in some sort of problem-solving conversation.

In the clinical setting, inviting people into a conflict-resolution process is the first and often one of the most important steps. It is the mediator's first opportunity to build trust and set the stage for a productive conversation. I find several guideposts helpful. First, the process must be voluntary for everyone throughout, including this first conversation to hear more about what I have to offer.[2] The goal of conflict resolution in the clinical setting is to explore whether a durable agreement can be forged. "Bullied acquiescence" is rarely durable, as witnessed by the many occasions in which a clinician "got the family to accept a DNR," only to find it repudiated shortly thereafter. Hence, "would you like to talk with this person" is an important beginning.

Second, it was important that the physicians be contacted first. They have a prior and fiduciary relationship with patients and families, however frayed that may be, and it would be impertinent and potentially counterproductive even to appear to "sneak behind the physician's back" via conversations with patients and families before the physicians knew what was afoot.

Third, for logistical reasons, conflict resolution in the clinical setting will almost always be initiated by someone other than the mediator/conflict-resolution person. Mediators don't wander the halls mumbling "anybody wanna mediate?" Rather, someone familiar with this option will think of the idea and reach out. It thus becomes important to help clinical colleagues—whether physicians, social workers, nurses, chaplains, or others—become familiar with what conflict-resolution services do, and do not, offer. A few weeks after the mediation described in this article, I provided an in-service session for that hospital's social workers, to discuss the case and update them on this sort of opportunity.

Later that morning I went to the social worker's office. She managed to reach the pediatrician on the phone, which permitted a helpful, even if brief, conversation. I emphasized that it was not my role to tell anyone what to do, but simply to listen and explore whether there might be room for some problem-solving conversations. I offered no guarantees but indicated that, in my experience, the process is often surprisingly helpful. The pediatrician responded, "oh would you, please?" He felt terrible about how badly things had gone downhill, regretted having mentioned DCS so quickly, and was eager for an opportunity to pull this mess out of the fire. He also seemed glad that there was someone who would have, and take, the time to sit and listen to the family. I was not able to chat with the hospitalist right then, but the social worker had briefly reached her, and she was amenable to the idea. The social worker and I then headed over to Henry's room to chat with his parents, who had expressed eagerness to meet.

I knocked, stuck my head part way into the room, and said hello. A gentleman with them asked, "may we have a moment to pray?" whereupon I nodded "of course" and waited outside in the hall. He was the family's minister and when he emerged I shook his hand, introduced myself and explained my purpose in being there. A warm, gracious person, he liked the idea and suggested that perhaps this family might wish to meet another parishioner up on another floor, since their child had a g-tube inserted about a year earlier. I thanked him for what sounded like a fine idea.

Successful conflict resolution requires building trust at every step. Open minds and a collaborative spirit do not emerge from suspicion and wariness. Here, respect for the pediatrician's important relationship, plus an honest expression of empathy for

the difficult position he'd been in with the family's refusal, helped him to convey how distraught he was, including regrets about his own role in precipitating the situation. Similarly, a chat with the family's pastor was another opportunity to build trust. This was not a sly politician's vote-getting process, but rather a form of transparency that can help to avert potential misimpressions.

The social worker introduced me to the family and departed. I explained that I don't work for the hospital and emphasized that "I'm not here to tell anyone what to do." I did not describe any sort of formulaic process, but rather offered to have a few conversations. I indicated that in situations like these, families often feel as though they have not really been heard, then inquired whether Mom and Dad felt this way. Emphatically yes, they replied. I emphasized that what they say to me in private would remain private, meaning that I would not tell others what they said to me unless they wanted me to.

I asked whether they might at some point be interested in getting together with the two physicians, provided that I would be there as a sort of moderator. Mom and Dad were very amenable to the idea. I also explained that, although technically I am an attorney, I don't practice very actively and that my role would not be to serve as anyone's attorney or advocate. "My job is not to take sides, but just to see if I can help people to have a productive, problem-solving conversation." Most people actually do find common ground in these, I noted.

As above, the emphasis is on voluntariness throughout the process. Pushing often sparks push-back. And trust requires transparency. It would not help for Henry's parents to learn, after the fact from someone else, that I am an attorney, or to make assumptions about how I might use that training. It was likewise important to establish, more generally, that I would not help anyone to press their agenda on anyone else. This stance is what mediators usually refer to as neutrality, impartiality.

Although I was able to say, "I don't work for the hospital,"[3] I recognize that many colleagues who might provide conflict-resolution services such as this could not make such a statement. Still, one can indicate that one is, for example, part of a conflict-resolution service whose independence has been assured by the way the service has been organized. Exact wording depends, of course, on how the service is actually chartered—an important issue that lies beyond the scope of this article.[4]

In addition to the mediator's independence and impartiality, privacy of conversations is also critically important. Indeed, confidentiality has long been one of the cornerstones of mediation and of mediation ethics.[5] Participants need to believe they are safe in telling the truth to the mediator. If Henry's parents were concerned that I would pass along to the doctors whatever they told me, they would likely be very guarded in their communication. Trust would be difficult to build, and I would not likely learn the "back stories"—the underlying events and concerns—that could heavily shape whatever resolution these parents might find acceptable.

Obviously there are some limits on privacy. Patient care decisions must, of course, be written into the medical record. And statements indicating serious intent to harm someone, or acts of child abuse, must be shared. However, generally I don't delve into all these exceptions at the outset unless I see specific reason to. Rattling off such a list would sound too much like a *Miranda* warning—not conducive to building trust. If at some point it seems like someone is about to say something that must be shared, the matter can be discussed at that point. In this case there was no plausible reason for concern.

In addition to fostering trust, the mediator must create a safe and hopeful atmosphere. Here, conveying to everyone the observation that most people, even those deeply enmeshed in conflict, actually find a workable agreement, can promote a note of optimism.

Henry's parents were eager to tell me about their experiences. I asked if it would be okay for me to jot things down as they spoke, so that I wouldn't miss anything important. Fine with them.

Overall, a major problem for the parents was a series of mixed messages. The doctors kept citing aspiration pneumonia as their biggest reason for the g-tube. But Henry had never had pneumonia, not once, so why the rush? Besides that, during the swallowing study, Henry was not in his usual feeding position. And for the last part he was slumped over falling asleep. So why are they so sure the study showed what he really can do? And after the test was done, Mom glimpsed the chest x-rays. She didn't see any river of milk flowing down into his lungs. Not at all. The report said something like "recent viral infection," not "aspiration." Aside from all that, here in the hospital they weren't letting the parents feed Henry at all with the bottle. He was only being fed by an NG (nasogastric) tube. But if it's so dangerous to give him a bottle, then why did the speech therapist give him a bottle right after the study? It made no sense. And then, when the surgery resident came to evaluate Henry, she expressed surprise at placing a g-tube for someone like Henry—she seemed to think it was premature.

The parents also were deeply upset about how they had been treated. The whole thing seemed like one big chain reaction. They were mandated, not asked, what to do. The doctors were looking at the textbooks . . . not at Henry. They had asked the doctors to state, in writing, that Henry would likely die soon without a g-tube. But

the doctors refused to do that. It seemed like they were just trying to avoid responsibility.

Mom and Dad were also worried about surgery. Because Henry still had poor muscle tone, anesthesia carried increased risk. It seemed to them that no one seemed to be taking that risk as seriously as they did. They were quite willing to let Henry have a g-tube when he genuinely needed it. But they were not at all persuaded that this was the time.

Our conversation lasted well over an hour, and the parents expressed gratitude that their concerns were being listened to carefully. I asked whether they were interested in meeting with the doctors to see if something could be worked out. I explained that I would be there, and described a bit more about the process. They were very willing, and I indicated that the social worker would probably help arrange the time and place.

I thanked them and returned to the social worker's office. At that point we were able to phone the hospitalist. The hospitalist, like the pediatrician, regretted very much how the whole situation had spiraled so badly downhill, and was glad for the chance to try to mend things. I then suggested to the social worker that we would need a comfortable conference room, ideally with the capacity to project images from the computer so that, if the occasion arose, we could all look at the swallowing study together. And of course we would need a laptop for the same purpose.

As things worked out, the next day I would meet with the two physicians at 10:30 a.m., followed by a meeting for everyone at 11:00.

Such "premediation" conversations are important for many reasons. They can de-escalate emotions significantly, as each person has the opportunity to be heard and taken seriously. Early conversations also enable the mediator to assemble at least a preliminary map of where the key issues lie, where there might be room for movement, and the points at which the people at the table might need some room for private conversation with the mediator. Mediators in litigation often use "caucuses," shuttling back and forth between the parties to carry messages, and sometimes to "lean" on one person or another to encourage compromise. Such a litigation-flavored approach has little or no place in the clinical setting, yet the opportunity for private conversations can be very important. They provide an opportunity for people to think out loud in a safe place where they will not be criticized, and to try ideas on for size and perhaps adjust their thinking, before an idea or observation is brought back to the common table.[6]

Two other things to note. First, I asked the parents' permission before I began taking notes. Successful conflict resolution requires many distinct micro-interventions, and asking for permission is one of them. It helps to build trust by making clear once again that this process would be entirely voluntary, and that they would be treated with respect.

Second, although this particular situation eventually used a meeting with everyone at the same table, a conflict-resolution process in the clinical setting has no set format. It might be a series of one-to-one conversations, or a series of conversations with variable groupings of people.[7] In this case the best strategy appeared to involve assembling everyone at the same time and place. Given the outlook and demeanor I had seen from each person, the prospects were good for a high-value exchange of information, leading to a reasonable resolution and perhaps rebuilding a relationship between them. That result is usually more likely if people can speak directly to one another, albeit with some assistance and perhaps coaching from the mediator.[8]

The next morning at 10:30 I returned to the social worker's office. The two physicians were there, along with the speech therapist, a college student who was shadowing the social worker, and the director of the social work department. I thanked them for coming and then turned to the student and the head of the department. While very much appreciating their interest and support, I indicated that the sheer number of people in the room can make a difference in a process like this, and it can be helpful if the family do not feel outnumbered. I encouraged them to remain for the rest of this preliminary conversation. They both accepted the idea graciously.

I asked the physicians—particularly the hospitalist, with whom I had only spoken briefly—what their primary concerns were, and we discussed them. I also let them know that, particularly early on, it might seem like the conversation was proceeding awfully slowly. The "method in the madness" of that, I indicated, was to help de-escalate emotions and set the stage for productive problem solving. I noted that, on the basis of yesterday's conversations, the parents seemed to have more flexibility than had been initially evident. After we chatted, I left to have a few minutes with the parents before we gathered in the conference room.

Determining who belongs in the room, particularly when people in conflict will be speaking directly with each other, is an important process question. I did want to include the social worker, whom the parents trusted, and the speech therapist who, like the physicians, would likely have useful information to share. (Little did I realize at the time, the speech therapist would hold something of a "key" that would open the problem-solving phase nicely.) On the other hand, from a process standpoint, the college student would be just an extra person in the room. And the director of social work could add an

aura of authority that the parents might regard as a power move.

Describing a bit of the process in advance—here, that it would start somewhat slowly—exemplified two important tools of mediation. First, it was "managing expectations" so that the physicians would not begin to think this was a waste of time. Second, "start slow to go fast" captures the reality that, when adequate time is used to de-escalate emotions and build trust for the process and for the mediator, people in conflict are usually better able to engage in a problem solving that, once begun, can proceed with remarkable speed. In sum, mediation requires strategy at every point.

I entered Henry's room. His parents had been exploring options and they were eager to tell me. Dad's sister was an emergency medical technician and would be willing to come to their home daily, as part of a program of intensive monitoring. If Henry showed signs of aspirating, they would be willing to consider a g-tube. They recognized that it might one day be necessary. Their main hesitation was whether that day was now.

I then presented an idea for their consideration. "Sometimes," I said, "it can be helpful when people hear things through a different voice. When we talked yesterday I heard about a number of mixed messages you've had. So here's my idea. Suppose I were to start out the session by describing those mixed messages to the doctors. I wouldn't be doing this as your advocate, as you know. But sometimes it can be helpful for people to hear things through someone else's voice. You'd be right there and can put in any additions or corrections, whenever you want. This is totally your call—what do you think?" I reviewed the list of mixed messages I'd heard. They affirmed the list and liked the idea. We left for the conference room, stopping by the social worker's office to gather up the rest of the group.

As noted, "a different voice" was offered as an idea for their consideration, not even as a suggestion. I made it clear I would embrace their decision, whatever it might be. Also of note, this was an idea about process, rather than a suggestion toward the substance of an agreement. As often taught in "Mediation 101," the mediator is the guardian of the process. We are not there to dictate the outcome, but we do bring skills to guide the process as effectively as we can.

As we got to the conference room I realized I'd left my laptop in the patient's room. The hospitalist offered to come with me, as her badge would allow us expedient passage through otherwise closed areas. We chatted en route, and I asked her whether time-limited trials were ever an option in a situation like this. She indicated that, under certain conditions, that might be a possibility.

The exact wording of such a question is important. I did not say "have you thought about a time-limited trial?" That would have been at best a suggestion, at worst an implied criticism. Rather, it was framed as an inquiry of genuine curiosity—a request to be educated. Overall, mediation in the clinical setting needs to be facilitative rather than evaluative: assist people to come to their own resolution, rather than suggest to them the outcome the mediator considers most reasonable. Otherwise, in these highly contentious situations, the mediator becomes "just another pair of fists in the fight"—not helpful for maximizing the likelihood that people in conflict will reach an agreement they genuinely embrace and will honor. At the same time, this question was a form of "priming." Priming involves quietly introducing concepts that can predispose parties to think, or at least consider, moving in certain directions.[9] It can place on the table an idea that otherwise might not be there. Parties are free to do with it as they please.

We fetched the laptop and returned to the conference room. Mom placed her cell phone on the table and asked whether it would be okay for her to record the session. I responded that, on one hand, it was important for people to speak freely, and that some people might feel a bit inhibited if a recording were being made. At the same time, I ventured that it would be important to make sure that whatever agreement they reach is captured clearly. I proposed that, when the parents and physicians arrive at a plan for going forward, I would be happy to write it up in my computer and pass it around for everyone to see and suggest any changes. Then when everyone was in agreement, we could print up a copy for everyone.

Mom's overriding concern was to ensure that she would not be trapped in a situation of mutual "that's not what I said—I never agreed to that!" Writing up the agreement honored that important need, even while preserving the overall privacy of the conversation.

As we began, I noted that in these conversations people almost always learn things they had not previously known, and that views usually evolve in the face of new information. I expected that this would happen today, too, and that on the basis of my conversations with everyone, I was quite confident that a good agreement could be reached.

I explained that the parents had received a number of mixed messages. I offered to describe them, not as an advocate, but simply to let them be heard through a different voice. With assent by all I began the description. At some point thereafter Mom and Dad spoke about the swallowing study. The hospitalist offered a reply and I asked if it might make sense to look at the images. The hospital-

ist retrieved them on the laptop. I couldn't manage to bring them up on the projector, but things worked out even better as everyone gathered around the laptop. Literally, the parents and physicians stood side by side, looking together at the problem.

The hospitalist pointed to various features—micro-aspirations leading to bronchial thickening and the like—noting that this explained Henry's persistent dry cough. She discussed the long-term concerns of continuing to expose the lungs to small amounts of inhaled feeds. She also indicated that, among her two dozen patients on g-tubes, some were also able to feed orally, and a couple were about to "graduate" from the g-tube. She added that, the better the nutrition, the better the child can benefit from physical therapy and other services. Conversely, fighting constant micro-aspirations consumes a heavy load of calories that, with a better nutrition route, would be directed instead toward Henry's physical development. The hospitalist also described the potential role of reflux in Henry's condition, indicating that some of Henry's micro-aspirations may well come from reflux (food coming back up) rather than from improper swallowing. Because of this, g-tube surgery often included a "Nissen fundoplication" to stop the reflux.

Everyone at the table, in essence, had a "do-over" on the conversation about the swallowing study and what it meant.

This phase of the mediation used several traditional mediation techniques. Observing, at the very outset, that new information was likely and that views usually evolve, was another example of priming. It gives people permission to change their minds while preserving their dignity. And a genuine expression of optimism helped to create a safe and hopeful space for productive conversation. Finally, standing side by side, looking together at the radiographs, is an example of a classic mediation strategy: focus on the problem, not the people.[10] Instead of dwelling on mutual distrust and disrespect for each other, parents and physicians alike now turned toward concrete facts, problem particulars, and the specific interventions that might address them.

Henry's parents had not previously linked the importance of nutrition with the opportunity to maximize the benefits of physical therapy, nor had they been aware that Henry might be able to eat orally even while on the g-tube, and perhaps one day to return to fully oral nutrition. At that point the speech therapist said, "sometimes before we decide whether a g-tube is needed, we do an in-house trial, typically for a week or so, in which a nurse or physician listens to the baby's chest before, during, and after feeds." The parents liked the idea, but expressed concerns that their insurance might not support such a lengthy inpatient stay.

Further discussion constructed three options: (1) there could be a three-day trial in the hospital with oral feeds, no nasogastric tube, and intensive monitoring, listing specific criteria that could end the trial and insert a g-tube; (2) the swallow study would be repeated, with Henry placed in a more favorable feeding position; (3) Henry would have an upper gastrointestinal study and a pH probe (measures acid reflux in the esophagus), tests that would need to be done anyway, for a g-tube.

I wrote them in my laptop and passed it around for everyone to review, to ensure that it captured their agreement correctly. Since everyone owned a computer, printouts would be unnecessary. I emailed the agreed-upon list of options to everyone at the same time, using Bcc: (blind carbon copy) to protect the privacy of each person's e-dress. The parents would review the options and convey their choice later that day.

That afternoon they chose the g-tube.

Epilogue: The next morning Mom asked the social worker whether perhaps she might be allowed to serve as a "parent mentor" to help other parents whose children were receiving a g-tube.

As I noted at the outset, this mediation did not exemplify any particular brilliance on my part. It relied on conflict-resolution tools familiar to mediators. The process is highly intentional at every point and, particularly in the clinical setting, seeks at every turn to build trust, empower the people at the table, and create a setting in which problems can be solved not by some outside "expert," but by those who are most deeply affected.

As discussed elsewhere,[11] ethics committees could be well-situated to provide healthcare institutions with a conflict-resolution service. Importantly, mediations such as that described here need not and should not be such a service's sole offering. Conflict resolution spans a panoply of services. Sometimes, for instance, the most important thing to provide is coaching. A resident or colleague about to undertake a difficult disclosure may benefit from the opportunity to discuss and strategize the conversation in advance, with someone who is trained in the skills of difficult conversations. In another instance one might simply offer a "sounding board" to help someone think through what s/he values most, what options make most sense.[12]

Also as discussed elsewhere,[13] conflict-resolution services would need to be carefully distinguished from traditional ethics consults that produce an advisory regarding what the requestor "ought" to do. To be sure, a good consult often begins by uncovering communication misfires, a need for further information and the like. Often when such matters are unearthed and addressed, the apparent problem disappears. This is why the American Society for Bioethics and Humanities strongly (and soundly) recommends that ethics consultants have training in skills of facilitation.[14]

However, mediation such as that described here differs fundamentally from a traditional ethics consult. At some point, if an issue still lingers after the traditional ethics consultant addresses communication issues and the like, s/he is ordinarily expected to say "I recommend X" or "I suggest that X, Y, or Z are ethically appropriate options."

That last step formally forswears the impartiality that is essential to mediation, and which sits as a bedrock for trust. One cannot say, at the outset, "I'm not here to tell anyone what they should do," and then later opine that "well, since you couldn't decide for yourselves, I'll now tell you that really I think you ought to do X." At that point the mediator has renounced a commitment and betrayed trust.

This is not to say that there is no room for traditional ethics consults. Mediation is not necessarily appropriate for every issue—not even for every conflict—and is not necessarily suited for every person. But once begun, the process must be respected. If somehow a mediation does not yield an agreement among those in conflict (uncommon, but not unheard of), and if some sort of advisory is needed, then the mediator should offer parties the option of a traditional consult. The mediator should not, him- or herself, become that consultant, but rather must refer the case to a consultant colleague.

At the same time, it can be entirely appropriate for an ethics committee to offer both kinds of service, so long as they are understood to be distinct. After all, resolving conflict is a form of preventive ethics. As emphasized in a recent discussion about disputes over end-of-life treatment, "most disagreements in ICUs arise not from intractable value conflicts but from breakdowns in communication that are amenable to communication interventions. . . . conflicts typically develop and worsen over time as communication breaks down and parties become entrenched in their positions."[15] On the whole surely it is better, whenever possible, to resolve such matters thoughtfully and by agreement than by a kind of vote taking that often leaves some people triumphant at the expense of others' distress.

NOTES

1. Nancy Dubler and Carol Liebman introduced the concept of "bioethics mediation" in the 1990s, greatly enhancing the options for ethics consults. See N. Dubler and C. Liebman, Bioethics Mediation: *A Guide to Shaping Shared Solutions* (Nashville: Vanderbilt University Press, 2011). "Clinical ethics mediation," covering roughly the same scope, likewise refers to techniques of conflict resolution and mediation to address ethical challenges in healthcare. Both arise from a recognition that many instances of what initially appears to be an ethics issue turns out, in fact, to be a product of miscommunication, inadequate listening, and conflict. Beyond this, mediation can help people in an ethical conflict come to a reasonable working resolution even if they do not agree on all the underlying values.

In contrast, "clinical-setting mediation" encompasses ethics disputes but additionally recognizes that the broad clinical setting of healthcare is fairly rife with conflict, much of it having little or no obvious connection with ethics. The disputes may be relatively ordinary workplace disagreements, e.g. whether one nurse is leaving too much work for a co-worker. Or researchers might argue about who deserves first authorship in their shared project. Or patients and families may oppose hospital visitation limits or other routine rules. Clinical-setting mediation is a way of addressing the broad panoply of conflict in healthcare and, in the process, recognizing that, because the stakes in healthcare are so high—life and death, literally—successfully addressing all sorts of conflict is part of safe care, not just patient and workplace satisfaction.

2. Voluntariness is just one of many ways in which clinical-setting mediation can differ from the mediations associated with litigation. Although many of the latter mediations are voluntary, they can be court ordered, and parties refusing to participate can potentially be cited for contempt. Moreover, even though the outcome of a mediation is generally voluntary (parties can simply fail to agree and go back to court for the judge to resolve their dispute), a contract sealing parties' agreement becomes legally binding.

In contrast, agreements in the clinical setting are rarely "enforceable," other than the simple irreversibility of a *fait accompli*. People can change their minds about a plan at any point until, e.g., a surgery has been completed. In these and other ways, clinical mediation differs markedly from litigation-mediation. For further discussion about the differences between mediations in the clinical versus litigation settings, see E.H. Morreim, "Conflict Resolution in Health Care," *Connections* 18, no. 1 (2014): 28-32; E.H. Morreim, "Conflict Resolution in the Clinical Setting: A Story Beyond Bioethics Mediation," *Journal of Law, Medicine & Ethics* 43, no. 4 (2015): 843-56; E.H. Morreim, "In-House Conflict Resolution Processes: Health Lawyers as Problem-Solvers," *Health Lawyer* 25, no. 3 (2014): 10-4.

3. Specifically, I am a professor in a medical school. Given that my institution does not own its own hospital, it has contractual relationships with several hospitals in town. When I am in one of those hospitals it is typically for the purpose of providing education for medical students and residents.

4. One option for creating a conflict-resolution service with a high degree of independence is the organizational ombuds. These are gaining traction in healthcare. Some healthcare institutions, e.g., have ombuds who focus strictly on employee disputes. See, e.g. M.D. Anderson Cancer Hospital, *https://www.mdanderson.org/about-us/for-employees/employee-resources/ombuds-office/what-we-do/index.html;* or see the National Institutes of Health Ombuds Office, *https://ombudsman.nih.gov.* Else-

where one might find ombuds-mediators to address patient-provider issues, as with the Kaiser system. See, e.g., M. Montijo et al., "Bridging Physician-Patient Perspectives following an Adverse Medical Outcome," *Permanente Journal* 15, no. 4 (2011): 85-8.

Whatever their focus, a well-constructed organizational ombuds office is designed to be independent, typically reporting only to top management and even then in only via general information about the ways in which conflict occurs and affects the organization. Similarly, a well-designed ombuds office has express protection for the confidentiality of all visitors' concerns. See, e.g., University of California Davis Office of the Ombuds, "Annual Report June 2014-July 2015," *http://ombuds.ucdavis.edu/local_resources/docs/2014-15%20Annual%20Report.pdf.* An ethics committee could design its own conflict-resolution service on a similar footing.

5. B.G. Picker, *Mediation Practice Guide,* 2nd ed. (Washington, D.C.: American Bar Association, 2003), 87-8. See also C. Moore, *The Mediation Process: Practical Strategies for Resolving Conflict,* 3rd ed. (San Francisco: Josey-Bass, 2003), 218-9, 376-7. In the litigation context, confidentiality means that parties can feel free to make statements and offers that cannot be used against them in a subsequent (e.g., court) proceeding, if the mediation fails to reach agreement. In the clinical context, privacy is critical to trust. In healthcare, people often decline to tell things to their physicians, wishing not to be judged stupid or lazy or noncompliant, or wanting to avoid being the "squeaky wheel" that causes annoyance or disdain from providers. The nonjudgmental acceptance a mediator offers, and the assurance that one's private thoughts, "dumb ideas" or embarrassing secrets will not go any further, is often essential to any willingness to share those things.

6. At the same time, often in the clinical setting it is important to bring people together for conversations around the table. After all, when people must continue in a relationship with each other following a mediation or conflict-resolution process, they must learn how to talk with each other in constructive ways. As discussed below, this particular case did indeed lead, the next day, to a conversation with everyone present. Strategically, however, the build-up to that meeting was carefully laid out, and, in this case, everyone needed private conversations in which to build trust and hope in the process and the mediator.

7. For detailed description of another clinical-setting mediation, see Morreim, "Conflict Resolution in the Clinical Setting," see note 2 above.

8. For additional discussion of coaching in the mediation context, see Morreim, ibid.

9. More specifically, "priming" refers to a phenomenon in which introducing one stimulus—perhaps a word or concept—can influence subsequent responses in the hope that the people at the table will be more receptive, later, to options involving those concepts. See M. Gladwell, *Blink* (New York: Back Bay Books, 2007), 53-8, 76.

10. As framed by Fisher and Ury, "separate the people from the problem." R. Fisher and W. Ury, *Getting to Yes: Negotiating Agreement Without Giving In,* 2nd ed. (New York: Penguin, 1991), 17.

11. Morreim, "Conflict Resolution in the Clinical Setting," see note 2 above.

12. In many ways, these functions are very much like an organizational ombuds, if well-designed for the healthcare setting. See note 4 above. See also C.L. Howard, The Organizational Ombudsman: Origins, Roles and Operations: A Legal Guide (Chicago: ABA Publishing, 2010); University of California, Davis, Office of the Ombuds, "Annual Report for 2013-2014" and "Annual Report for 2014-2015," *http://ombuds.ucdavis.edu/local_resources/docs/AnnualReport2013-14.pdf* and *http://ombuds.ucdavis.edu/local_resources/docs/2014-15%20Annual%20Report.pdf.*

13. Morreim, "Conflict Resolution in the Clinical Setting," see note 2 above.

14. *Core Competencies for Healthcare Ethics Consultation*, 2nd ed. (Glenview, Ill.: American Society for Bioethics and Humanities, 2011).

15. G. Bosslet et al., "An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units," *American Journal of Respiratory and Critical Care Medicine* 191, no. 11 (1 June 2015): 1318-30, 1320.

Cases from MedStar Washington Hospital Center

The Case of Ms D: A Family's Request for Posthumous Procurement of Ovaries

Laura Guidry-Grimes

ABSTRACT

The MedStar Washington Hospital Center clinical ethics team became involved in a case when the family requested the posthumous removal of a patient's ovaries for future reproductive use. This case presents a novel question for clinical ethicists, since the technology for posthumous female reproduction is still in development. In the bioethics literature, the standard position is to refuse to comply with such a request, unless there is explicit consent or evidence of explicit conversations that demonstrate the deceased would have wanted this option pursued. Ms D's case, we suggest, offers an exception to this default position; complying with the family's request could have been ethically permissible in this case, had it been medically feasible.

A CASE WITH A NEW ELEMENT

A declaration of whole brain death often causes an emotionally distressing situation for members of the patient's family, especially when they are holding onto hope for a miraculous recovery. Ethics consultants may be called to help handle a family's objections when they perceive the medical team as giving up too quickly, and consultants can assist in discussions about the end of life and the next steps. The case of Ms D included these features, but included a new ethical challenge: *How should we respond to a family's request for the posthumous removal of ovaries for future reproductive use?* The request prompted us to consider specifics about how the medical team should properly support a family who wants to honor their deceased loved one in this manner, the patient's reproductive intentions, and the ethics of posthumous consent for reproduction.

In this article and the analyses that follow, we report how we worked through these issues. We argue that, other things being equal, complying with the family's request could have been ethically permissible in this case (were it medically possible). Within the bioethics literature, the standard position is to refuse to comply with a request to assist in posthumous assisted reproduction, unless there is explicit consent or evidence of explicit conversations that demonstrate the deceased would have wanted this. Ms D's case, we suggest, offers an exception to this default position.

THE CASE

Ms D, a 31-year-old woman, was admitted to our hospital with an initial complaint of anemia. She had a complicated past medical history due to vascular Ehlers-Danlos syndrome, a genetic condition that caused the walls of her blood vessels to be fragile and rupture, which led to numerous cardiac in-

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cidents throughout her life. Her medical history included aortic and mitral valve replacements, and she took Coumadin and aspirin regularly. A few days after being admitted, Ms D experienced nausea, vomiting, and a change in mental status. She was transferred to the neurosurgical intensive care unit (ICU) and received a computed tomography (CT) scan and magnetic resonance imaging (MRI). Shortly thereafter, she became obtunded (had diminished alertness and responsiveness to pain). The MRI revealed that she was bleeding in her cerebellum (a large portion of the brain, in the back of the head between the cerebrum and the brain stem, that coordinates voluntary movements, posture, and balance) with no identifiable cause. She remained on a ventilator in the ICU. Ms D's poor prognosis due to the combination of abnormal coagulation, intracranial hemorrhage, and subsequent multisystem organ dysfunction were explained to her family.

Several days passed without significant change, and the medical team suspected that Ms D qualified for whole brain death based on neurological criteria. The medical team needed to complete the final confirmatory test, an apnea test. At a family meeting with the patient's mother and life partner of the last 11 years, the intensivist explained that, on account of the patient's severe brain injury from a baseball-sized clot and the results of other tests (such as lack of responsiveness to light and tickling at the back of the throat), the medical team was relatively certain that the patient had already died. The mother said that, speaking from her faith perspective, God needed more time to work a miracle. The lead ethicist suggested that if a miracle were going to occur, performing an apnea test now would not prevent it. After completing the test, the medical team informed the family that Ms D had died.

The ethics consult did not end after this meeting. Before leaving, Ms D's life partner and mother requested that the medical team remove and preserve the patient's ovaries for future reproductive use. The life partner said he had paperwork from Ms D's visit to a fertility clinic as evidence that she would have wanted him to take this step. The partner said that he and Ms D planned on starting a family with her eggs, his sperm, and a friend who offered to serve as a surrogate. We scheduled a family meeting for the next day. To prepare, the team worked together to research the scientific and medical feasibility of posthumous reproduction with a woman's ovaries, ovarian tissue, or eggs. Our preliminary searches through medical news and scientific databases suggested it was not possible.[1] The lead ethicist spoke with the physician in our hospital who specializes in obstetrics, gynecology, and clinical genetics—Melissa Fries, MD (whose article, "Analysis: OB/GYN-Genetics," follows this article[2]). Fries doubted the feasibility of posthumous reproduction for Ms D.

The following day, the ethicists asked Fries to attend the meeting with the family, and we also invited Veronica Gómez-Lobo, MD, from our neighboring hospital, Children's National Medical Center, who specializes in fertility preservation for pediatric cancer patients (whose article, "Analysis: Fertility Preservation," follows[3]). In the pre-meeting, we discussed how we would break the news to the family that posthumous reproduction was not medically possible. Additionally, it appeared that there could be another insuperable barrier, even if the procedure were possible: Based on the physicians' understanding, reproductive materials were the legal property of Ms D, and a woman's rights regarding her eggs could not be transferred to her next of kin or domestic partner after her death without documentation that this is what she would have wanted ("Analysis: A Legal Perspective," by Jack Schwartz, JD, follows[4]). Given these medical/scientific and legal obstacles, our aim in the family meeting was to inform the family of the lack of reproductive options, make sure the family members were heard, and aid them in their grief.

When the mother and life partner joined us, they showed us the paperwork from Ms D's recent visit to a local fertility clinic. She had gone to the clinic only once, but she had discussed a desire to leave her life partner and her mother with a baby. Fries and Gómez-Lobo explained in detail that there were no feasible reproductive options for Ms D. Her partner mentioned that he had planned on using his retirement savings to pay for *in vitro* fertilization (IVF) with Ms D, and he expressed regret for not taking this step sooner, so they could have created a child before her death. On their way home from this visit, the mother and partner gave the ethicists consent to present Ms D's story in detail for publication.

ANALYSIS FROM THE CLINICAL ETHICS TEAM

The ethics behind posthumous reproduction was new to us. Although it is not presently medically feasible to use a patient's oocytes, ovaries, or ovarian tissue for procreation, the ethical questions are not moot. For one thing, we had set up a meeting to discuss the family's request, and we wanted to take their request seriously—meaning we did not want to dismiss it as simply infeasible, and so not

worth discussing. Second, it was possible that, upon hearing about current scientific limitations with posthumous female reproduction, the family would persist in their request to preserve the patient's ovaries just in case the technology became available in the future.[5] Third, the members of our ethics team wanted to think through some of the ethical complexities in the current case to prepare us for subsequent cases; especially since posthumous sperm retrieval is medically possible and not unheard of in clinical settings, we wanted to develop our ethical insights on this topic.

There are two importantly separate issues: whether the medical team and ethicists should *permit* or *prohibit* certain requests from going forward, and what moral responsibilities the requestors have in relation to their request. We could have moral qualms with the ways that patients and surrogates exercise their rights and make requests. We think to ourselves: "They *can* do X, but *should* they do X?" We need to be clear on which practices and policies should be in place, even if, in particular cases, there could be questions about the motivations of or reasons given by individuals who would benefit from those practices and policies. Institutionally, we need to determine whether we should permit the fulfillment of requests for posthumous removal of reproductive materials, and, if so, under what circumstances.

This analysis homes in on the issues that were most pertinent to this case: the nature of our obligations to the family regarding their request and how best to support their interests, the reproductive intentions of the patient prior to her death, and the ethics of posthumous consent to remove ovaries for procreation.

OBLIGATIONS TO THE FAMILY

Our obligations to the family were at the forefront of our minds as we consulted on this case. We considered the interests of Ms D's mother and her partner especially, since they were the members of the family who were most involved in her life and the ones making the request. They were also the ones feeling the loss of Ms D most intensely.[6]

Prolonging the Family's Grief

First, we were sensitive to how their request was a likely reflection of their grief. Data on posthumous sperm cryopreservation indicate that most requests for sperm are abandoned by the requestor after a few months, after the requestor has had more time to process her or his emotions.[7] Loved ones might pursue reproductive possibilities with a deceased patient's reproductive materials out of intense grief or guilt. On the one hand, this is not necessarily problematic; a requestor's motives for reproducing are generally complex and layered, and wanting to honor the deceased and bring more joy into the requestor's life through posthumous reproduction are understandable desires. On the other hand, this might not be an ideal situation for any child. As the European Society of Human Reproduction and Embryology (ESHRE) Task Force on Ethics and Law notes, "There is a certain danger for the autonomy of the child if the parent looks at the child as a 'commemorative child' or as a symbolic replacement of the deceased."[8]

ESHRE recommends a psychiatric evaluation of the requestor and one-year waiting period before posthumously collected reproductive materials are used.[9] This type of policy could help families make decisions about posthumous reproduction in the most responsible and autonomous manner, so grief does not overwhelm their judgment. At the same time, subjecting families to intense scrutiny about their choice may be an overstep if the medical team ends up interrogating family members and imposing personal values on them unfairly. It would be unfair for clinicians to demand families to prove they have the purest possible motives for pursuing posthumous reproduction, when policing motives and reasons in this way falls outside of the bounds of clinicians' expertise. It also sets up a concerning precedent, since the motives for pursuing other forms of reproductive technology are not subject to this high level of policing. We regularly allow families to make suboptimal decisions (within bounds) that implicate clinicians; giving families this leeway is part of what it means not to be imperialistic or imposing with our personal values.

Procreative Liberty of the Partner

Broadly, "procreative liberty" refers to having the ability and opportunity to pursue reproductive options according to one's own values and preferences. Whether procreative liberty rights exist, and the extent of those rights, are debatable.[10] If Ms D's partner has a right to reproduce and have a child, though, this does not mean that he has a right to have a child with Ms D, specifically. Even if we grant that using Ms D's body for reproductive purposes could be ethically permissible, this conclusion is a far cry from saying that Ms D's family has a *right* to her body.

Financial Burden

Lastly, a sensitive issue that arose in the family meeting was Ms D's partner's plan to empty his retirement account for the sake of paying for reproductive technology. Given how high stakes this decision could be for him (and for anyone looking to empty retirement savings), we would want to be sure he had time to reflect, so he could make the most informed decision possible. This concern about finances also could be a reason to implement a waiting period for using reproductive materials in the wake of a loved one's death.

INTENTIONS OF THE PATIENT

When the ethics team discussed Ms D's case, we wondered whether she intended for her family to pursue posthumous reproduction. The question of her intention is worth considering because her family believed that their request fit with what Ms D intended to happen after her death. She did not explicitly express her intention to have her ovaries removed and preserved posthumously for reproductive use, but we do have some evidence of what Ms D *did* intend to happen with her body: (1) she recently visited a fertility clinic after discussing IVF and surrogacy with her mother and partner; (2) she affirmed her desire to be an organ donor via designation on her driver's license and through conversations with her family.

Did she intend to have her body used for the benefit of others? Yes; specifically, she intended to help those waiting for organs for transplant. Did she intend to *consider* reproductive options with her genetic material? Yes; her visit to the fertility clinic indicates that she was open to this possibility. Beyond these, we are limited in what we can say Ms D's intentions were. If the medical team was not convinced that the patient intended her body to be used in this manner, the clinicians could experience moral distress with this request. On the other side, there could be moral distress for the family if they are prevented from honoring what they believed Ms D's intentions to have been.

POSTHUMOUS CONSENT

In a 2005 survey of Utah residents, 397 women and 307 men between the ages of 18 and 84 were asked what they would find acceptable (and presumably would authorize) related to posthumous ovarian tissue donation. While almost 75 percent of the respondents thought it was acceptable to donate unfertilized oocytes for scientific study, the percentage dropped to approximately 57 percent when respondents were asked about the donation of oocytes for fertilization and implantation for posthumous reproduction.[11] The study indicates that many people have nuanced preferences on the topic that would make a difference in what they would consent to regarding the posthumous donation of reproductive materials.

In the bioethics literature, there is a presumption against inferring consent for posthumous reproduction; for this option to be ethically viable, it is argued that explicit consent is necessary. The ESHRE summarizes this view: "Because of the special value of autonomy in the context of reproduction, an opting-in system is preferred to an opting-out system"; it even suggests that "the presence of cryostored gametes or embryos shows that a parental project existed, but it does not demonstrate that the deceased accepted the continuation of the project after his or her death."[12] A statement from the Ethics Committee of the American Society for Reproductive Medicine reads: "Until there is more experience with posthumous reproduction, this Committee thinks that a policy of allowing posthumous reproduction only when the deceased has specifically provided an advance directive and the surviving spouse or other designee agrees is a sound one."[13] Along similar lines, Orr and Siegler comment, regarding a case in which a man tried for 10 years to impregnate his wife, "Although this history indicated his desire to become a father, this alone could not be construed as consent for either sperm collection in this circumstance of impending death or for posthumous collection."[14] But could the moral presumption against allowing posthumous reproduction, absent explicit consent, ever go the other way?

The moral emphasis on respecting autonomy, even after death, drives the opt-in system for organ donation in the United States. It is worth addressing the analogy/disanalogy between posthumous reproduction and organ donation. In our opt-in system for organ donation, we allow families to authorize the procurement of organs when the deceased had been silent regarding her or his wishes. We err on the side of trusting the family to know what the individual would have wanted, even if she or he were silent on it. We furthermore want to honor their decisions as a familial unit in how they choose to respect the loved one who died.[15] Similar reasoning could be applied to the case of posthumous removal of reproductive materials.

Robert Orr and Mark Siegler argue, "Giving consent for autopsy or for organ retrieval for transplantation is giving to benefit others. But requesting

sperm retrieval after death without the consent of the dead man is not the same; in fact it is not giving at all—it is instead taking, because its aim is to benefit the person making the request."[16] According to Orr and Siegler, the lack of an altruistic motive behind requests for posthumous procurement of reproductive materials makes a crucial moral difference. This argument has numerous flaws, however. Consenting to autopsy will often not have any clear altruistic motive, and not all organ donations will be purely or even primarily altruistic.[17] Additionally, not all posthumous reproduction requests will be devoid of altruistic motive. A family or partner could want to pursue this option because they want to "do right" by the individual who died and give her or him what she or she would have wanted, even if doing so requires rigorous efforts and sacrifice on their part. They might also believe that they can offer a loving family and a good life to a child who would otherwise not exist. Ms D's partner and mother wanted to pursue posthumous reproduction partly for each other's sake.[18]

Nonetheless, based on the prevailing standard of not presuming consent on behalf of the deceased, it appears that we should not recommend that the medical team comply with the family's request in Ms D's case, since we do not have explicit consent from her to use her body in this manner. Arguably, proceeding with posthumous reproduction absent explicit consent could (1) undermine the autonomy interests of the deceased and (2) be disrespectful to the individual who has died, or set precedent for disrespectful treatment of the dead. We contend that the moral presumption against permitting posthumous reproduction, absent explicit consent, is not absolute. The first set of concerns about harming[19] a deceased patient by undermining her or his autonomy is ultimately misplaced, but the second set of concerns about being respectful provides appropriate ethical guidelines in these situations. We will still need to analyze the nuances and specifics of each case to determine what is and is not respectful to the individual. In this case, we tentatively concluded that pursuing posthumous reproduction in Ms D's case was ethically permissible.

Autonomy Interests and Duties to the Deceased

Rebecca Collin notes that, according to the prevailing standard, "the presumption against consent effectively prohibits posthumous reproduction in the very situations where it is most likely to be requested," since it is unlikely that someone would have made his or her preferences explicit on this issue.[20] So how do we determine whether the duty to respect autonomy applies in this case? We often speak of duties to the dead in the sense that we are concerned about doing right by the dead *for their own sake.* But does it make sense to speak of "her own sake" when the patient is deceased? Does she have a "sake" to speak of?

Joel Feinberg argues that there can be posthumous harm, even when there is no existing individual to experience those harms. He believes that a "person is harmed when someone invades (blocks or thwarts) one of his interests."[21] Feinberg suggests that we can have duties to the deceased that are not exactly for their own sake, since they have no good of their own; yet, our sense of moral obligation is not merely a concern for moral character (for example, against cultivating callousness towards promises) or duties to the living (for example, helping with the grieving process), either. Rather, Feinberg contends that we still owe it to the dead to fulfill their interests because those interests do not lose their moral significance, even when the interest-bearer is not able to enjoy their fulfillment.[22] Feinberg's view of interests, though, is not without its complications. In response, Ernest Partridge argues, "Death cancels not only the possibility of [subjective] satisfaction but also the very point of fulfillment"—in other words, interests only have moral pull when there is an interest-bearer to whom they pertain.[23]

Part of the difficulty in resolving this issue is that we do not know for certain what happens to a person after her or his death; different philosophical, cultural, and religious worldviews will provide answers, but there is no way of knowing for certain. It is epistemically closed off to us—that is, we do not know and could not know whether interest-bearers (and thus, their interests) persist past death. As such, we cannot know if we are capable of harming the dead. Since we cannot know what happens to us and our interests after death, whether there are duties to the dead for their own sake (such as respecting their previously expressed autonomy interests) is, *in principle, unknowable*. Duties that are unknowable cannot possibly obligate us. We cannot abide by a principle of caution (for example, by acting on the presumption that we can harm the dead), since any number of unknowable duties could conflict or cancel each other out. We have no way to deliberate on unknowable duties. This is not to say that we should not care about our treatment of the dead; we still have (*prima facie*) moral obligations to carry out wills, preferences regarding organ donation, prior promises, and proper burial or cremation. The point is that these obligations do not

amount to duties for the dead's own sake. So why then do we have any moral obligations in relation to the deceased? The properly placed concern is one of respect: We should show proper acknowledgment of the loss of the individual's life.

Respectfulness toward the Deceased

Many of our "death practices," such as those dealing with the distribution of assets and determining what to do with a deceased person's body, are built around trying to respect who the person was. Through respecting the dead in this manner, we show our appreciation for the value of life, as well as (perhaps) admiration for and gratitude toward the person who lived. Respecting the dead therefore contributes to cultural and interpersonal virtues, as we commit to not taking death lightly. Partridge argues that it is part of our "moral personality" to imagine ourselves outside of our particular circumstances, which includes considering how we want our body to be treated and our family to fare after we die.[24] It would be inconsistent with our moral stances toward living persons if we ceased to care about how they were treated after death.

When it comes to Ms D's case specifically, we have evidence that her family was trying to honor her memory and respect her prior values in their request. Their request apparently took into consideration who she was, what she wanted for her family in the future, and what steps she planned to take in terms of her own reproduction. Their request to retrieve and preserve the patient's ovaries would not require any more bodily intrusion than would be part of normal organ procurement procedures, and the patient had consented to the latter—leading us to the conclusion that this level of bodily intrusion would not be disrespectful according to the patient's own values. Given these considerations, pursuing posthumous reproduction in Ms D's case, even absent explicit consent, would be ethically permissible.

CONCLUSIONS AND RECOMMENDATIONS

In this analysis, I have discussed some of the ethical issues that were most pressing at the time of the consult, as well as issues that arose later. Although there is a widely agreed-on position in bioethics that we should not fulfill these requests absent evidence that this is explicitly and specifically what the deceased would have wanted, Ms D's case suggests that there are exceptions to this general rule. Whether to comply with these requests, when feasible, should be determined on a case-by-case basis. These requests should be taken seriously and not dismissed out of hand, openly or privately.

We offer the following recommendations, which are not meant to be comprehensive:

- Medical teams should not give families false hope about possibilities that are not feasible, given current technological limitations and legal barriers that could exist. Opening the door to these discussions when there is no possibility these persons will have what they want could lead to unnecessarily prolonged grief.
- A mandatory waiting period for different stages of posthumous reproduction procedures (for example, procuring ovarian tissue, using the tissue for the production of eggs) could enable autonomous decision making for the family.
- Talk with the family about what the patient intended to happen to his or her body after death. Find relevant evidence of the patient's intentions, such as through an organ donation registry or documentation at a fertility clinic.
- See whether there is explicit consent for posthumous reproduction. When a patient donates gametes prior to death at a fertility clinic, it is standard procedure to ask what the patient wants to happen to the gametes after death.
- If there is no explicit consent for posthumous reproduction, ask the requestor if he or she ever had explicit conversations on this possibility with the deceased. If the requestor can provide evidence or a clear accounting of conversations that indicate that the request fits with what the deceased would have wanted, then there is a moral presumption in favor of fulfilling the request.
- If evidence about what the deceased would have wanted is missing or unclear, there could still be good moral reasons to give the family leeway in making this decision. Some particularities of the case should be considered, including the following:
  - The values and life plans of the deceased, especially in regards to reproduction and posthumous treatment of his or her body, tell us how to pay respect to this individual specifically.
  - Consider which institutional policies and practices already exist when it comes to families' and partners' requests in relation to a deceased patient's body. Depending on the nature of the case, current policies and practices could be altered to accommodate what the clinical team and ethicists think ought to be permitted or disallowed.

PATIENT AND FAMILY CONSENT

This case has been anonymized, but no other details have been de-identified or modified. The family provided consent for the patient's case to be used and discussed in this publication, which they believe the patient would have wanted.

ACKNOWLEDGMENTS

We are immensely grateful to the family for giving us the opportunity to discuss Ms D's case in this publication. We appreciate the thoughtful contributions from our commentary authors. Evan DeRenzo, PhD, Nneka Sederstrom, PhD, Jamie Carlin Watson, PhD, and the editorial staff at *JCE* provided helpful feedback on earlier drafts.

NOTES

1. A.W. Loren et al., "Fertility Preservation for Patients with Cancer: American Society of Clinical Oncology Clinical Practice Guideline Update," *Journal of Clinical Oncology* 31, no. 19 (July 2013): 2500-11; Ethics Committee of the American Society for Reproductive Medicine, "Fertility Preservation and Reproduction in Patients Facing Gonadotoxic Therapies: A Committee Opinion," *Fertility and Sterility* 100, no. 5 (November 2013): 1224-31; I. Demeestere et al., "Live Birth after Autograph of Ovarian Tissue Cryopreserved During Childhood," *Human Reproduction* 30, no. 9 (2015): 2107-9; A. Mizukami et al., "The Acceptability of Posthumous Human Ovarian Tissue Donation in Utah," *Human Reproduction* 20, no. 12 (2005): 3560-5; B.K. Campbell et al., "Restoration of Ovarian Function and Natural Fertility Following the Cryopreservation and Autotransplantation of Whole Adult Sheep Ovaries," *Human Reproduction* 29, no. 8 (2014): 1749-63.

2. M. Fries, "Analysis: OB/GYN-Genetics," in this issue of *The Journal of Clinical Ethics* 27, no. 1 (Spring 2016).

3. V. Gómez-Lobo, "Analysis: Fertility Preservation," in this issue of *The Journal of Clinical Ethics* 27, no. 1 (Spring 2016).

4. J. Schwartz, "Analysis: A Legal Perspective," in this issue of *The Journal of Clinical Ethics* 27, no. 1 (Spring 2016).

5. Interestingly, Michael Soules suggests that "ovarian cryopreservation technology has proceeded far enough that it can now be considered reasonable to offer cryopreservation to [sic] women shortly after death or during a persistent vegetative state." See M.R. Soules, "Commentary: Posthumous Harvesting of Gametes—A Physician's Perspective," *Journal of Law, Medicine & Ethics* 27 (1999): 362-5, 362-3.

6. In analyzing obligations to members of patients' families, their genetic counseling needs should not be overlooked. It is important to remember, though, that a family could knowingly, willingly, and happily choose to pursue reproductive technologies even when there is a high likelihood that any resulting child will have significant medical difficulties or impairments. Interested readers can find arguments along these lines in the following: A. Asch, "Describing Bioethics: Convergence and Contrast with Disability Rights," in *Handbook of Disability Studies,* ed. G. L. Albrecht, K. D. Seelman and M. Bury (Thousand Oaks: Sage, 2001), 298-316; A. Ho, "The Individualist Model of Autonomy and the Challenge of Disability," *Bioethical Inquiry* 5 (2008): 193-207.

7. ESHRE Task Force on Ethics and Law, "ESHRE Task Force on Ethics and Law 11: Posthumous Assisted Reproduction," *Human Reproduction* 21, no. 12 (2006): 3050-3.

8. Ibid., 3052.

9. Ibid.

10. For an overview and discussion of these debates, see E. Brake and J. Millum, "Parenthood and Procreation," *Stanford Encyclopedia of Philosophy* (Fall 2014), ed. E.N. Zalta, *http://plato.stanford.edu/archives/fall2014/entries/parenthood/.*

11. Mizukami et al., "The Acceptability of Posthumous Human Ovarian Tissue Donation in Utah," see note 1 above, 3562. Notably, the survey respondents were asked about transferring embryos to a separate couple desiring pregnancy. Respondents were not asked about the specific issue in Ms D's case—a surviving partner wanting to create an embryo for transfer to a gestational surrogate.

12. ESHRE Task Force on Ethics and Law, see note 7 above, 3051.

13. Ethics Committee of the American Society for Reproductive Medicine, "Fertility Preservation and Reproduction in Patients Facing Gonadotoxic Therapies," see note 1 above, 1229.

14. R.D. Orr and M. Siegler, "Is Posthumous Semen Retrieval Ethically Permissible?" *Journal of Medical Ethics* 28 (2002): 299-303.

15. The U.S. Department of Health and Human Services states: "If the deceased had not registered and there was no other legal consent for donation such as a driver's license indicator, the OPO [organ procurement organization] will seek consent from the next of kin." See U.S. DHHS, "Organ Donation: The Process," *http://www.organdonor.gov/about/organdonationprocess.html.* This standard has its supporters among ethicists, but there are others who are inclined toward a stricter standard that gives less leeway to families in making a decision to donate an organ. A stricter standard, for example, would demand that some evidence be provided that organ donation is what the deceased would have wanted.

16. Orr and Siegler, "Is Posthumous Semen Retrieval Ethically Permissable?" see note 14 above, p. 301.

17. G. Moorlock, J. Ives, and H. Draper, "Altruism in Organ Donation: An Unnecessary Requirement?" *Journal of Medical Ethics* (28 March 2013): online, open access. doi:10.1136/medethics-2012-100528, *http://jme.bmj.com/content/early/2013/03/27/medethics-2012-100528.full.*

18. In his discussion of posthumous gamete retrieval, Soules remarks: "What may seem like a simple and altruistic request has many complex ramifications," Soules,"Commentary: Posthumous Harvesting of Gametes," see note 5 above, p. 364. Here we have a physician whose perception of altruism with these requests is directly at odds with Orr and Siegler's. Furthermore, "al-

truism" is philosophically complex, and as a concept it has competing definitions and criteria, which makes attributions of altruism tricky and debatable (see Moorlock, Ives, and Draper, "Altruism in Organ Donation, see note 17 above). Moreover, lack of altruism (whatever that ends up meaning) does not negate consent or authorization in many other decisions and contexts. Surrogates are otherwise not expected to make decisions with an aim towards benefitting others; focusing on the interests of the family unit and the patient is expected, supported, and morally justifiable.

19. Our discussion focuses on harming, but there are relevant philosophical distinctions among harm, harming, wrong, and wronging. Wronging someone usually is said to involve violating rights or fundamental interests, but then we would need to show that rights and interest persist past death. To say we can do something wrong in relation to the dead is a different claim; this is to suggest that we could do something ethically impermissible in our treatment of the dead, and the impermissibility of acts can depend on ethical considerations besides those involving rights or fundamental interests of the deceased. For an analysis that highlights some of the reasoning that can be used to argue that the dead can neither be harmed nor wronged, see the following book: J.S. Taylor, *Death, Posthumous Harm,* and Bioethics (New York, Routledge, 2012).

20. R. Collins, "Posthumous Reproduction and the Presumption against Consent in Cases of Death Caused by Sudden Trauma," *Journal of Medicine and Philosophy* 30 (2005): 431-42.

21. J. Feinberg, "Harm and Self-Interest," in *Law, Morality and Society: Essays in Honour of H.L.A. Hart*, ed. P.M.S. Hacker and J. Raz (Oxford, U.K.: Clarendon Press, 1977), 284-308.

22. J. Feinberg, "The Rights of Animals and Future Generations," in *Philosophy and Environmental Crisis, ed. W. Blackstone* (Athens, Ga.: University of Georgia Press, 1974), 43-68.

23. E. Partridge, "Posthumous Interests and Posthumous Respect," *Ethics* 91, no. 2 (January 1981): 243-64.

24. Ibid., 261.

Analysis: OB/GYN-Genetics

Melissa Fries

ABSTRACT

Ovarian salvage from a patient with brain death is not available and will not preserve viable ova for future reproduction. Previous interest in assisted reproductive technology is only the first step in this process, which requires careful assessment of maternal risks and potential for recurrent genetic disease.

The case of Ms D, described by Laura Guidry-Grimes in this issue of the journal,[1] illustrates the conflict between family members' and patients' desires and the frontiers of medical technology. The ethical question of whether preservation of reproductive potential after death has been critically addressed by Guidry-Grimes, specifically commenting on the "we *can* . . . but *should* we?" quandary. For this family, their interpretation that Ms D had sought preliminary infertility care and expressed interest in surrogacy—in the face of her known severe medical concerns—was that she desired to provide a child of her genetic background to her family, regardless of the outcome of her own life. Even if Ms D had been able to express a well-thought-out desire for this, she had not yet received full counseling with infertility experts to discuss whether her health would allow it. There are maternal health circumstances that can preclude such actions. The lengthy process (two to three weeks) of inducing ovulation and harvesting ova is not easy, and it requires the patient's consent throughout the procedure. Ms D, with her medical concerns, would have been a very high-risk patient for ovulation induction—the fragility of her tissue could have led to ovarian rupture and heavy bleeding, and there would have been similar potential risk in the acquisition of her ovum.

In addition, part of the counseling process of assisted reproductive technology is to clarify what to do with the frozen ova or embryos in the face of death of the mother. Knowing this could have established a clear line of intent and action regarding Ms D's wishes. Her not-unexpected medical complication led to brain death before this happened. Her family's request to harvest ova or ovarian salvage is in line with what they perceived the patient would have desired, but it did not take into consideration that Ms D might not have been considered a candidate for this treatment by assisted reproduction (ART) specialists.

Without such ART guidance, maintaining maternal body/biological support for three weeks in an attempt to stimulate the patient's ovaries would have been unjustified, risky, and of uncertain productivity. Likewise, there are technologic limitations to the success of directly harvesting ovaries and attempting ovarian salvage by that process. There has been very limited success of *in-vivo* ovarian tissue maintenance with subsequent stimulation to produce viable ova. The practice at this time is limited largely to adolescent girls who require chemotherapy that

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could impact their fertility. It is not intended to harvest ova from salvaged ovaries, but instead to support the ovaries briefly until they can be transplanted back into the patient and stimulated later in the patient's life. Ovarian transplant remains a research effort at this time. In addition, no established research program exists that is able to receive a patient's ovaries, maintain them in perpetuity, and stimulate them. Thus, the family's belief that saving the ovaries would save Ms D's reproductive potential is not founded in current medical practice.

Ms D's type of Ehlers-Danlos syndrome is likely Ehlers-Danlos type IV, a defect in the COL3A1 gene. The condition results from pathologic mutations within the gene, that may vary from family to family, and is autosomal dominant in its inheritance; that is, the mutation is passed from an affected person to 50 percent of his or her offspring. Half of Ms D's ova would be expected to have her particular mutation in this gene. Advances in pre-implantation genetic diagnosis have allowed testing of cells of a very early embryo to determine if they carry the deleterious mutation. If Ms D's ova had been harvested and used for embryo development, testing for the mutations prior to the implantation of the embryo would have been a possibility**.** Ms D's family appeared to be accepting of her medical condition and willing to support a child who had her condition. However, this potential had never been addressed with Ms D, and it would be the value that *she* placed on the presence or absence of the mutation that had caused her illness that would be pertinent in this decision. There is a wide variation in choice in these circumstances: some adamantly wish to prevent disease recurrence in their offspring, and others feel prevention is of no importance.

Ms D's fortitude had overcome her many medical challenges during her lifetime. Her family and her long-term partner had been devoted to her and respected her for her strength and determination. They had had the experience of seeing her close to death and, miraculously, pull through. The final worsening of her condition was inevitable—the median age of death of patients with this disease is 48. The family's grief at the loss of this beloved woman was profound, influencing their wishes to hold on to some part of her, even if the technology were not yet available to support it. Similar beliefs regarding procedures such as for cryopreservation or cloning are ethically unsupportable; others, such as private umbilical cord stem cell banking, have capitalized on parental belief in future benefits—only to find that one in 400 to one in 200,000 children can use their own cord stem cells.[2] Advances in medical technology do occur, but embracing them prematurely can lead to costly disappointment. Balancing the "we *can* . . . *should* we" quandary requires a clear understanding of the true possibility of "we *can*."

PATIENT AND FAMILY CONSENT

This case has been anonymized, but no other details have been de-identified or modified. The family provided consent for the patient's case to be used and discussed in this publication, which they believe the patient would have wanted.

NOTES

1. L. Guidry-Grimes, "The Case of Ms D: A Family's Request for Posthumous Procurement of Ovaries," in this issue of *The Journal of Clinical Ethics* 27, no. 1 (Spring 2016).

2. M. Sullivan, "Banking on Cord Stem Cells," *Nature Reviews Cancer* 8, no. 7 (2008): 555-563.

Analysis: Fertility Preservation

Veronica Gómez-Lobo

ABSTRACT

This commentary considers the viability of ovarian tissue cryopreservation (OTC) in the case of an adult who qualified for brain death. Although there has been some success with OTC in achieving pregnancy when the tissue is reimplanted in the original donor, attempting OTC in the case under discussion would have not been medically feasible.

In my position at Children's National Medical Center, my responsibilities include assisting in fertility preservation counseling and procedures for girls with cancer who are scheduled for treatments that could limit their future fertility. This experience is what prompted the ethics team at MedStar Washington Hospital Center to contact me for a second meeting with Ms D's family, described in the article, "The Case of Ms D: A Family's Request for Posthumous Procurement of Ovaries."[1]

In regards to ovarian tissue cryopreservation (OTC), there are a few important points worth highlighting. While this procedure is still considered experimental, it has resulted in more than 60 documented pregnancies (and probably more undocumented). In all of these procedures, the ovarian tissue is placed back in the *original* donor. In Ms D's case, if her family had requested OTC, the tissue would have been transplanted into someone else, and the available recipients might not have had any blood relation to Ms D.

This sort of request, were it to have occurred, would not have precedent for a successful pregnancy. It is likely that ovarian tissue implanted into someone else would be rejected, and it would submit the recipient to risks of immunosuppression and possibly infectious risk. In addition, pregnancy from *in-vitro* maturation of oocytes from ovarian tissue has not been accomplished to date, although there have been increasing scientific advances in this direction; whether fertilization becomes possible in the future will also depend on federal rules regarding use of embryos.

Moreover, Ms D had not consented to the surgery or experimental protocol, and the current protocol specifically states that the tissue belongs to the patient, which, on this ground at least, would have prevented posthumous donation of her reproductive materials.

PATIENT AND FAMILY CONSENT

This case has been anonymized, but no other details have been de-identified or modified. The family provided consent for the patient's case to be used and discussed in this publication, which they believe the patient would have wanted.

NOTES

1. L. Guidry-Grimes, "The Case of Ms D: A Family's Request for Posthumous Procurement of Ovaries," in this issue of *The Journal of Clinical Ethics* 27, no. 1 (Spring 2016).

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Analysis: A Legal Perspective

Jack Schwartz

ABSTRACT

This commentary summarizes the uncertain state of the law regarding consent for posthumous gamete retrieval. The emergence of a legal framework will be aided by the kind of ethical analysis prompted by this family's request for removal and preservation of a deceased patient's ovaries.

In this case of Ms D,[1] in which clinicians and ethics consultants had their hands full with difficult medical, ethical, and (potentially) genetic counseling issues, the law poked its head up like a prairie dog from its burrow. During a discussion with the clinical team to prepare for a family meeting, the topic of property rights[2] in Ms D's eggs was mentioned.

Comments about the law by physicians or other clinicians risk introducing a distracting element and can siphon attention toward a side issue, one that may not actually have anything to do with the case at hand. Fortunately, in this case the legal question proved not to be a distraction. The family meeting was aimed at supporting family members in their grief once they learned that there were no feasible reproductive options for Ms D. This exemplified good practice: Do not let assumptions or vague worries about the law distract from full engagement with the actual issues.

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To be sure, in a case in which the law might have direct impact on the options under consideration, then it should be understood accurately and given due regard in the ethical analysis. Had the retrieval of Ms D's ovaries for future reproductive use been medically feasible, an important legal issue would have emerged: Does the law demand Ms D's consent as a prerequisite to the procedure?

One source of law that potentially would do so is a statute. State legislatures, however, are rarely to be found announcing policy on the frontiers of assisted reproductive medicine and genomic science, and so it is unsurprising that, as a legal scholar recently pointed out, "In the United States, there is currently no statutory restraint or prohibition on gamete retrieval or storage."[3] The American Bar Association's Section on Family Law has proposed that explicit prior consent be made a statutory prerequisite to the collection of gametes or embryos from the deceased.[4] This proposal, however, has not been enacted anywhere.

Nor has any case quite like Ms D's been litigated to a reported decision. This is also unsurprising, given the slow and accretive common law adjudicatory process. The case law about posthumous gamete retrieval is a patchwork, arising from varying fact patterns, and cannot be said to yield a definitive principle. The Massachusetts Supreme Judicial Court, applying inheritance laws in a case involving children conceived with stored semen after the death of their father, held that "affirmative consent" to posthumous parentage was required; "a decedent's silence, or his equivocal indications of a desire to parent posthumously," would not suffice.[5] But that

is merely one case, in one state, under one set of facts. It is far too soon to say that explicit prior consent is always required.

Law still has much to learn about the collection of gametes from the deceased. The still-open legal space around cases like Ms D's should be seen as an opportunity for clinical ethicists to help shape the law through the kind of nuanced and reflective ethical analysis demonstrated by this case study.

PATIENT AND FAMILY CONSENT

This case has been anonymized, but no other details have been de-identified or modified. The family provided consent for the patient's case to be used and discussed in this publication, which they believe the patient would have wanted.

NOTES

1. L. Guidry-Grimes, "The Case of Ms D: A Family's Request for Posthumous Procurement of Ovaries," in this issue of *The Journal of Clinical Ethics* 27, no. 1 (Spring 2016).

2. Attaching the term "property" to gametes is itself problematic. "Some decisional law [. . .] has suggested that while gametes may have some of the aspects of property, they are not technically property in the fullest sense of the word." C.P. Kindregen, Jr., "Genetically Related Children: Harvesting of Gametes from Deceased or Incompetent Persons," *Journal of Health & Biomedical Law* 7, no. 2 (2011): 147-73, 153-4.

3. C.P. Kindregen, Jr., "Dead Soldiers and Their Posthumously Conceived Children*," Journal of Contemporary Health Law & Policy* 31, no. 1 (2015): 74-95, 76.

4. American Bar Association Section on Family Law, "Model Act Governing Assisted Reproductive Technology," Section 205, *http://apps.americanbar.org/family/committees/artmodelact.pdf.* The ABA proposal would allow for a narrow exception: "In the event of an emergency where the required consent is alleged but unavailable and where, in the opinion of the treating physician, loss of viability would occur as a result of delay, and where there is a genuine question as to the existence of consent in a record, an exception is permissible."

5. *Woodward v. Commissioner of Social Security*, 435 Mass. 536, 552 (2002).

Perspectives

Ethical Considerations of Whole-Eye Transplantation

Wesley N. Sivak, Edward H. Davidson, Chiaki Komatsu, Yang Li, Maxine R. Miller, Joel S. Schuman, Mario G. Solari, Gerard Magill, and Kia M. Washington

ABSTRACT

Whole eye transplantation (WET) remains experimental. Long presumed impossible, recent scientific advances regarding WET suggest that it may become a clinical reality. However, the ethical implications of WET as an experimental therapeutic strategy remain largely unexplored. This article evaluates the ethical considerations surrounding WET as an emerging experimental treatment for vision loss. A thorough review of published literature pertaining to WET was performed; ethical issues were identified during review of the articles.

INTRODUCTION

As of 2008, reports indicate that 37 million people worldwide suffered from irreversible vision loss, with 20 percent, or 7.4 million, having vision consisting of only light perception or worse.[1] The majority of irreversible blindness is due to age-related diseases such as macular degeneration, diabetic retinopathy and glaucoma,[2] followed closely by trauma and ocular tumors.[3] The irreversible nature of this vision loss largely results from permanent optic nerve damage. Damaged axons of the retinal ganglion cells (RGCs)—the output neurons from the retina that form the optic nerve—do not regain their function following insult. Whole-eye transplantation (WET) could potentially provide a blind recipient with viable RGCs capable of regeneration and reintegration, as well as the optical system necessary for capturing and transmitting images to the visual cortex.

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WET is not a novel concept for the treatment of vision loss, but it is only now that it is becoming technically feasible and emerging as a potential experimental therapy. As early as the 1920s, Koppanyi and Kolmer demonstrated that the eyes of various cold- and warmblooded vertebrates could be removed and transplanted back into the eye socket, and that certain functions of the eyeball were retained.[4] Not until 1977 did an advisory council for the National Eye Institute (NEI) form and call for a ''limited and thoughtful laboratory effort'' in the area of eye transplantation. The NEI council stated, ''any effort to transplant a mammalian eye is doomed to failure by the ganglion cell axon's inability to withstand cutting, by the difficulty of insuring adequate circulation of blood to the transplanted eye during or shortly after the operation, and lastly by immune rejection of foreign tissue,'' yet, they concluded, ''the subject [of eye transplantation] is of such overriding clinical importance that it merits research attention.''[5]

Substantial progress has been made in the field of optic nerve regeneration since the NEI council originally made these statements back in 1977. Over the last 40 years, significant advancements have been made to the extent that WET is now nearing emergence as an experimental therapy for treating irreversible vision loss.[6] The intent of this article, however, is not to provide an overview of the advances that have made the possibility of WET clinically feasible in the future, but rather to begin to explore key ethical issues surrounding WET and its implementation as an experimental therapeutic strategy.

Over the past decade, vascularized composite allotransplantation (VCA) of the hand and face has emerged as a reconstructive option for devastating tissue loss in some patients.[7] This is a novel specialty, and more than 200 VCA procedures have been performed around the world, including 95 hand and 30 face transplants. When the first articles on the ethics of facial transplantation were published in the early 2000s, the first face transplant had not yet been performed. Lantieri, a French surgeon who was one of the pioneers of face transplantation, had postulated that the triad of anatomic dysfunction, patient characteristics, and team experience would dictate whether facial transplantation could be done ethically.[8] We are witnessing a similar evolution of the ethical questions surrounding WET, as seen in the early developmental phases of facial transplantation. Just like facial transplantation, WET is not to be considered as lifesaving, but as life-enhancing. Unlike facial transplantation, however, WET has the potential to restore vision, and, as such, to return what was previously thought to be a permanently lost sensation. Given these concerns, it is important to begin to explore the ethical considerations surrounding WET as an emerging experimental treatment for vision loss.

METHODS

A review of articles available pertaining to WET was performed and the resulting ethical concerns are discussed in terms of standard ethical principles.

RESULTS

Autonomy

To date, there have been no WET procedures performed, so it remains uncertain whether acute or chronic graft rejection and graft versus host disease (GVHD) episodes will occur at a frequency comparable with that of solid organ transplantation. Expected infections with this type of procedure can be inferred from other types of transplantation and include Candida, cytomegalovirus, Epstein-Barr virus (EBV), Herpes simplex, Herpes zoster, Molluscum contagiosum, Pseudomonas aeruginosa, and staphylococcal infection. Cancers are of great concern following any transplantation. For example, following facial transplantation, there have been three reported cases of cancer in the literature: one case of cervical dysplasia requiring hysterectomy, and two cases of post-transplant lymphoproliferative disorder; one was HIV related, and the other resulted in death.[9]

Organ donation has created ethical concerns regarding the privacy of patients, donors, and their families. The recognition and identity of donors and patients following WET would not seem to be of concern, but may be when WET and facial transplantation could be combined. Aversion to ocular donation for use in corneal transplantation procedures has already been documented.[10] WET is likely to be viewed by the public as an extension of, or analogous to, corneal transplantation, and thus may not be met with the same degree of sensationalism as facial transplantation, but the possibility does exist for the combination of WET and facial transplantation procedures. Public education and awareness of WET as a novel procedure are critical to assure the privacy of patients.

Providing ongoing support and psychiatric treatment for organ donors and recipients, and support for their families, is required to assure the long-term continuity of care and reflects a care team's concern for the best interest of patients and donors. While some donor families may choose to meet organ re-

cipients to explain their decision to donate the eyes of their family member, members of the care team must strive to preserve the confidentiality of all patients, donors, and family members.

The dignity of donors and their family members also must be protected. Respecting the integrity of a donor's body is an important value for the surgical team, and prostheses should be made to restore the deceased donor's body after recovery, should there be a desire for open casket viewing. The surgical team should spend time with the donor's family to help prepare them for the high likelihood of seeing the recipient in the news following the initial WET procedures.

Beneficence and Nonmaleficence

The need for, and subsequent consequences of, long-term immunosuppression is an important concern, due to the risk of infection, cardiovascular effects, and the possibility of kidney damage. The risk of post-transplant lymphoproliferative disorder (PTLD) is a real concern. For reference, there have been three cases of lymphoma reported in vascularized composite allotransplantation (VCA), two faces and one lower extremity.[11] One face transplant patient and one lower extremity transplant patient have succumbed to this fatal condition.[12] With two cases of PTLD in face transplant alone, this is a 7.7 percent risk so far in the first 26 recipients.[13] Albeit small numbers of VCA have been performed to allow meaningful extrapolation with solid organ PTLD risk, it is important to consider the statistics.

By comparison, according to the U.S. Organ Procurement Transplant Network/United Network for Organ Sharing database, the incidence of PTLD between 1999 and 2008 are as follows: for kidney recipients, 1.58 percent; for liver recipients, 2.44 percent; for heart recipients, 2.24 percent; for lung recipients, 5.72 percent. The incidence of other post-transplant malignancies, such as Kaposi's sarcoma, and bronchial and lung cancer in solid organ recipients is higher than it is for the general population of 55 to 59 year olds.[14] It remains to be seen if ocular transplantation carries with it the same risks as other organ systems, but it may be equivalent, if not decreased, given the immune-privileged nature of the anterior chamber of the eye.

The acceptance of risk varies depending on the procedure proposed, but the acceptance of risks of immunosuppression could change, if the incidence of PTLD or post-transplant malignancies rises substantially.[15] An aspect of nonmaleficence that must be discussed is that a donor may never have considered eye donation as a possibility, so there cannot be an assumption of his or her implied consent. As the eye is visible, unique, and highly personal, the donor's family must be involved in the consent process, as there should be no unwilling participants. In this complex process, the process of procurement itself will need to be protected, as bad publicity can result in a drop in the rate of solid organ donation, with the consequent deaths of those on waiting lists.

Losee and colleagues addressed the selection of patients as a way mitigate medical risk through a standardized evaluation to limit the incidence of PTLD and noncompliance with immunosuppression, which they found to be highest, respectively, in children and adolescents.[16] Ruling out patients who have pre-existing medical problems (history of malignancies, HIV infection, traumatic brain injury), or co-existing medical problems (diabetes or heart disease), or family history of diseases that could impact outcomes (amyloidosis, congenital bone diseases, familial neuropathies or malignancies) may reduce overall risk. In addition, an assessment of adherence may minimize postoperative harm while acknowledging that the rate of non-adherence across 147 studies that assessed various organ systems was 22.6 cases per 100 patients per year.[17]

Justice

Age considerations may be important to WET in so far as younger patients may gain the greatest benefit due to higher propensity for nerve regeneration. But adolescents also have historically high rates of non-adherence with immunosuppression in solid organ transplantation and higher rates of PTLD that could affect survival.[18]

Decisions regarding the selection of patients for solid organ transplant must include considerations of justice, but must also consider the lifesaving nature of the procedures. Rating scales such as the Stanford Integrated Psychosocial Assessment for Transplantation instrument (SIPAT) incorporate considerations of justice. These rating scales standardize psychosocial selection processes for transplantation, and may have prognostic value regarding readmission rates for rejection, infection, and mortality. Scores that are greater than 42 on the SIPAT are thought to be incompatible with successful transplantation; however, measures may be undertaken to improve the score, retain the candidate for transplant, and improve the outcomes of recipients.[19] Similar systems that will be perhaps even more stringent will need to be constructed and investigated if WET becomes an established therapy.

CONCLUSION

Whole eye transplantation (WET) is highly experimental. While it was long thought to be impossible, recent scientific advances suggest that WET may soon be possible. The ethical implications regarding WET as a therapeutic strategy remain largely unexplored. This article evaluates the ethical considerations surrounding WET as an emerging experimental treatment for vision loss. Loss of vision has devastating impacts on a person's overall health and psychosocial well-being. The gravity of functional impairments and the inability to reconstruct the eye justify the exploration of WET as a potential therapeutic strategy.

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NOTES

1. American Foundation for the Blind, "Statistical Snapshots from the American Foundation for the Blind," *http://www.afb.org/section.aspx?SectionID=15.*

2. C. Owen et al., "How big is the burden of visual loss caused by age related macular degeneration in the United Kingdom?" *British Journal of Ophthalmology* 87, no. 3 (2003): 312-7; C.G. Owen et al., "The epidemiology of medical treatment for glaucoma and ocular hypertension in the United Kingdom: 1994 to 2003," *British Journal of Ophthalmology* 90, no. 7 (2006): 861-8; G.S. Scotland et al., "Cost-effectiveness of implementing automated grading within the national screening programme for diabetic retinopathy in Scotland," *British Journal of Ophthalmology* 91, no. 11 (2007): 1518-23.

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12. Ibid.

13. Ibid.

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Let's Not Forget about Clinical Ethics Committees!

Franco A. Carnevale

ABSTRACT

The aim of this article is to highlight the under-recognized merits of clinical ethics committees (CECs), to help ensure that the development of roles for clinical ethics consultants do not unwittingly compromise the valuable contributions that CECs can continue to provide.

I argue that CECs can offer distinctive contributions to the clinical ethics consultation process that can complement and enrich the input provided by a clinical ethics consultant. These distinctions and complementarities should be further examined and developed. This will help to optimize the synergistic contributions that CECs and clinical ethics consultants can make to promote the ethical treatment of patients and their families.

Clinical ethics committees (CECs) have played, and continue to play, a valuable role in the development and practice of clinical ethics. Most clinical settings, in the past and to this day, have been unable to hire a clinical ethics consultant. This may be due to financial constraints or the limited availability of adequately trained experts to assume such a role, among other reasons. CECs have therefore served as a valuable resource for: (1) developing ethics-related policies, (2) promoting clinical ethics education, and (3) providing advisory support to clinical teams through clinical ethics consultations.[1]

Alongside this important work, many settings have developed clinical ethics consultant roles; one or more individuals with clinical ethics training who can be called to provide consultations for clinical cases that raise ethical concerns.[2] These individual consultants can also be helpful resources for clinical ethics education, which they may provide formally and informally. Some informal educational involvement (for example, unit-based rounds) can also provide pro-active input into a current case that can help pre-empt escalation into a "full-blown" ethical dilemma.

Despite the long-standing existence of these two clinical ethics practice models (that is, CECs and clinical ethics consultants), the literature has provided little substantive analysis of the relative merits of the two models. The aim of this article is to highlight the under-recognized merits of CECs, to help ensure that initiatives to promote the development of clinical ethics consultant roles do not unwittingly compromise the valuable contributions that CECs can continue to provide alongside clinical ethics consultants. In writing this, I am drawing on more than 17 years of experience as chair of a CEC (even longer as a member), clinical ethics consultant, educator, and researcher.

Some literature has already discussed ways in which CECs and clinical ethics consultants can function "side by side."[3] As an advisory body, a CEC can offer a rich diversity of perspectives, given the com-

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mon interprofessional composition of such committees, providing a scope of considerations that would be difficult for a single ethics consultant to provide. On the other hand, a consultant can offer a more expedient response to emerging concerns and engage in pro-active discussion and educational activities that would be difficult for a committee to perform. Moreover, an individual ethics consultant can sometimes provide a clearer response to a presenting concern because the consultant will articulate one opinion, based on an advanced expertise in clinical ethics. A CEC consultation can sometimes appear more cumbersome and less coherent. It can consist of somewhat diverse, sometimes even conflicting, viewpoints, drawing on varying orientations toward clinical ethics within the CEC, which on occasion may be difficult to bridge into a consensus.

Given this common distinction between the relative merits of these two models, it is understandable that some may conclude that the individual consultant is the optimal model. However, this kind of distinction may draw largely on a caricature of CECs that conceals the diverse interprofessional perspectives on the presenting case that can illuminate complex underlying ethical dimensions of the case, as well as more richly informed strategies for addressing the case. (Please note that this presumes that CEC members have at least a basic to midrange level of preparation in clinical ethics, and that the CEC functions in a manner that seeks to elucidate and bridge these diverse perspectives.) Moreover, an interprofessional CEC, with members who have some clinical ethics education and background experience acquired through the activities of the CEC, can provide profession-specific guidance on questions emerging from a particular case that a sole consultant would be less adequately prepared to provide. (That is, even if settings have access to more than one ethics consultant, the input of the consultant would be enriched by the broader, interprofessional perspectives of a CEC.[4])

CECs and individual consultants can develop a complementary synergy in the support they provide to clinical services. This complementarity is optimized if (1) the CEC chair is not the setting's clinical ethics consultant, to help ensure that the former does not simply replicate the orientation and activities of the latter); and (2) any member of the CEC can be approached with an ethical concern, fostering an "inclusive" view of what counts as an ethical concern, facilitating the recognition of less dominant ethical discourses, such as the perspectives of nurses and social workers as well as patients and families. For example, there is a growing acknowledgment of the complex ethical challenges confronted by nonphysician health professions that have been under-recognized by clinical ethics,[5] which interprofessional CECs can help reconcile. CECs should develop policies and procedures to inform staff and members of the patient community about processes for seeking a consultation and ensure clear communication pathways among CEC members, the CEC chair, and the clinical ethics consultant.[6]

To illustrate, consider a case involving a newborn with hypoxic-ischemic-encephalopathy, in which the parents have asked to have all life-sustaining treatments withdrawn (including enteral nutrition and hydration) if the child is likely to survive with significant disability. Such a case raises complex questions regarding diagnostic and prognostic certainty, the thresholds for evidence that are required for making life-and-death decisions, the extraordinary vulnerabilities of "imperfect babies," conceptions of best interests for these newborns, decisional authority for determining a child's best interests, and how the latter should be reconciled with the potentially conflicting interests of others involved in the case (for example, siblings, parents, healthcare professionals, and hospitals with limited resources). Family members and healthcare professionals bring their own particular "moral orientations," which a clinical ethics consultant can help elucidate and relate to relevant ethical and legal norms.

A CEC can enrich this process of analysis and decision making by promoting rich interprofessional examinations—fostered through the active engagement of clinical-ethics-prepared physicians, nurses, social workers, mental health professionals, chaplains, lawyers (among others), as members of the CEC seek to help define good practice from each disciplinary perspective. This can be further complemented by the participation of nonprofessional CEC members (for example, a patient or family representative, community member, and so on).[7] Individual members of the patient's treating team as well as the patient and family can benefit from more richly-informed consultations. Given the logistical challenges in conducting this form of CEC consultation properly, this consultation process may be reserved for particularly complex cases.[8]

In conclusion, future developments in clinical ethics consultation models should not focus merely on "which is better: a CEC or an individual consultant?" Rather, they offer different and potentially complementary clinical ethics practice models, with some operational overlap, yet significant distinctions

that should be further examined and developed. This will help optimize the complementary contributions that each model can make toward promoting the ethical treatment of patients and families.

NOTES

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Moving Clinical Deliberations on Administrative Discharge in Drug Addiction Treatment Beyond Moral Rhetoric to Empirical Ethics

Izaak L. Williams

ABSTRACT

Patients' admission to modern substance use disorder treatment comes with the attendant risk of being discharged from treatment—a widespread practice. This article describes the three mainstream theories of addiction that operate as a reference point for clinicians in reasoning about a decision to discharge a patient from treatment. The extant literature is reviewed to highlight the pathways that patients follow after administrative discharge. Little scientific research has been done to investigate claims and hypotheses about the therapeutic function of AD, which points to the need for empirical ethics to inform clinical addictions practice.

The latest data from the Substance Abuse and Mental Health Services Administration, for 2011, conservatively reports that 126,718 clients admitted to drug addiction treatment—7.3 percent of admissions—were expelled from treatment.[1] The existing literature has not thoroughly examined the multiple and varied pathways that patients follow after they are ejected from treatment. Additionally, across drug categories, no study has longitudinally tracked this empirically.

Different theoretical orientations follow different lines of reasoning in conceptualizing patients' outcomes after administrative discharge (AD). The reasoning can be dogmatic, and may either exaggerate or understate the ramifications of AD. Each stance makes political and emotional appeals according to a particular model of addiction and associated ideologies. The *choice philosophy*, for example, views addiction as a matter of weakness or as a lack of willpower among "addicts," and underlies the theory of "hitting rock bottom." The assumption is that progressive rehabilitation of the will requires strong doses of punishment (that is, AD) with the right mixture of consequences for the "addict" to stop abusing drugs.

The *moral theory of addiction* implies that free choice is present in addiction, but the fundamental culprits in drug addiction are characterological deficits—a sociopsychodynamic that maintains problem drug use. The idea that addiction is a choice implies a lack of willpower, and the language of the moral theory sees moral failing as an outgrowth of a degenerative personality structure. Thus, AD is part of a therapeutic process for a discharged patient that induces introspection, catalyzes motivation for change, and fosters character development, all of which are dimensions of the choice model and the moral theory of addiction.

In marked contrast, the *disease model* views addiction as a chronic condition that is mostly determined by neurobiology, and, as White notes, thus "posit[s] addiction as a disease of the will marked by a progressive loss of volitional control over [alcohol or drug use] and related decision-making."[2] In this model, AD is inconsistent with the chronic, relapsing nature of addiction of many patients. Wil-

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son Compton notes that AD can prematurely arrest the continuation of care, and, in turn, assails the goal of figuring out what treatment approach, modality, and intervention method will be most therapeutically useful to a patient.[3]

Given this, studies exploring the long-term consequences of AD and the perspectives of those who have been discharged are needed (see table 1 on the models of choice, moral, and disease in the AD debate, and the clash between the arguments and ideological priors that bias thinking when it comes to AD). In essence, the choice and moral theories of addiction affect the threshold of tolerance for safety violations and rule infractions (for example, drug use). A medically critical question left unanswered in the literature is whether AD might be beneficial for patients or categorically counter-therapeutic. This article surveys the extant literature and presents an evidence base that captures the posttreatment trajectories of patients who are administratively discharged, and follows this with a discussion on future directions.

LITERATURE ON POST-TREATMENT AD

Svensson and Andersson at the University of Malmö assessed the outcomes of 35 people with a long history of heroin addiction who were undergoing medication-assisted therapy (MAT) with methadone or buprenorphine following involuntary discharge (that is, AD) and a three-month exclusion from MAT.[4] Based on the reported experiences of 25 males with an average age of 43.2 years and 10 females with an average age of 46.0 years, the authors observed a general trend in the respondents' lives after AD. These former patients first experienced difficulty phasing out the methadone or buprenorphine medication, and those who were unable to properly taper off the medication in small doses were abruptly forced into withdrawal. Simultaneously with, or subsequent to, their discharge, the former patients often became homeless, as their housing was a condition of participating in treatment, before reaching a state of physical and mental deterioration. To maintain their heroin and illicit methadone or buprenorphine use, four patients returned to prostitution, and 13 of the 35 patients engaged in criminal activity, although most received welfare payments and pensions on which they could live.

The pathways that patients follow after AD, and the consequences that ensue, are consistent with past research on opioid addiction and AD from MAT. According to research by Coviello and colleagues, narcotic "addicts" generally want, and are in dire

TABLE 1. Reasoning regarding AD using the choice model, the moral model, and the disease model of addiction

Elements of the choice model and the moral model of addiction:
- Baseline volitional control over the connection between intent and behavior is higher in congruence
- Drug user is viewed in moral terms as "bad" and addiction is less a matter of chronic disease management or a behavioral health problem
- Addiction has genetic implications; however, its etiology is psychodynamically rooted in unresolved trauma, unprocessed parent–child relationship dynamics, etc.
- Repeated rule infractions (whether "minor" or otherwise) constitute a litmus test or proxy for a client's motivation and choice for initiating recovery, motivation for treatment, readiness for treatment, receptivity to engagement, and expected trajectory
- Drug use is a function of the psychological, social, and emotional drivers for coping with stressors, masking pain, facilitating social adjustment, etc.

Elements of the chronic disease model of addiction:
- Baseline volitional control over the connection between intent and behavior is lower in congruence[1]
- Use/non-use behavior is more of a manifestation of addiction or a residual effect of past drug use
- Substance use disorders are a primary health problem, and the standard for patient care is analogous to other chronic diseases (e.g., diabetes or cancer)
- Rule breaking is generated by irresistible impulses and neurobiological determinants; addiction is a chronic, severe, and progressive medical condition
- Drug use is a function of a "hijacked" dopamine reward system: disordered motivational priorities, impaired inhibitory control, erosion of executive function[2]

NOTES

1. W.L. White, C. Scott, M. Dennis, and M. Boyle, "It's Time to Stop Kicking People Out of Addiction Treatment," Counselor 6, no. 2 (2005): 2-13.
2. W.L. White, "Toward a Philosophy of Choice: A New Era of Addiction Treatment," *Counselor* 9, no. 1 (2008): 38-43.

need of, such treatment.[5] Not accessing MAT puts them at risk for grave health consequences, including HIV and other blood-borne diseases, seroconversion, death by overdose, and criminal behavior.[6] Svensson and Andersson report that "patients with opiate addiction who were involuntarily discharged face a significantly impaired life situation and significantly increased mortality."[7]

Mitchell and colleagues interviewed six individuals with a mean age of 37 years, a mean history of 15.8 years of drug use (heroin and/or cocaine), and a mean of four prior treatment episodes that ended prematurely due to AD from a methadone-assistance program as a result of a partner's discharge, conflict with staff or other patients, lodging threats, absence for more than a week, social welfare's refusal to pay for treatment, or "side abuse" (using alcohol/illegal drugs or psychopharmacological drugs obtained outside of the program).[8] This study found that when most participants had their treatment terminated within 12 months, they "showed no indication of giving up at that point, and often fought to continue their treatment at their original program . . . [and drew] . . . informational and emotional support from family members, peers, pastors, and even needle exchanges to help them find and gain entry into a new program after administrative discharge."[9] The authors noted the resourcefulness and resilience of the program participants and concluded, "Even among patients who are prematurely terminated, one may still see a dramatic reduction in drug use and a greater willingness and likelihood of returning to treatment. Reduction in drug use over time, as well as other changes that may not be apparent in a single treatment program experience, might be identified when a longer-term perspective is taken."[10]

It would be misrepresentative of the aforementioned findings on opiate users to characterize the consequences of AD similarly for all other drug use categories. Indeed, a false equivalency is achieved when no distinction is made between the variety of drug use profiles found in addiction treatment programs—ranging in severity from mild, moderate, to severe—compatible with the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (*DSM 5*). Thus, the consequences of AD and posttreatment pathways for a patient with marijuana addiction will generally not be the same for a patient with opiate addiction. For example, Svensson and Andersson note, "patients who begin MAT often come from harsh backgrounds, with a history of mental problems, suicide attempts, poor physical health, crashed personal relations and experiences of incarceration,"[11] while Hoffmann relates, along the continuum of drug addiction severity, "the vast majority of those in treatment with a mild diagnosis likely can moderate use and achieve remission,"[12] which is coherent, to some degree, with the choice or moral model of addiction. Hoffmann notes that "the vast majority of those who meet the *DSM 5* criteria for a severe diagnosis will require abstinence to achieve remission,"[13] a therapeutic paradigm that is seemingly in line, to some extent, with the disease hypothesis of addiction.

Since mild, moderate, and severe addiction cases are integrated within the general treatment population, it is necessary to contextualize any discussion about AD in terms of the threshold of tolerance for safety violations and rule infractions (for example, a nonfraternization policy[14]) by distinguishing patients with addiction profiles that are indicative of a loss of control similar to the disease theory of addiction, and requiring abstinence, from those patients who might benefit from some moderation or a behavioral adjustment approach regarding drug use, which is more compatible with the choice or moral theory of addiction.

To further an understanding of how AD can impact patients, critical biopsychosocial questions about the consequences of this clinical practice must be raised. For example: How many administratively discharged patients achieve successful long-term recovery, experience a remission of symptoms, or report improvement in behavior while in treatment in the weeks and months following AD from the previous treatment program? What factors are predictive of post-discharge consequences, and what variables moderate or mediate such consequences? These questions may elucidate the relationships between specific clinical profiles and post-AD pathways. However, since no known longitudinal study exists in the literature, the effects of AD are not entirely understood, including whether the experience can be converted into a source of resiliency, behavioral modification, and motivation that will improve patients' recovery outcomes.

CONCLUSION

Data indicate that multiple drug addiction treatment episodes are the norm for a sizable portion of the overall treatment population, and that they have "facilitative effects" on the initiation, stabilization, and maintenance of recovery.[15] Multiple treatment episodes are also associated with greater retention in methadone treatment, and, according to Williams and White, "may serve as a proxy for problem se-

verity, complexity (co-occurring psychiatric illness), and chronicity."[16] Interestingly, the rates of discharge for those who have undergone several instances of treatment due to AD remain an undefined population parameter in the literature. Speculation abounds as to the possible reasons. One possible reason is that members of the substance use disorder population are generally difficult to locate, as they are represented among higher incidences of family estrangement, residential mobility, spontaneous relocation, disconnected phones, unreliable contact information, limited education, homelessness, and criminal offense that often compel them to conceal their identity and location.[17] Additionally, those who are discharged may be a worse-off group to the extent that continued drug use or the socioeconomic factors related to, and accompanying, biopsychosocial aspects of addiction, are severe or persistent enough to precipitate AD; instability adds further difficulty to efforts to locate them. Moreover, the how, when, and why of AD likely make a significant difference in whether patients desire to stay in contact with a treatment program or make themselves unavailable after leaving.

Field historian William L. White suspects that a study examining AD "would reveal the underbelly of addiction treatment by exposing the untherapeutic consequences of this practice."[18] Moreover, while it is hard to predict if, and when, AD will become obsolete, it may be that as the treatment and prevention field evolves into a medical practice, and evidenced-based care becomes the norm in addiction treatment, and is followed with fidelity, AD will become an outmoded practice.

This polarized analysis of AD and the disease paradigm of addiction have wide acceptance in the shifting addiction landscape and highlight the recovery care management of addiction as a chronic disease. These tenets have been aided by the mainstream guidance of the Affordable Care Act and the Mental Health Parity and Addiction Equity Act. Research that methodologically explores the long-term consequences of AD on patients' lives might not only produce controversial findings, but run counter to the service priorities and research imperatives of institutes and agencies (for example, the National Institute on Drug Abuse, the Center for Substance Abuse Treatment, and so on) that are vested in a presupposition of chronic disease. Field historian William L. White offers the following thoughts:

> The majority of research dollars are now focused on unraveling the neurobiology of addiction in the hopes of medication, vaccines and related interventions that will enhance recovery outcomes and provide new avenues of prevention. There is far less long-term performance research on the treatment system itself, but I have not seen a study that focused specifically on what happens to people after being essentially kicked out of treatment. . . . That is unconscionable at this stage in the development of addiction treatment in the United States.[19]

In the case of AD, empiric research that is informed by the perspectives of patients would add an evidence-based response regarding the immediate and long-term costs of AD on addiction and recovery,[20] which would offer guidance on program policy, procedures, and practices. Rigorous study focused on understanding the diverse pathways to recovery that are experienced by patient groups would better grasp the trajectories of AD as a distinguishing feature in AD outcomes, and the possibility that AD would be demonstrated as a promising practice.

With more clearly defined patient subgroups and treatment program components (for example, graduation ceremonies[21]), modality, philosophy, staff background and experience, and clinical and demographic profiles of clinical subpopulations, a greater distinction can be made to clarify what factors contribute to discharge,[22] the subsequent outcomes for patients, and ways to lower the potential for AD in the development of national guidelines that establish best practices. In this way, programs could be ethically guided in setting appropriate limits on what constitutes the practical grounds for AD and how to engage therapeutically in the process of making determinations regarding AD. In so doing, the clinical examination of AD can move beyond the realm of moral rhetoric to a basis in empirical ethics.[23]

NOTES

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21. I.L. Williams, "Drug Treatment Graduation Ceremonies: It's Time to Put This Long-Cherished Tradition to Rest," *Alcoholism Treatment Quarterly* 32, no. 4 (2014): 445-57.

22. White, Scott, Dennis, and Boyle, "It's Time to Stop Kicking People out of Addiction Treatment," see note 20 above.

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Law

Legal Briefing: Mandated Reporters and Compulsory Reporting Duties

Thaddeus Mason Pope

ABSTRACT

This issue's "Legal Briefing" column, one product of a Greenwall Foundation grant, reviews recent developments concerning compulsory reporting duties.[1] Most licensed clinicians in the United States are "mandated reporters." When these clinicians discover certain threats to the safety of patients or the public, they are legally required to report that information to specified government officials. Over the past year, several states have legislatively expanded the scope of these reporting duties. In other states, new court cases illustrate the vigorous enforcement of already existing duties. I have organized all these legal developments into the following eight categories:

1. Overview of Mandatory Reporting Duties
2. Controversy over the Benefits of Mandatory Reporting
3. New and Expanded Duties to Report
4. Criminal Penalties for Failing to Report
5. Civil Liability for Failing to Report
6. Disciplinary Penalties for Failing to Report
7. Legal Immunity for Good-Faith Reporting
8. Protection against Employers' Retaliation

1. OVERVIEW OF MANDATORY REPORTING DUTIES

Clinicians are in a special position to detect and discover significant threats to the safety of patients or the public. Consequently, all U.S. jurisdictions impose legal duties on most licensed clinicians to report such threats, so that protective measures can be taken.[2] Reportable information falls into four rough categories.

First, clinicians must report harms and risks to individuals who may not be able to protect themselves. This includes abuse or neglect of a child[3] and abuse or neglect of a dependent, vulnerable adult.[4] It also includes substance abuse by pregnant women.[5] Second, clinicians must report threats to the public health. These threats might come from communicable infectious diseases,[6] from conditions that can impair driving ability,[7] or from a patient's threat to harm another.[8] Third, clinicians must report indicia of criminal activity. This includes injuries from deadly weapons such as knives and guns as well as injuries suspected to be the result of assaultive or abusive conduct.[9] It also includes domestic violence.[10] It does not matter that the clinician judges there is little prospect for future harm. Fourth, clinicians must report their own colleagues in four situations: (1) when they are impaired by drugs or alcohol, (2) when they engage in sexual misconduct with a patient, (3) when their health condition puts patients at serious risk, and (4) when they deviate substantially from professional standards.[11]

In any of these four situations, the amount of evidence normally sufficient to trigger the clinician's reporting duty is quite low. Clinicians must make a report so long as they have just a "reasonable suspicion" or "reasonable cause to believe" that the in-

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formation is reportable. Depending on the state and on the type of information, the report is typically made either to law enforcement or to a state agency. Failure to report can result in three types of sanctions: (1) criminal penalties, (2) civil penalties, and (3) discipline from the clinician's health licensing board. I offer examples of each in the following sections.

While under reporting often leads to sanctions, over reporting rarely does. Clinicians have legal immunity for making a good-faith report. Even if they are mistaken, clinicians cannot be sanctioned for breaching confidentiality or for prompting an ultimately unnecessary investigation. Consequently, existing legal incentives lean heavily in one direction. They encourage clinicians to err on the side of caution and report.[12] In short, if you are in doubt, if you are unsure whether an incident is reportable, then it probably is.

Finally, while mandatory reporting duties are imposed by state law, federal privacy law defers to these mandates. The Health Insurance Portability and Accountability Act (HIPAA) allows mandated reporters to disclose protected health information without the individual's written authorization. "A covered entity may use or disclose protected health information to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law."[13] "Required by law" is, in turn, defined as "a mandate contained in law that compels . . . disclosure of protected health information and that is enforceable in a court of law."[14]

The ethics guidelines of the leading professional societies are in accord. The American Medical Association (AMA) *Code of Medical Ethics* advises: "When a jurisdiction mandates reporting suspicion of violence and abuse, physicians should comply. However, physicians should only disclose minimal information in order to safeguard patients' privacy."[15]

The American College of Physicians *Ethics Manual* similarly provides:

> Physicians should protect public health by reporting disease, injury, domestic violence, abuse, or neglect to the responsible authority as required by law. Confidentiality . . . is not absolute. It may have to be overridden to protect individuals or the public or to disclose or report information when the law requires it. . . . If breaching confidentiality is necessary, it should be done in a way that minimizes harm to the patient and heeds applicable federal and state law.[16]

2. CONTROVERSY OVER THE BENEFITS OF MANDATORY REPORTING

The purpose of mandatory reporting laws is to mitigate and prevent harm. But it is unclear whether some reporting duties prevent more harm than they create. On the one hand, broadening mandatory reporting duties lowers the risk of false negatives. Fewer risks will go undetected, uninvestigated, and unmitigated. On the other hand, broadening reporting duties increases the risk of false positives. A low threshold for reporting means that many reports go unsubstantiated.[17] Many individuals will be investigated and many family relationships disrupted for no reason.

Moreover, even if reporting led only to true positives (substantiated cases of harm), it sometimes creates risks that arguably outweigh benefits. For example, it is highly intrusive and disruptive to a family when a child protection agency, an adult protection agency, or law enforcement investigates a report of abuse or neglect. Sometimes the harm is even more concrete and direct. For example, reporting a case of suspected domestic violence often leads to a victim being "punished" by her batterer.[18] Similarly, if mental health patients feel that they have no safe outlet, then they will not share violent thoughts. The risk of savagery will go undetected and unaddressed. Indeed, mandatory reporting is correlated to increased rates of homicides and teen suicides.[19]

Furthermore, breaching patients' confidentiality to make a report can destroy the integrity of the treatment relationship. If patients know that information will be shared, they may be less open and honest.[20] And breaching confidentiality may decrease patients' trust not only in the current care-provider, but also in the entire system. So, the patient may avoid healthcare altogether. Weinberger and colleagues note, "Blanket reporting laws that compel physicians and other health professionals to report patients . . . may have unintended consequences. They can . . . create a disincentive for them to seek treatment, and undermine the patient-physician relationship."[21] This increases risks not only to the patient but also to the public. For example, legislation requiring physicians to report illegal immigrants could cause patients with tuberculosis to delay seeking care, thus causing the disease to spread.[22]

With respect to reporting child abuse, the U.S. is an outlier. Many countries give clinicians a "right" to report, but the U.S. is one of the few that imposes a "duty" to report.[23] Moreover, U.S. law is still evolving. Several states continue to adopt, implement, and

strengthen various kinds of mandatory reporting laws. The scope of clinicians' reporting duties is expanding.[24]

Yet, as one prolific commentator, Ben Mathews, observes, "the field lacks a detailed evidence base about their consequences." Accordingly, he recommends that "jurisdictions which introduce the laws should carefully monitor their implementation."[25] The AMA *Code of Medical Ethics* similarly advises that "if available evidence suggests that mandatory reporting requirements are not in the best interests of patients, physicians should advocate for changes in such laws."[26] Accordingly, it may be time to pause and reassess the benefit and risks of all the compulsory reporting duties imposed on clinicians.

3. NEW AND EXPANDED DUTIES TO REPORT

Over the past year, a number of jurisdictions have expanded clinicians' duties to report. They have done this in two ways. First, the countries of England, Wales, and Ireland, and the U.S. states of Pennsylvania and Michigan identified new types of information that are reportable. Second, the U.S. states of Connecticut and Missouri did not change the types of information that are reportable, but expanded which clinicians have a duty to report.

England and Wales

Female genital mutilation (FGM) comprises all procedures involving partial or total removal of the external female genitalia for nonmedical reasons. FGM has been illegal in England and Wales since 2003. Effective 31 October 2015, the 2003 law introduced a mandatory duty to report. It requires healthcare and social care professionals to report "known" cases of FGM in minors to the police. "Known" cases are those in which either a girl informs a person that an act of FGM has been carried out on her, or when a person observes physical signs on a girl that appear to show that an act of FGM has been carried out.[27]

Ireland

Ireland is considering an even broader new reporting duty for healthcare professionals. Irish Health Minister Leo Varadkar announced plans to legislate mandatory open disclosure of any mistakes involving patients.[28] The minister described incidents in which medical professionals fail to adhere to a duty of candor and disclose the relevant information as being "the equivalent of a hit-and-run." In early 2016, Minister Varadkar aligned his proposal with that in a major report of patients' safety.[29] The Health Information and Patient Safety Bill now limits its mandatory reporting to only adverse events that result in death or serious harm.[30]

Pennsylvania

In 2015, a major package of child abuse laws took effect in Pennsylvania. The laws are the result of recommendations by the Pennsylvania Task Force on Child Protection that convened in the wake of the high-profile Jerry Sandusky scandal at Pennsylvania State University. One law expands the definition of child abuse. For example, it lowers the threshold for physical injuries that can indicate child abuse, by replacing "serious physical injury" with "bodily injury."[31]

Michigan

Current Michigan law requires clinicians to report a person suffering a wound or other injury inflicted by means of a knife, gun, pistol, or other deadly weapon. A 2016 bill would additionally require clinicians to report a person suffering from a burn injury when there is suspicion of arson.[32] Unlike most mandatory reporting, focused on health and safety, this new law is directed at solving crime.[33]

Connecticut

While some expansion of mandatory reporting duties pertains to types of reportable information, other expansion pertains to who is a mandated reporter. For example, before October 2015, Connecticut imposed a duty to report impaired healthcare practitioners on only physicians and physicians' assistants. But new legislation now extends that duty to all licensed healthcare professionals. "Any health care professional . . . shall . . . file a petition when such health care professional . . . has any information that appears to show that a health care professional is, or may be, unable to practice his or her profession with reasonable skill or safety."[34]

Missouri

Like Connecticut, Missouri has sought to expand the number of mandated reporters. Existing law requires certain healthcare providers to submit a report when they have "reasonable cause to suspect that [an elder] has been subjected to abuse or neglect."[35] The law applies to a wide range of clinicians, from optometrists, to dentists, to pharmacists. But the list is not comprehensive. In 2016, legislators introduced a bill to add emergency medical technicians, fire fighters, and first responders to the list of mandated reporters.[36]

4. CRIMINAL PENALTIES FOR FAILING TO REPORT

The failure of a mandated reporter to make a timely report is a criminal offense. A quick perusal of the daily headlines shows that the targets of many recent criminal prosecutions are school officials and daycare providers.[37] For example, Susan Clark was recently convicted of failing to report sexual abuse at Miracle Meadow, a school for children with at-risk behaviors. But school officials are hardly the only defendants. Prosecutors have also been targeting healthcare providers.

California

In January 2016, a jury convicted Theresa Hamilton-Casalegno of failing to report the abuse of a dependent adult.[38] Hamilton-Casalegno was the chief executive officer of Rideout Health, a healthcare system north of Sacramento. In 2013, a nurse had used soft restraints, without a physician's order, to tie down and wash a patient suffering from acute psychosis. This was abuse. If the patient became agitated during the bath, the nurse should have sought an order for restraints. Hamilton-Casalegno knew about the abuse and decided not to report it. Rideout Health's senior vice president for quality was found guilty of the same offense.

5. CIVIL LIABILITY FOR FAILING TO REPORT

In addition to criminal penalties, a mandated reporter's failure to report can result in civil liability. Particularly if the individual intended to be protected by the report is later injured, then that individual or the individual's family may sue for money damages. The claim is that had the clinician made a timely report, the victim's injuries probably could have been prevented.

Pennsylvania

In late 2015, the Superior Court of Pennsylvania determined that patients may pursue medical malpractice actions against healthcare providers who fail to report suspicions of child abuse.[39] K.H. was born prematurely in 2002. Over the next several months, K.H. was hospitalized repeatedly for problems including rib fractures. A number of specialists discussed their suspicions of possible child abuse. But no one reported the potential abuse. Later, when K.H. was almost six months old, his father shook him so violently that he experienced an intracranial hemorrhage resulting in permanent brain damage. The trial court ruled that the case could not go forward because the child abuse statute included no civil liability provisions. But the Superior Court disagreed. It found that while the statute does not specifically allow for civil remedies against healthcare providers, it does not give them immunity or otherwise preclude finding them negligent in an "ordinary" medical malpractice action.

Montana

Across the United States, there is significant variability in so-called *Tarasoff* duties, the duty of psychotherapists and psychiatrists to warn potential victims.[40] In 2015, Montana clarified the duty in that state. Justin Schiller was involuntarily committed to the Montana State Hospital in June 2008. Several months later, he saw his former girlfriend, Catherine Woods, at a bar with a male friend. When Woods left the bar, Schiller killed her.

Woods's parents sued the hospital for breaching its duty to warn Woods of Schiller's potentially violent behavior. But the trial court granted summary judgment to the hospital. The Montana Supreme Court affirmed.[41] The relevant statute imposes a duty to report "only if the patient has communicated . . . an actual threat of physical violence by specific means against a clearly identified or reasonably identifiable victim." It was not sufficient that the Montana State Hospital knew of Schiller's tendency to be aggressive toward Woods. The hospital would have been obligated to report only if Schiller had communicated a specific threat of violence against Woods.

California

In late February 2016, the California Court of Appeals affirmed a trial court ruling that a physician did not breach his duty to report domestic violence.[42] In 2009, Jesse Crow murdered his wife of six months, Ryann Bunnell, and dumped her body into San Francisco Bay. Bunnell's mother sued Crow's father, a physician who had treated Bunnell several months before her death. Bunnell's mother claimed that the physician violated the law by failing to report suspected abuse.

In the prior incident, Crow had run over Bunnell's foot with his truck. He called his physician father to treat the injury. Both he and Bunnell were intoxicated and both explained that it was an accident. They told the physician that she fell as she climbed into the truck when Crow was backing it up. The court held that this was insufficient evidence to establish that the physician knew or reasonably suspected that Ryann's injury was the result of assault or abuse. Furthermore, the court held that even

if the physician had a duty to report, Bunnell's mother could not establish causation. She herself had reported abuse to the police. Their investigation did not lead to the prevention of Bunnell's murder. A report by a physician probably would not have led to a different or better outcome than the police investigation that actually took place.

In a second California case, in 2011, Renee Joy was involuntarily admitted to Aurora Vista Del Mar Hospital facility for a psychiatric hold. Another patient entered her room and attacked her. Joy was reportedly choked, raped, and sodomized. She sued the hospital for failing to keep the other patient in his room, failing to hire properly qualified personnel, and other negligence. She also sued the hospital for failing to report the rape of a dependent adult. But at the end of 2015, a jury returned a verdict in favor of the hospital.[43] The jury apparently believed the hospital witnesses and concluded that either the abuse did not happen or that it was reported.

Washington

Ho Im Bae was one of four residents at Lakeside Adult Family Home. Less than three months after being admitted, she died from acute morphine intoxication. Morphine was not one of Bae's prescribed drugs, and her death was ruled a homicide. The personal representative of Bae's estate brought a civil action for damages against two nurses for failure to report Bae's abuse under the Washington vulnerable adult protection act. The trial court granted summary judgment to the nurses. In February 2015, the court of appeals affirmed.[44] The first nurse was not required to make an immediate report because she did not observe any abuse. The second nurse did report suspected abuse almost immediately after learning about it. Thus, neither breached their duty.

6. DISCIPLINARY PENALTIES FOR FAILING TO REPORT

In addition to criminal sanctions and civil liability, mandated reporters' failure to report can result in discipline from their health licensing board.

Australia

Nathem Al-Naser owned and managed Belconnen Medical Center where he employed Maged Khalil. In 2012, Khalil engaged in sexual relations with a patient. That patient later told Al-Naser, who then treated the patient for the effects that relationship had on her health. But Al-Naser did not report Khalil and allowed him to continue working. In 2015, the Medical Board of Australia took Al-Naser to the Australian Capital Territory Civil and Administrative Tribunal (ACAT). In a February 2015 judgment, the ACAT reprimanded Al-Naser, barred him from supervising other physicians for two years, and imposed other limitations.[45]

7. LEGAL IMMUNITY FOR GOOD-FAITH REPORTING

Making a compulsory report may require clinicians to breach their duty of confidentiality. It can also be intrusive and disruptive to the person who is investigated. For example, a child abuse report may lead to parents losing physical custody of their children. The individuals who are adversely affected by a clinician's report may want to retaliate with a lawsuit. But so long as the report was made in good faith, the clinician has legal immunity.

Iowa

Clinicians are afforded immunity not only for reporting, but also for aiding and assisting in the assessment of a report. In June 2009, three-week-old Ethan Neiderbach presented to an emergency room with a broken arm. His injuries suggested child abuse. But one physician thought the father's explanation was plausible, and the investigation was stopped. The following month, young Neiderbach was hospitalized with a bleeding brain and at least 15 rib fractures. His parents were convicted and jailed for more than 20 years. Neiderbach's adoptive parents sued the physician for failing to report the initial injury. But the Iowa Supreme Court construed the statutory immunity provision broadly. It decided that a claim for failing to report may proceed to trial only when the plaintiff shows the doctor acted dishonestly.[46]

Ohio

In January 2016, Molly Blythe filed a lawsuit against physicians at Promedica Toledo Hospital.[47] Those physicians diagnosed Blythe's daughter, KB, with shaken baby syndrome. They reported Blythe to an Ohio children's services agency. The state removed both KB and her twin sister from Blythe's care. But the state later dismissed its abuse complaint. In her lawsuit, Blythe claims that the shaken-baby diagnosis was groundless. She seeks unspecified punitive and compensatory damages. But the case is unlikely to succeed, because physicians have immunity, so long as they acted in good faith. Blythe must establish not only that the physicians were mistaken, but also that there was no plausible basis for the finding of child abuse.

California

In 2010, Jill Jones told the Santa Monica UCLA (University of California Los Angeles) Medical Center that she had been holding her sleeping infant, G.J., in her arms when she tripped, and G.J. fell out of her arms, tumbled down several stairs, and landed on his head on the hardwood floor. Physicians determined that G.J.'s injuries, including a fracture on the back of his skull, were consistent with that explanation of the accident.

But Claudia Wang, the medical director of UCLA's Suspected Child Abuse and Negligence team, thought that the baby's injuries were unusual and potentially inconsistent with the parents' explanation. So, Wang had Jones bring baby G.J. back to the hospital. Wang made a report to the Department of Children and Family Services and to the UCLA police department. Notably, Wang also recommended admitting G.J. into the hospital to determine whether the baby had a metabolic bone disorder that was causing the fractures.

Wang later admitted that her primary purpose in making this recommendation was to prevent Jones from taking G.J. home. Wang's plan worked. G.J.'s parents believed that they were not allowed to take him home. Wang effectively seized the baby and took him into custody, even though there were no exigent circumstances indicating he was in imminent danger.

A social worker later issued a hold on G.J. based on Wang's suspicions. G.J.'s parents lost physical custody for months. But this was all unnecessary. Eventually, a juvenile court found that G.J. had not been abused and would not be at risk of abuse in the future.

G.J.'s parents sued for violations of their federal and state constitutional rights. The trial court denied Wang summary judgment on the basis of qualified immunity. In September 2015, the U.S. Court of Appeals for the Ninth Circuit affirmed.[48] The parents' claims concern Wang's efforts to keep G.J. hospitalized so that the parents couldn't take him home. Since Wang had already made the report before physically seizing G.J., reporting immunity did not apply.

In December 2015, the American Academy of Pediatrics, the California Medical Association, and other societies urged the Ninth Circuit to reconsider. They argue that the ruling will have a chilling effect on physicians and will impede their ability to treat, evaluate, and protect child abuse victims. Briefing on the motion for a rehearing will continue through March 2016.

8. PROTECTION AGAINST EMPLOYERS' RETALIATION

When a healthcare employee reports patient safety or patient rights violations by their employer, the employer may retaliate by terminating the employee. But most mandatory reporting laws protect whistleblowers.

Maine

Torrey Harrison was a licensed clinical social worker for Granite Bay, in Portland, Maine. Granite Bay provides services to adult clients with cognitive and physical disabilities. In 2010, she noticed that dependent adults doing maintenance work were not getting paid. In addition to this exploitation, Harrison noticed several other problems indicating neglect and abuse: (1) the electricity had been shut off at a group home, (2) alarmed windows (to prevent residents' wandering) were broken, and (3) another office was understaffed. She filed complaints with the Maine Department of Health and Human Services. Granite Bay subsequently fired Harrison.

Harrison sued Granite Bay for wrongful termination. The trial court ruled in favor of Granite Bay, because of an exception to whistleblower protection. It held that since reporting was part of her job duties, Harrison was not protected from retaliation. In January 2016, the U.S. Court of Appeals for the First Circuit reversed. It held that there is no "job duties exception" to whistleblower protection. The court of appeals remanded the case to the district court where it may now proceed.[49]

Texas

Tammy Jennings was employed by Loyds of Dallas as a caregiver. In 2014, she reported resident neglect issues involving inadequate medications and food. A few days after Jennings made these complaints, she was terminated. Jennings sued for wrongful termination. The trial court denied Loyd's motion to dismiss. In late February 2016, the Texas Court of Appeals affirmed, allowing the lawsuit to proceed.[50]

CONCLUSION

Compulsory reporting remains an important tool for identifying, mitigating, and preventing threats to the health of patients and the public. Over the past year, many states have expanded the reporting duties of medical mandated reporters. And many states have enforced compliance with these duties

through criminal, civil, and disciplinary sanctions. But we must assess whether these mandatory reporting requirements are in the best interests of patients and the public. As many of the above examples indicate, holdings remain inconsistent, and some are open to debate. Thus, there is much still to be done.

NOTES

1. This article was incidentally funded by the Greenwall Foundation's bioethics grants program, "Making a Difference in Real-World Bioethics Dilemmas." This program is designed to support research to "help resolve an important emerging or unanswered bioethics problem in clinical care, biomedical research, public health practice, or public policy." The purpose of the funded project, with David J. Casarett, is to provide guidance on what obligations hospice staff have to report instances in which they believe that a patient may have received assistance in committing suicide from a friend or family member or, in states where such assistance is illegal, from a healthcare provider.

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3. See note 1 above, pp. 1127-8.

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5. Greene et al., "The Ethics of Care," see note 2 above.

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