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At the Bedside

How to Retain the Trust of Patients and Families Even When We Will Not Provide the Treatment They Want

Edmund G. Howe

ABSTRACT

How might clinicians best try to retain the trust of patients and family members after clinicians oppose giving a treatment? If clinicians can maintain the trust of patients and families in these situations, this may soften what may be the greatest possible loss—the death of a loved one.

I discuss what clinicians seeking to retain trust should *not* do—namely impose their values and reason wrongly—and introduce strategies that clinicians may use to reduce both. I present five principles that clinicians can follow to try to retain trust, with examples that illustrate each. I suggest specific interventions that clinicians can make, especially when they anticipate that a patient and/or family may, in time, want a treatment that is futile.

In this issue of *The Journal of Clinical Ethics (JCE)*, Steven Perry and Arvind Venkat report a case in which clinicians believed that they should stop a young woman's life-sustaining treatment because she had a rapidly degenerative autoimmune neurologic condition, and so a grim neurologic progno-

sis.¹ Her father, who had been estranged from his family for many years and who had been located by social workers, did not agree with the medical team. Consequently, the patient received continued life-sustaining treatment and was transferred to a long-term care facility. This raises the following question: How might clinicians best try to retain the trust of patients and families after clinicians oppose giving a treatment? This question arises in many contexts, but is paradigmatic of cases in which clinicians won't provide treatment they consider to be futile.

How to retain trust is a question of utmost importance, especially in this context. If clinicians can maintain trust in these circumstances, it may soften what may be the greatest possible loss—the death of a loved one. Trust may prevent further hurt for families who expected the medical team to save their loved one, but instead seemed to make choices that caused the patient's death. In extreme cases, family members have expressed the turmoil they feel by forming a barricade around the patient's bed, to protect the patient.² Such struggles may leave family members passive and embittered, with tragic after effects. For example, family members who become sick may not seek care or seek care soon enough. Could this tragic loss of patients' and families' trust for clinicians possibly be avoided?

In this issue of *JCE*, Autumn Fiester responds to Perry and Venkat's letter, and she suggests that some shared resolution may be possible.³ Fiester says that

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she is “partisan about process, but not about the outcome in any but the most obvious ethical conflicts.” She adds, “if the daughter [in this case] were capable of hearing [her father’s] reasons, she might have considered them appropriate,” and that this may be “why the mother ‘acquiesced’ to the long-term placement rather than withdrawal of therapy.”

But what happens when a shared resolution is not possible? How can clinicians best try to retain the trust of patients and family members? I shall address these questions here.

WHAT NOT TO DO

Clinicians can lose the trust of patients and family members by imposing their own moral views unnecessarily or by using flawed ethical reasoning.

Don’t Impose Moral Views Unnecessarily

Clinicians have exceptional medical knowledge. They may assume that because they have this exceptional knowledge, they also must have exceptional knowledge regarding ethics. As Robert Veatch said decades ago, clinicians may have this exceptional expertise, but, if they do, they must demonstrate it. It cannot be assumed.⁴ Exceptional expertise in ethics would include knowledge of approaches that those trained in ethics would deem optional (although these may be open to debate and, in practice, are usually only self-assessed).

Clinicians routinely assess the limits of their medical knowledge. For clinicians, there may be no single capacity more important than recognizing the point at which they lack medical knowledge. Edmund Pellegrino, a much renowned and respected physician and ethicist who recently died, believed this capacity was so important that when he interviewed students applying to medical school, he would ask them increasingly harder and harder questions until they were stumped. Most students would admit it when they didn’t know. If a student didn’t admit this, however, it was much less likely that Pellegrino would recommend that the student be admitted.⁵ We all can (and do) overestimate what we know, and may deny our inability to know when we don’t know, much less acknowledge what we don’t know, and when. Pellegrino’s “test” therefore taps a predilection we all have. Even so, it may distinguish those who have the integrity and strength to admit a lack of knowledge from those who don’t.

Even when clinicians have ethical expertise and know where it ends, they mustn’t introduce their expertise unwisely. This is primarily for two rea-

sons. First, patients and families may not want this. Even when clinicians’ ethical views are sound, sharing an ethical view may make it emotionally harder for patients and families to make a different choice. Second, patients and families may bristle, reflexively, should clinicians seem to imply what they should do. We all may react in this manner, even when the other person is right.

Here is an example of how clinicians possibly could go too far in trying to further an optimal ethical outcome by introducing their own moral values. An elderly woman lived at home, even though she was more or less bedridden. There were many things she couldn’t do for herself, but she could call for emergency assistance if needed. Her adult son lived with her and went to work each day to support them. He joined her as much as he could, but was not home 24 hours a day. A visiting nurse told her supervising physician about their circumstances. This doctor and his colleagues thought it medically obligatory that the woman enter a nursing home so that she could have attendants nearby at all times. Their medical model indicated that care should be available 24 hours a day. The problem was that she lived for being with her son, and if she went to a nursing home she would live far away from him. Fortunately, in time, the medical team recognized this, and they accepted her living as she was. They did not impose what they had believed their “medical model” required, and the woman continued to thrive.⁶

Don’t Engage in Flawed Moral Reasoning

Clinicians, as anyone, may adopt flawed moral views. These views may stem from emotional bias. Without knowing this, they may rationalize their flawed views to justify them after the fact. They may impose a flawed view not because it is right, but because they have the power to do so, and they may not be able to see the difference. James Adam Wasserman, Shannon Lindsay Stevenson, Cassandra Claxton, and Ernest F. Krug, III, in this issue of *JCE*, suggest that this may be the case, and it may occur more often than previously believed.⁷ In “Moral Reasoning among HEC Members; An Empirical Evaluation of the Relationship of Theory and Practice in Clinical Ethics Consultation,” they report that, in their study, ethics committee members frequently appeared to have made immediate moral judgments and rationalized their judgments afterwards.

Their conclusion, if valid, is disturbing. It might indicate that we may “cherry pick” our ethical views and then rationalize them, falsely, more than we think we do. Here is an example from my own ex-

perience. An elderly Greek man who had been a bricklayer was hospitalized with kidney failure, other serious and progressing heart and lung problems, and dementia. He couldn't express what he wanted, but it was clear that he still very much enjoyed being with his family. Likewise, his children and grandchildren cherished being with him, and arranged for a family member to be with him during his every waking hour. They wanted him to have kidney dialysis, but the medical team refused, as they believed he would live no more than a week or two at most. Thus, instituting dialysis would prolong the patient's death, not his life, and would be futile.

Other interventions may also be seen as futile because they are perceived as prolonging the death of a patient. At the same time, treating a patient will sustain life, and, as was the case for this patient, give him the opportunity to continue to interact and find joy in his family members, and they in him. Therefore, when clinicians assess these situations, they should keep both of these ideas in mind, and seek an optimal synthesis.

In this case, without dialysis, the patient died shortly afterward, as all expected. The team's decision may have been the best one, but this may illustrate the possibly limited logic the team may have used. That is, it might have placed more moral weight on what dialysis would not have accomplished for the patient, rather than on what it would have accomplished, because the former seemed to be more in line with their medical model.

When the team told the patient's family that the patient would not receive dialysis, the team offered the option of transferring the patient to another facility, if one could be found that would provide dialysis. The family chose not to look for another facility. The team reasoned, in light of this, that the family most likely did not really want dialysis. Perhaps, the team thought, the family was afraid to say they didn't really want dialysis, or even to admit this to themselves. Perhaps, the team reasoned, the family felt too guilty to know they felt this way, much less to say that dialysis need not be started.

This possibility is plausible. Some family members have reported they felt "too guilty" to request interventions for a loved one, such as sedatives and analgesics when the loved one is withdrawn from a respirator.⁸ In these instances, family members may say they feared that the medications would make the difference between a patient's continuing, or not continuing, to breathe. Family members may have feared that if they requested the medications, it might have caused the patient to die.

Still, for this family, that was only one of several possibilities. Maybe they simply felt helpless and gave up. If the medical team had considered other explanations for the family's not pursuing a transfer—for example, giving up—the team might have responded differently. For example, they might have asked the family, "Do you want to pursue a transfer? Because if you do, would you like some help making phone calls?" Doing this could have had additional, important positive effects. For example, it may have increased the likelihood that such a place would have been found, and, more to the point, might increase the family's trust in the medical team.

AN APPROACH THAT MAY REDUCE MORAL ERROR

Joshua Greene, in his book *Moral Tribes*, presents an approach that may help clinicians reduce moral error.⁹ Its subtitle, *Emotion, Reason, and the Gap Between Us and Them*, captures and conveys his focus. Greene addresses the gap between our emotions and our reasoning, and suggests when we may be wise to give more moral weight to one versus the other. For example, he asks when we should particularly listen to what we feel, and when we should not. His beliefs may or may not ultimately be valid, but it would seem they may provide a means by which we can check our conclusions, and, having done so, come out better. I will describe his main points here.

Use Emotion More When Acting as an Individual

Greene asserts that when we are acting toward others as individuals, our minds tend to work differently from when we are acting as members of a group—as members of our "tribe" (thus the title *Moral Tribes*). When we act as individuals, he believes, we are more prone to act to fulfill our own self-interests, even when that may cause harm to others. When we are doing this, an emotion within us may suddenly burst forth and shout, *No—don't do this!* Greene says this is an especially fast and strong "emotional alarm bell" that has come about through evolution, to enable us to better avoid harming others. Without this emotional alarm system, he writes, we'd be "moral monsters." He calls these situations "Me versus Them."

Greene contends that there was an evolutionary benefit to this system because we needed others to survive. To survive we had to be socially connected. This alarm system alerts us to the possibility we may be doing something morally wrong. It moves us to

be more empathic toward others and be less automatic in putting our own needs first. Greene asserts, consistent with the findings of Wasserman and colleagues, that when we are acting for ourselves, we are vulnerable to rationalizing falsely, in ways that most serve our own interests. If our emotional alarm goes off, it may be our only inkling that we are doing something that, once examined, may be ethically wrong. (Greene's belief that this alarm exists as an evolutionary adaptation is speculative, as are other moral behaviors explained in this way. This "alarm" could be no more than a reflective pause that is made possible after the push for immediacy.)

Such an "alarm" went off for me recently. I'm glad it did. A patient told me over the phone he had just entered a lottery, saying, "I think I might win." I replied, dryly, "Possibly." Clearly disappointed, he said, "You're supposed to help me feel better. Now, you've just made me feel worse." Then he said, "Let's talk about medications." Thinking about it later, I felt anxious, and I considered whether this was an alarm bell telling me that I'd done the patient harm. I called him back and said, "I'm sorry. I know that winning the lottery would be very important to you." In reply, he said, "I know you only meant to help."

Use Reason More When Acting as a Group Member

When we are acting as a member of a group, we are more likely to act based on our feelings rather than on reasoning. Greene says this also is an evolutionary response, to protect members of our tribe. When an event seems to threaten our group, Greene asserts, our feelings direct us primarily to the needs of the group, and may not reflect other values that moral reasoning might suggest. (Another explanation might be that we automatically favor the best interests of our own group when threatened.)

An example of such a value is distributive justice, which might benefit strangers or those worst-off, but not necessarily those in our group. An emotional response to protect members of the group may have been present among the clinicians in the case involving the patient and her estranged father. The patient's father had been estranged from his family and was a stranger to the medical team. When we have feelings that are protective of our group, Greene says, we should consider placing less moral weight on the possible validity of our emotions and place more moral weight on our reasoning. Fiester's response to Perry and Venkat, which I considered above, may be an example of the kind of corrective moral reasoning that Greene urges. Fiester writes, "I don't know the father or what his reasons were, but if he were morally opposed to withdrawal, that

would in no way be an illegitimate moral concern, even if he was delinquent in his relationship with his daughter while she was still healthy."¹⁰

This type of response may be helpful when we want to discount the view of a family member because he or she hasn't visited the patient often. We may feel the family member is a "stranger," but perhaps that fact shouldn't, as Fiester says, invalidate his or her views. Fiester adds, "If [the father's] resistance to withdrawal wasn't the morality of withdrawal *per se*, but instead related to the state of his relationship with his daughter, that may constitute a different, but also possibly justified, ground for refusing withdrawal."¹¹ In this way, Fiester suggests that the relationships between patients and others, in and of themselves, may warrant moral weight. Placing greater moral weight on the importance of a relationship to the parties involved may change how we balance various factors when we make ethical decisions, and, possibly, how they come out.

When our predominant feelings are to protect members of our group, our feelings may be telling us, "unthinkingly," that we should oppose a perceived enemy. When this is the case, we may subscribe to that feeling too quickly—and so be more likely to be morally wrong. Greene calls these situations "Us versus Them." Here, he says, we should not act so much on the basis of our emotions, and we should check out our conclusions to a greater extent. We should use "slower" moral reasoning. "Let's agree, then," he writes, "that when we . . . disagree, we'll stop and think."¹²

Applying Moral Tribes to Other Situations

To illustrate how clinicians might apply Greene's approach, I will apply it to two different ethical questions raised by articles in this issue of *JCE*. One article asks when clinicians should save men's sperm; other articles consider when (if ever) clinicians should agree to "repair" a woman's hymen, when this is requested for cultural reasons. In " 'Let Me Keep My Dead Husband's Sperm': A Systematic Review on Ethical Issues in Posthumous Reproduction and the Introduction of an Ethical Decision-Making Tool," Nikoletta Panagiotopoulou and Stamatios Karavolos ask when a clinician should save a patient's sperm, and provide several questions that clinicians may ask to assist in making this decision.¹³ How might Greene's framework help here? In this instance, we might see ourselves as primarily responding in the interest of our own group. For example, we might see ourselves as having to adhere to our medical, professional standards, or,

alternatively, to the interests of our greater society. In regard to this latter interest, we may see ourselves as having a duty to limit medical spending. We may see society as having given us this duty, not by law, but by default. Or we might have strong feelings for the person who is requesting the sperm, for instance, a woman whose husband died unexpectedly and suddenly, and who is bereft.

Using Greene's view, our "emotional alarm," that reflects empathy for the woman, might go off. We might feel for her, and, if we do, Greene would suggest that we should listen to it. To save the recently deceased husband's sperm might have a negligible societal effect, in this instance. Doing so might set a precedent, but these same circumstances may occur only rarely. Saving the husband's sperm might mean more to this woman than anything else, ever, for the rest of her life. This possibility reflects one example of how people may derive profound meaning from very different things—in this instance, this woman may find profound meaning in the memory of her husband. The wish to be remembered is a traditional source of meaning: historically, people have willingly died in battle to be remembered, as was related, for example, in the *Iliad*. Considering this, we might return to the estranged father, and even the patient's mother, who wanted to keep their daughter alive. Some of us may prioritize having just a few more days, hours, or even minutes with a loved one as sublime and uniquely precious. When we attempt to apply "corrective" moral reasoning, we should consider situations like this.

Wasserman and colleagues raise the importance of justice in moral reasoning. Adding the value of justice to Greene's emphasis on the importance of listening may lead us in an unanticipated direction. We might conclude that saving sperm is, in some instances, so exceptionally important that, if we can't assist everyone who requests it, we might design a fair system to assist those who do. Perhaps we might need to set up a system like the one we now have for kidney transplant. Or we might randomize sperm saving so that it is fairly available to all.

How might Greene's views be applied in the second situation, of a woman who, for cultural reasons, requests surgical repair of her hymen?¹⁴ (Greene's views may be worth considering not because he is necessarily right, but because his pragmatic rubric may be helpful in this context.) It would seem highly likely that we might respond based on loyalty to our own group. In the United States, we highly value gender equality, and we might be initially inclined to refuse to help, based on considerations of "Us versus Them." Our gut feeling might be to strongly

oppose such surgery, but Greene would advise that we not listen so much to that feeling, but instead to value our reasoning to a greater extent. This kind of response might place less moral weight on any self-righteous anger evoked in response to the gender inequality and injustice that appears to be expressed in this woman's culture. If we are able to respond more with reasoning than with emotion, we may be able to place greater moral weight on the plight of the woman and on what is most important to her. As we did in the case of the woman who asked to preserve her deceased husband's sperm, we could ask whether considering the needs of the woman who asked to have her hymen reconstructed could significantly affect other, "larger" factors, such as cultural views in her home country—and the extent to which this may or may not matter.

As I mentioned above, there are strong historical and cultural drives to be remembered, and to remember, that may factor into a woman's request to save her partner's sperm. A consideration of a request for hymen restoration likewise calls forth historical precedents; for example, banishment as punishment for doing wrong. Such a request can remind us of the importance of ongoing, meaningful relationships with loved ones—prospective marital partners and family members.

We could envision requests for these procedures as existing along a spectrum, which may help us, to a greater extent, determine what moral features are essential as we attempt to reason through where to "draw the line." For example, requests to save sperm could be considered in relation to women's requests to freeze their eggs because they have cancer and want the chance to conceive a healthy child later, after treatment. Hymen repair could be considered along a spectrum that includes cosmetic surgery for both women and men.

One consideration already raised is the unique meaning some find in even the shortest extra time with a loved one before death. In this instance I think of a woman I met who held her newborn son for just 10 minutes before he died in her arms. Still, now years later, she continues to see these as the most meaningful moments of her life. Should we add to this type of special meaning, and place in the same category, a woman's request to save sperm—or, in the appropriate culture, having an "intact hymen" at one's wedding, to preserve familial ties? Or should a line be drawn between these, somewhere?

Finally, our reasoning should alert us to related examples in our own culture. One example is our culture's interest in losing weight—not in avoiding obesity—but in being "sufficiently thin." Another

contemporary concern, particularly among women, may be having “thigh gap.”¹⁵ Some view this interest in being thin as a less-than-healthy “obsession,” particularly because, for some, such a pre-occupation with dieting, which they can’t stop, is no less than life-deadening. Our own cultural bias must be subjected to the same scrutiny as we reason and assess patients’ requests involving cultural beliefs with which we disagree, as this may affect and change what we conclude.

FIVE KEYS TO GAIN AND RETAIN TRUST

As noted above, a patient’s trust in a clinician may soften what may be the greatest possible loss—the death of a loved one. I propose five general principles that may be most helpful when we wish to gain and retain the trust of patients and their families. These may be especially important for clinicians who want to retain trust, who anticipate that they may later feel they must refuse, or at least oppose, giving a patient a treatment that the patient or family want.

The moral foundation of such efforts is an attitude of humility. To best establish conditions that maximize the possibility that clinicians will be able to authentically engage patients and family members, clinicians should view patients and family members as equal, vulnerable people.

1. Reduce Fear

Our neural responses have been “wired” through evolution to protect us from harm and death. One of these responses is to fight, flee, or freeze when we experience fear. The implication of this for clinicians doing ethics is far-reaching. If we evoke fear in patients or families, they may become unable to focus on anything else. For example, fear may impair their capacity to hear and understand. Given this, not evoking fear should be our first, top priority. How might we not do this? A master here was the psychiatrist Milton Erickson. He sought to help patients, and he frequently did when no one else could. He often used indirect hypnosis or suggestion. This was necessary to insure that patients felt sufficiently safe to be able to hear his suggestions that they could get better and what they could do better.¹⁶

Erickson’s primary general rule was to “go with” his patients’ resistances. In practice, this meant he would be accepting of whatever they felt. He would move forward with patients, but only to the degree that they could and would accept it. The relevance of this to clinicians doing ethics, especially when

they might stop providing futile care, is this: rather than trying to persuade patients and families about what they should do, at least initially, clinicians should try to proceed as Erickson did. This may mean taking unusual measures. For example, to help a patient feel safe, a clinician could, at first meeting the patient, ask the patient whether it would be acceptable to proceed as the clinician usually would. That is, the clinician could ask, “Would you like to begin by my sharing with you what I think is most important, or would you prefer for us to discuss your concerns first?” The clinician might then affirm the validity of what the patient wants, and how the patient wants the clinician to respond.

Here is a specific example. At this point in the discussion, a patient and family may say that they want CPR (cardiopulmonary resuscitation) because they feel that every last moment of life is precious. This view may be uncommon, but if they feel this way and are willing to share it, a clinician can indicate that she or he can “see” their point of view. (A clinician may see this statement as an expression that the patient and family have not adequately processed their grief, or that they misunderstand the costs and benefits of CPR. This perception may be unwarranted—perhaps that is what the patient and family really want most.)

After the patient and family state their wishes, the clinician may say that, notwithstanding the patient’s and family’s stated preference, the clinician may have contradictory obligations that should be discussed, namely that, at some point, the medical team may have to deny a treatment that the team deems futile. The clinician can ask the patient and family whether they want to know the reasons for this requirement. If they do, the clinician can say that part of the reason would be that the treatment would not benefit the patient. The clinician could then ask the patient and family whether or not they agree. They may not. For example, a patient and family may believe providing CPR, no matter what, will be best because it will comfort family members and make the patient’s death less painful for the family. The clinician could discuss this perception with them. If they continue in their original preference, the clinician could then assure them that she or he will voice their preference fully for them, if and when decisions about futility are being made.

In discussions around CPR, it can be very productive to ask patients and families a question that is not often asked: How do you imagine you would feel if the patient survives CPR, but still has little chance of continued survival? The clinician could share that some patients have felt dread. For ex-

ample, some patients then ask, bitterly, why they were kept alive.

I recall a patient who begged a loved one to end his life for him. The patient had metastatic cancer and said, "it's unbearable, just waiting to die." (A similar situation may have moved Samuel H. LiPuma and Joseph P. DeMarco to write "Expanding the Use of Continuous Sedation Until Death: Moving Beyond Last Resort Protocols for the Terminally Ill," in this issue of *JCE*.¹⁷) After this patient died, his loved one confided to me, weeping, that he felt terrible because he wasn't able to help the patient die. I said, "That you weren't able to help may have meant more to him. It may have conveyed how deeply you really cared for him, because you couldn't take his life."

I don't know whether I was right about this, but these are the kinds of accounts, of the dread and suffering that may follow CPR, that a clinician may be able to share after using Erickson's approaches to support patients and family members. This kind of sharing may be less possible if a clinician starts with telling the patient and family that they should agree to a DNR (do-not-resuscitate) order. As Erickson found, patients and families may have less fear when they have nothing to resist. Having less fear, they may feel more willing to discuss realities that are in conflict with their original preferences. Then they may be more able to make a different choice.

2. Give Over as Much Control as Possible to Patients and Family Members

Many patients and family members feel better if they have more control. Their response to having more control may be disproportionately great, and this may be further increased when a patient or loved one might be dying, or is actively dying. There are many examples, ranging from patients with dementia feeling great relief from knowing they can pull up their pajamas because they have an elastic waistband, to the relief felt by knowing that if the pain gets too bad there is a way to obtain pain relief.

An example illustrating this disproportionality in the context of impending death is the following. A premature baby was in an incubator. His mother knew he might die. The baby had on a knitted cap that a hospital volunteer had made. In the incubator the cap fell off. The mother felt exceptionally, disproportionately distressed. Perhaps she was displacing all her profound fear of her child dying onto this. She struggled over whether to ask the neonatologist—busy with other things—to replace the cap. Although she was exceptionally timid in this respect, she did ask, and felt extraordinary, instant relief.

The lesson seems clear. Clinicians should seek ways to give patients and families more control, whenever they can. An easy-to-follow way to do this is to ask, before doing anything to which they can imagine anyone might object.

3. Imagine What May Be Ambiguous or Misinterpreted

Some patients and families scrupulously analyze clinicians' every word and nonverbal behavior. They ask themselves not only what clinicians are saying, but why they are saying whatever they say. Thus, clinicians should always explain *why*. And they can do still better. When they say something ambiguous, patients and families may misinterpret it and feel fear. Like the mother of the neonate with the cap, patients and families may feel too afraid to ask whether their misinterpretation is correct. Clinicians may help by imagining any possible ambiguity before speaking, clarifying beforehand what they mean and what they don't. It may be impossible to anticipate others' misinterpretations, but in some cases it is quite possible, as in the following case.

A patient had to remain in a hospital to stay alive; she needed a daily treatment that required she be there, and had been for months. Her family was like the family of the patient described above who had dementia and needed dialysis to live even just a few days longer. Her family visited her every day, around the clock. A clinician who had recently become more aware of the importance of ethical principles such as autonomy, from a course he had taken, feared that the patient might not know that she could refuse further treatments and die. "She might want to free up her family so that they can go on with their lives," he told me. He told the patient this. She then chose to refuse treatment and died the next day. When the clinician said this to her, what did she hear? Did she hear that she should die, or that she could make this choice? I wonder.

The clinician's statement may have been ambiguous. It might have been helpful for her clinician to share ahead of time what he meant and what he didn't. For instance, he could have said, "It's clear how much your family loves you and how precious it is to them to be with you. They care for you so much, I'm sure what they want for you is whatever you want. If you want to continue treatments at the hospital, I can't imagine there would be anything they would want more than this."

When a clinician tells a patient and family that they might later want a treatment that the clinician

sees as futile, it may be ambiguous. The patient and family may infer from this, for example, that the clinician is saying this because the patient is imminently dying, or because the clinician wants the patient and family to accept stopping a treatment that the clinician wants to stop. Clinicians can reduce this risk by anticipating such ambiguity and by clarifying, in advance. On the other hand, clinicians are not clairvoyant. But the dangers of misinterpretation are great, as these examples show. Further, patients and family members may feel deeply hurt when they misinterpret a statement, and may become even more unwilling to ask whether what they have inferred is correct. If a clinician says in advance what they *don't* mean to say, it may convey to patients and families what the clinician wishes to avoid saying, and also that the clinician wants to hear about other possible misunderstandings of what they are saying.

4. Discuss Questions that May Be Stressful

Patients who are dying may not want to discuss their dying. They may want to discuss instead what they always have enjoyed, such as sports or art. As Kessler notes, "Sometimes it's best to say: 'Hey, did you know that the Lakers won five in a row?'"¹⁸ In fact, one patient said that this is the worst part of dying: some people treat you as if you are only who you were in the past. Patients may want to continue to enjoy ordinary interactions, and continue the flow of living as long as they can. But some patients may want and need to discuss what, to them, are very difficult questions regarding their dying. Clinicians may too often conclude that they should give patients and families only the information they need, but to be silent if they ask for a personal opinion. Clinicians may do this to be impartial, but patients and families often want their advice.

For example, a patient was dying from amyotrophic lateral sclerosis (ALS—also called Lou Gehrig's disease). The patient and his wife were greatly at odds because he wanted to call additional experts, but, due to this illness, he couldn't pick up or dial the phone. His wife felt "unglued" because she believed there were no more experts with additional expertise to call—she felt that they had talked to all of the top experts already. I suggested to her that she could see herself as just her husband's hands, giving him the means to make phone calls, which he lacked. Thus, she need not at all concern herself with whether or not his calling more experts made sense. She did this. He died, feeling loved by her, nestled in her arms, in the summer, under the stars.¹⁹

This patient's dying was fraught with emotional pain, and he and his wife's relationship had become greatly strained. A simple reframing of how his wife saw herself allowed both of them to change.

Conventionally, clinicians don't give advice, as I did in this case, which proved to be very helpful. Another convention is that clinicians typically don't give patients and families a way to reach them at home. Doing this may help patients and families to feel less alone, should a crisis arise, and may do a great deal to increase trust.²⁰ It is important for clinicians to foster and retain the trust of patients and families, especially if they later have to oppose or refuse giving a treatment.

5. Explore Meaning, and Accept that Patients and Family Members May Feel None

Often clinicians can help patients who are dying find additional meaning in life. One patient, for example, found meaning in making a video for his child about how to be a good grandparent, which included this advice: "When your adult children are grown and have children, they will ask you why you are so different now. You can say it's the job of a grandparent just to have fun."

Victor Frankl supported helping people find meaning in all situations,²¹ but some, even with support, may not find any. Frankl gave an example involving Yehuda Bacon, "one of Israel's leading artists." After just being released from a concentration camp, Bacon reported, "I saw a funeral with a huge coffin and music, and I started to laugh: 'Are they crazy, to make such a fuss over one corpse?' If I went to a concert or theater I would calculate how long it would take to gas a crowd of that size, how many clothes, how many gold teeth would be left. How many sacks of hair they would make?" The lesson seems clear: some patients and families will find no new meaning. Then clinicians must try to find other ways to support them. What could they do instead? They could, even if only for a short time, just *be* with them, even if they remain silent.

A clinician I described in the last issue of *JCE* helps pregnant women through labor and childbirth.²² When her own mother was dying, she used her professional skills to "connect best" with her mother. She said to her mother, "talk later, for now, just breathe with me." She says that to "connect with" a patient in "dire emotional or physical pain" one must "be fully present one moment at a time." Compassion "doesn't come from words," it comes from "being physically and emotionally present, concerned and grounded." It is a paradox that this

approach, which does not attempt to provide meaning, may provide the most.

Clinicians may help some patients find new meaning by saying how they feel. Irving Yalom, a psychiatrist, is considered a leading expert on group psychotherapy. In recent years, he has focused on existential concerns. He shares this instance as an example. A patient described seeing in his mind's eye his wife, who was alive, as dead and beckoning him to join her. Later, the patient said, just before leaving the psychotherapy session, "I'm wiped out." Then he asked Yalom, "Are you?" "Not at all," Yalom replied. But then Yalom says, he "slapped himself" and said, "No, I can't do this." (Greene might see this as an example of an "inner alarm" going off). "The truth is," he said to his patient, "I am tired . . . and I'm grateful I have no one else on my schedule today." Yalom didn't know what to expect in response. But the patient said, "I knew that. . . I know when you're just trying to be therapeutic."²³

SPECIFIC INTERVENTIONS

There are several specific interventions that clinicians can use to try to retain the trust of patients and families when they may later have to oppose or refuse giving a treatment. I shall discuss these interventions in the order in which clinicians may best use them, from before they see the patient, to after the patient has died.

Initial Steps

Enact a Policy

Hospitals may or may not have a policy on futile treatment. Refusing to provide a treatment that is futile when there is no policy in place risks evoking the profound distrust of the patient and family, and, in general, it may be best to refrain from doing so in this environment. The possible harm to patients and families may be unwarranted. If no prior policy exists, clinicians are challenged to explain why they believe that the "criteria" they propose for not giving the patient a treatment, on the ground that it is futile, have been met. Without the backing of an established policy, such a refusal may be perceived as discriminatory by the patient and family. The lack of policy allows such ambiguity, and the dangers of ambiguity that were outlined previously may not be avoidable.

When a policy does exist, it might be ideal, if it would be agreeable to the patient and family, for clinicians to invite them to apply the criteria stated in the policy to their situation, so that they might be

better able to see the clinicians' view for themselves. An appeal to policy may have a downside: the patient and family may see this as a one-size-fits-all, cookie-cutter response, and feel this slights them by neglecting their particular sensibilities and needs. Accordingly, clinicians could state that, working together with the patient and family, they would be open to reconsidering anything they may have missed. Before beginning such conversations with the patient and family, clinicians might want to rethink what stopping the treatment unilaterally would accomplish, and weigh that against any exceptional, competing considerations. As noted above, for example, some patients and families may consider gaining any possible extra last moments of life to be of extreme importance.

Discuss Who Will Speak for the Family

It is essential for clinicians who seek to establish trust with patients and families to first inquire and determine whether they will speak with just one member of a family or several members. This may be particularly a concern—and, to some degree, may be a different ethical concern—if the family wants only one member, such as the eldest son, to speak for them because this is the practice in their culture.²⁴ If the patient and family want just the eldest son to speak for them, some clinicians may find this unacceptable.²⁵ If this disagreement can't be resolved, clinicians could use the same steps as when no agreement can be reached regarding a futile treatment.

That is, clinicians might first say that they can understand why the patient and family may disagree with them, and perhaps even feel enraged at being challenged. After all, the patient and family may be wondering, "Who is this person, to deny us what is so precious within our culture?" In this situation, clinicians could say, "If it's okay with you, I'd like to explain how I thought about this," and share what they think, and why.

Disclose Future Hopes

Before beginning medical treatment, clinicians should inform the patient and family that if an ethical issue arises in the course of treatment, they will be asked to return to the hospital to review what happened. Clinicians should explain that returning will allow the staff to learn from them, and, more importantly, for all parties to retain trust in each other. Declaring a genuine hope that the staff may want to learn from the patient and family, and that the staff values their trust to such an extent, may help establish a fertile soil in which trust can grow.

All of the steps described above risk being applied in a perfunctory manner. The key is to apply them in a way that is not formulaic. Clinicians can note and respond to even nonverbal cues that patients and family members may show in response to each intervention.

Talk to the Patient and Family before a Treatment Is Not Provided

Alert Early that Treatment May Not Be Provided

Once clinicians see that a future treatment may be futile, they can alert the patient and family to this possibility. It would be ideal to share several examples from the hospital's futility policy, such as when a patient has heart failure or is not able to eat by mouth, to better convey that this kind of decision involves others as well, not only this patient and family.

Share that this May Be Frightening

Clinicians can share with patients and families, prior to beginning a discussion, that they know what they are about to say may be frightening. Clinicians can say this same thing before saying they won't meet only with the eldest son (if this is the case).

Clinicians can explain why they are sharing this information, and why it is being shared so much in advance—especially given that it may be frightening, and most likely won't even occur. The reason is to better prepare the patient and family for what may happen. Knowing about these possibilities early on may help them be better prepared, at least cognitively. They may be better prepared emotionally, as well. In general, it may be helpful to prepare for any difficult information in this way. For example, as our parents age, we come to realize that they will die. Clinicians can acknowledge that receiving this kind of information may be very upsetting.

Clinicians can say, for instance, "I can imagine that, as I am first telling you this, you may feel very upset. Please know that if you do feel this way, I can imagine how that might be. I don't know what you are experiencing or how painful this is for you, but if you feel as though you would like to tell me, I would really like to know."

Clinicians might take a leaf from Yalom's book, and share what they feel. For example, they might say, "It is very painful for me to imagine what you may be feeling. It is particularly painful for me, imagining that a future disagreement about futility could occur, and knowing that presently I may be causing you great fear, even by just mentioning the possibility. I also fear greatly that if this occurs, our judge-

ment that a treatment is futile may be wrong, but we may be too fearful, or just unable, to see this."

Forewarn the Medical Staff.

Finally, clinicians who decide a treatment is futile and will not be provided should alert the staff about it beforehand. It may evoke much discussion and dissent. But it may greatly enhance the clinicians' later likelihood of "success."

Meet after a Treatment Is Not Provided

Once it is decided that a treatment is futile and won't be provided, clinicians can proceed as follows. They can state how they can see how the patient and family may not want to go along with this decision, offer to transfer the patient, and offer to help in finding a place that will provide the treatment the patient and family want.

Clinicians can ask the patient and family if they'd like to know the reasons that the treatment must be declined for the patient—and not ask whether patients and families want to know the content of the hospital's futility policy (if there is one). The clinician may clarify that the reason for refusing to treat is for the patient (when this is the case). In rare circumstances, the reason may not concern the patient, but be to conserve limited resources. Clinicians may (rightly or wrongly) see this as part of their responsibility, at least by default. If so, clinicians may especially want to review or even rethink their decision, and if, after doing so, they still believe that not providing an intervention is what should be done, this also should be shared with the patient and family.

Meet after All Is Said and Done

Clinicians should invite family members to express their hesitations, anger, and concerns, and then support them. At the end of the patients' hospital stay, clinicians should ask whether it would still be all right to invite the family to return to the hospital to share their views, and reassure the family that they can always change their mind later about doing this. If the family does return, clinicians should prepare the staff on what may occur. That is, family members may feel angry, and they will be encouraged to express this. John Fletcher, a renowned expert on ethics and ethics consultation, viewed making this kind of invitation, and the intervention of encouraging and supporting families to later share whatever they felt, to be critically important. I recall him saying to such a family, when he was invit-

ing them and they were reluctant to come, “We really need you.”

Help the Staff

Staff may be most reluctant to participate in this kind of intervention. What families say may be very hard to hear. Clinicians may wish to arrange, beforehand, a specific time to debrief staff after they meet with the family. A trusted staff member can be engaged to facilitate the discussion. With this specific planning, staff may be more willing to come. This may, of course, also benefit them.

CONCLUSION

In this introduction, I have discussed several ways to retain the trust of patients and families. Clinicians may consider using these approaches for a reason that was expressed by Elias Canetti: when a cheetah is chasing a herd of gazelles, the gazelles’ fear may abate when the cheetah singles out one particular member of the herd.²⁶ Traditionally, the principal moral role of clinicians is to help those who are worst-off. In these instances, these families may be the singled-out gazelles.

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NOTES

1. S. Perry and A. Venkat, “Letters: Possible Unintended Consequences of Including Equal-Priority Surrogates,” in this issue of *JCE*.

By “clinicians,” I mean to include ethics consultants and ethics committee members throughout this piece.

2. For several approaches to preventing this, see A.M. Fiester, “What Mediators Can Teach Physicians About Managing Difficult Patients,” *American Journal of Bioethics* 128, no. 3 (Mar 2015):215-6.

3. A. Fiester, “Letters: Response to Perry and Venkat,” in this issue of *JCE*.

4. R.M. Veatch, “Generalization of Expertise,” *Hastings Center Studies* 1, no. 2 (1973): 29-40.

5. Dr. Pellegrino was the first person who agreed to be an associate editor for *JCE*.

6. For this contrast between the applications of medical and ethical models to people wanting to change their gender, see J.L. Nelson, “Still Quiet After All These Years: Revisiting the Silence of the Bioethicists,” *Journal of Bioethical Inquiry* 9, no.3 (September 2012): 249-59.

7. J.A. Wasserman et al., “Moral Reasoning among HEC Members: An Empirical Evaluation of the Relationship of Theory and Practice in Clinical Ethics Consultation,” in this issue of *JCE*.

8. I have received this anecdotally from several sources.

9. J. Greene, *Moral Tribes: Emotion, Reason, and the Gap Between Us and Them* (New York: Penguin, 2013).

10. Fiester, “Letters: Response to Perry and Venkat,” see note 3 above.

11. *Ibid.*

12. Greene, *Moral Tribes*, see note 9 above.

13. N. Panagiotopoulou and S. Karavolos, “‘Let Me Keep My Dead Husband’s Sperm’: A Systematic Review on Ethical Issues in Posthumous Reproduction and Introduction of an Ethical Decision-Making Tool,” in this issue of *JCE*.

14. C. Mitchell, “The Value of Virginity”; S. Bastami, “When Bleeding Is Vital: Surgically Ensuring the ‘Virginal’ State”; F. Jarral, “A Hymen Epiphany”; M-J. DelVecchio Good, “On Hymenoplasty”; S. Schuster, “Hymen Restoration: ‘My’ Discomfort, ‘Their’ Culture, and Women’s Missing Voice”; P. deLora, “The Value of Virginity and the Value of the Law: Accommodating Multiculturalism”; G. Heinrichs, “Is Hymenoplasty Anti-Feminist?”; R.A. Shweder, “Doctoring the Genitals: Towards Broadening the Meaning of Social Medicine,” in this issue of *JCE*.

15. A. Mascarelli, “Does Girls’ Focus on ‘Thigh Gap’ Lead to Eating Disorders?” *Washington Post, Health and Science*, 1 July 2014, E1, E4.

16. M.H. Erickson, *A Teaching Seminar with Milton H. Erickson*, ed. J.K. Zeig (New York: Brunner/Mazel, 1980).

17. S.H. LiPuma and J.P. DeMarco, “Expanding the Use of Continuous Sedation Until Death: Moving Beyond the Last Resort for the Terminally Ill,” in this issue of *JCE*.

18. D. Kessler, *The Needs of the Dying* (New York: Harper, 2007), 22.

19. A.O. Ozanne, “Finding Meaning Despite Anxiety Over Life and Death in Amyotrophic Lateral Sclerosis Patients,” *Journal of Clinical Nursing* 22, no. 15-16 (August 2013): 2141-9.

20. V.E. Frankl, *The Will to Meaning* (New York: New American Library, 1969), 8.

21. *Ibid.*, 79.

22. E.G. Howe, “Professionalism: One Size Does Not Fit All,” *The Journal of Clinical Ethics* 26, no. 1 (Spring 2015): 3-15, quoting B.L. Fredrickson, *Love 2.0: Creating Happiness and Health in Moments of Connection* (New York: Penguin, 2014), 148.

23. I. Yalom, “Narrowing the Gap: Striving for Honesty in the Therapy Room,” *Psychotherapy Networker* 39, no. 2 (March/April 2015): 39-44, 46-47, 50, p. 50.

24. M. Park, C.A. Chesla, R.S. Rehm, and K.M.Chun, “Working with Culture: Culturally Appropriate Mental Health Care for Asian Americans,” *Journal of Advanced Nursing* 67, no. 11 (2011): 2373-82.

25. M. O’Brien and A. Fiester, “Who’s at the Table? Moral Obligations to Equal-Priority Surrogates in Clinical Ethics Consultations,” *The Journal of Clinical Ethics* 25, no. 4 (Winter 2014): 273-80.

26. E. Becker, *Escape From Evil* (New York: Free Press, 1975), 110, citing E. Canetti, *Crowds and Power* (London: Gollance, 1962), 303.v