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At the Bedside

Beyond the Basics: More Ways that Ethics Consultants Can Help Patients

Edmund G. Howe

ABSTRACT

The primary task of ethics consultants is to work with patients—and sometimes also their families—to discern and then meet patients' and families' needs and wants to the extent possible. That is primarily a cognitive endeavor. Yet the feelings of patients and ethics consultants may determine what they can work together to accomplish. This article considers their feelings. It looks at sources of distrust and their hoped-for resolution, specific means to enhance patients' decision making in their relationship with ethics consultants, and a new, highly different approach that may enhance their relationships more than most commonly used ways of relating.

In this issue of *The Journal of Clinical Ethics* (*JCE*), in "Developing Skills in the HEC Communication Competency: Diagnostic Listening and the ADEPT Technique," Autumn M. Fiester

presents five steps that ethics consultants can use to best discern patients' wishes.¹ These approaches are on our field's cutting edge and should benefit *most* patients to the greatest possible extent. But these approaches may not benefit all patients; some may need additional assistance. In this article I will discuss a few of these interventions. This article is dedicated to patients who will need additional help.

I will present some new interventions that ethics consultants can use. First, I will discuss a reason that patients may not respond to the interventions that Fiester describes, and suggest how ethics consultants may best respond in these cases. Second, I will discuss three approaches that ethics consultants can use that may benefit all patients. Third, I will present an essentially new approach to ethics consultation,

Edmund G. Howe, MD, JD, is Professor of Psychiatry and Director of Programs in Medical Ethics at the Uniformed Services University of the Health Sciences in Bethesda, Maryland; and Editor in Chief of *The Journal of Clinical Ethics*. The opinions and assertions expressed herein are those of the author(s) and do not reflect the official policy or position of the Uniformed Services University of the Health Sciences or the Department of Defense. Neither I nor my family members have a financial interest in any commercial product, service, or organization providing financial support for this research. References to non-federal entities or products do not constitute or imply a Department of Defense or Uniformed Services University of the Health Sciences endorsement. This research protocol was reviewed and approved by the USUHS in accordance with all applicable federal regulations. This work was prepared by a military or civilian employee of the US Government as part of the individual's official duties and therefore is in the public domain and does not possess copyright protection. Public domain information may be freely distributed and copied; however, as a courtesy it is requested that the Uniformed Services University and the author be given an appropriate acknowledgement.

called “an ethics of imperfection.”² I will describe this approach and discuss how ethics consultants can use it.

OVERCOMING DISTRUST

One reason patients may not respond optimally to diagnostic listening is that they feel distrust.³ In this section I will discuss distrust and some possible ways to overcome it.

Sources of Distrust

Patients may distrust ethics consultants before they even meet them. If patients feel distrust, their feelings, geared to “fight or flight,” may displace their capacity for reflection.⁴ Thus, to benefit some patients maximally, ethics consultants may need to first establish trust.

There are many reasons patients may feel distrust. One reason is that they may fear an ethics consultant will side with medical staff if the patient wants an intervention that careproviders consider futile. A paradigmatic case is that of patients who are dying but who want to start kidney dialysis, because it may help them to live longer. They may fear that an ethics consultant will not support this treatment because the consultant sees it as death-prolonging, rather than life-prolonging, and will persuade careproviders to not start dialysis.

Another reason for distrust is that patients may know that ethics consultants are employed by hospitals, and consultants may believe it is more important to remain close to staff than to patients. Fiester, in another article, states that when mediation is involved, mediators should be neutral.⁵ The need for neutrality extends to other parties as well. For example, if a hospital lawyer is on a hospital ethics committee, the lawyer “wears two hats”: that is, when speaking with hospital administrators, the lawyer should say what is in the hospital’s best interest. But as an ethics committee member, the lawyer should state what is ethically best, when that differs from what is best for the hospital.

Patients may feel distrust whether or not they disclose it. Some patients refer to ethics consultants as “the ethics police.” I have heard that some patients on a ward for seriously ill patients informed new patients that if they wanted an intervention they thought would enable them to live longer, they should tell ethics consultants and other careproviders that they wanted the intervention because it was their re-

ligious belief that they had to do all they could for God, so God would do what He could.

Patients may fear that ethics consultants will share truths patients don’t want to hear, for example, that the patients might want to consider palliative care. In my own experience, a patient refused to talk further with an ethics consultant who mentioned hospice care.

For some patients, distrust comes wholly from within. For example, some patients find it difficult to tolerate ambiguity.⁶ These patients tend to see ambiguity in what others do and then assume whatever meaning is the most negative for themselves. For example, I heard this from a careprovider who saw a patient for the first time: The careprovider asked the patient, “What can I do for you?” and the patient took this as a slight. The patient thought that the careprovider had assumed that he knew why he didn’t feel well. Thus, he replied, “How should I know? You’re the doctor, not me!”

Intolerance for ambiguity tends to be greater in patients who are anxious. Since illness often evokes fear, patients are particularly prone to having anxiety and an intolerance for ambiguity. Their responses may, in one way, be adaptive, as responding in this way may make them feel less vulnerable. They may more readily perceive plausible threats, and so be better prepared for the worst.

But responding in this way—fearing the worst and then showing fear, even if only non-verbally—can exact a dear price. In response, ethics consultants (and others) may feel attacked and become defensive. When we bristle, we may validate patients’ initial response of feeling threatened and thereby increase their negative response. This may create an ever-increasing vicious cycle of distrust between patients and careproviders.

This unwanted possibility suggests two initial tasks: the first task is, when we even sense verbal or nonverbal hostility, to not take it personally and react. This may require practice. Our colleagues and trainers, as Fiester suggests, may see our unwitting, defensive tones and stances better than we do and can offer critical feedback. The second task is to see within ourselves how patients who are less tolerant of ambiguity may need to respond as they do to feel less vulnerable. Seeing patients in this light may help us to understand and empathize to a greater degree with patients, and may help patients to not have a defensive reaction.

Patients may respond in different ways when they feel distrust. Some may respond with anger. But others may respond by being overly compliant, to avoid the risk of offending an ethics consultant or careprovider, as patients may fear that doing so could adversely affect the care they receive. Such a hidden response may be intentional or occur outside of their awareness, reflexively. In either case, it may effect worse outcomes. Seeking to hide what they most want, to any extent, may cause patients to accept an outcome that is not what they want. How might we best address this? I will discuss this now.

Allaying Distrust

Ethics consultants and other careproviders may try to increase patients' trust in several ways. The end goal of all these is to help patients feel safer.⁷

Some interventions are subtle. For example, we can leave our cell phone with someone outside a patient's room to avoid interruption. Another example is a pediatrician I know who takes a small chair with him when he goes on hospital rounds. That way, when he sees a child, he can always sit by the bed at or below the child's eye level. These interventions provide an optimal setting for building trust. These examples are just a few among many that can help patients feel more safe.

When patients feel safer, we may take initiatives that have more of an impact. Ethics consultants can talk about the ethics consultation process and why they were consulted. After this, consultants can seek to explore with patients any feelings of distrust they may have, if they want to do this. Ethics consultants cannot know in advance which patients feel distrust. Thus, if they hope to benefit more patients, they may need to do this with every patient.

Ethics consultants may already know, in some cases, that a patient is distrustful. Careproviders may indicate that a difficulty already has arisen when they request an ethics consult.

Should this be the case, ethics consultants may begin by asking patients if they have any concerns about the ethics consultants' working for the hospital, and thus possibly having a mixed allegiance. Ethics consultants should add that some patients have this concern, which may make it easier for patients who have these concerns to disclose them. Merely taking the initiative to ask patients this question may increase patients' trust, because, by asking, ethics con-

sultants indicate that they feel concerned enough to raise the issue, even when they know it may be uncomfortable for both parties to discuss. Often this may have more of an effect than the content of what is said.

If ethics consultants acknowledge that they do feel mixed allegiance, it may paradoxically increase, rather than decrease, patients' trust, although logically this may not seem likely. This is because when ethics consultants take the initiative to raise the question of mixed allegiance and acknowledge a potential conflict, it may increase patients' trust more than possibly having a mixed allegiance may diminish their trust.

I have seen a similar paradoxical result with careproviders who work for the state in a forensic role. These forensic examiners include psychiatrists and psychologists who evaluate alleged offenders for insanity when they are suspected of having committed a crime, and other physicians who assess patients for medical harms they claim came about as a result of working in a federal or state agency, such that they would be due compensation. When these examiners conduct interviews, they must state that they are working for the state, not those who are being interviewed. This can cause the people interviewed to trust examiners more, rather than less, because they have been forewarned. Examiners have to be careful: if they forewarn those they interview too much, in an effort to be transparent, those interviewed may begin to feel too much trust for the examiners. Those being interviewed may even provide self-incriminating information, and so work against their own interests, which is not what examiners, or law enforcement, want or intend to happen.

When ethics consultants share with patients the circumstances under which they may not support what patients want, it may be somewhat reassuring to patients, like those who are being interviewed by forensic medical examiners. First, ethics consultants should ask patients whether they would want to discuss consultants' dual loyalties together. This will indicate to patients that ethics consultants will leave choices up to them, when possible.

Ethics consultants may, on the other hand, feel committed to support what patients want, even if that goes against what consultants personally believe. They may believe their overriding obligation is to patients, as physicians do. How far should ethics consultants go? Most may share their own views and then, if the staff dis-

agrees, stop. Should they ever persist? Ethics consultants may be willing to bring patients' appeals to hospital administration, an outside ethics committee, a court, or even the press. For example, one ethics consultant opposed a surgeon's refusal to repair a patient's heart valve; the surgeon refused because this would be the second time the surgeon would repair the same heart valve for the same patient, who continued his use of illegal intravenous drugs. Jeffrey Spike reported a case in which a mother badly injured her baby and, as a result, was going to jail. She wanted to hold her child one last time before she was incarcerated. Some of the staff involved opposed this, but the ethics consultant did not. He asserted his view and prevailed.⁸

As these two examples suggest, when an ethics consultant supports what a patient wants, against the wishes of staff, it takes courage. How courageous should an ethics consultant be? My view is that an ethics consultant—as any care-provider—should be willing to make a sacrifice for a patient. An example is a patient who calls late Friday night saying he just noticed he has no more sleep meds. I believe we should help the patient find a pharmacy that is open all night and re-prescribe the sleep med, so the patient can get the meds and be able to sleep that night.

Ethics consultants should arrange for themselves or another consultant—someone they have informed about the patients they are following—to be available around the clock. A guideline on when careproviders should not continue to sacrifice their own needs is to stop when the stress of doing so lingers too much. I fear that I, as others, may unconsciously come to feel resentful. The feeling may be not only outside our conscious awareness, but wholly irrational. We may, without seeing it, take out this resentment on patients. A drawback is that this guideline is elastic: we may use this rationale to not meet patients' important needs and instead meet less important needs of our own.

Some ethics consultants are more resilient to stress than others. For example, some ethics consultants, in situations when they oppose others, will be less affected by social stress than other consultants. Those who are more resilient may be better equipped to help patients pursue what patients see as their own best interests. If there was an imaginary "spectrum of courage," where would we see ourselves—and should we ever share that perception with patients? This question may seem to be going too far in an ef-

fort to be as ethical—or even as human—with patients as possible. Later in this article I will discuss "an ethics of imperfection," and relate some of the possible gains of sharing our own vulnerabilities with patients. Doing this may actually enhance patients' trust in us.

Here's an example of my experience of vulnerability drawn from my practice. This may be an example of the kind of vulnerability that ethics consultants might be willing to share. When this question arose for me, it was among the most stressful I have experienced in my career. A patient who was a careprovider told me something she had done that was wrong. She had not harmed another person, but had sought to help. Still, my patient had violated a professional norm. She had an obligation to report this, as I did if she didn't. I obsessed over what I should do, and, depending on my decision, whether I would have the courage to follow through. She reported herself. But I fear that had she not, I would have lacked the courage to report her.

Ethics consultants may go still further. They may tell patients that patients may decline to accept a consultation, and ask patients if this is what they want to do. Some patients may say "yes" because they feel—perhaps rightly—that they can make any decisions that will affect them wholly and better on their own. They may see discussing their options with an ethics consultant as burdensome and unnecessary.

Ethics consultants and careproviders may oppose the use of this approach. They may see it as absolutely contraindicated, because to them an ethics consultation may be necessary to give patients the best possible care. Careproviders may feel that patients need an ethics consult as much as they need a cardiac consult or an infectious disease consult. And some careproviders may see a relevant moral difference between cardiac and infectious disease consults and an ethics consult. Some may see giving patients a choice about whether to accept an ethics consult as a way to show respect for patients' autonomy. Some may perceive ethics consults as of less benefit to patients because they are less quantitative; that is, for example, ethics experts may differ widely on an optimal ethical outcome or on where an ethical line should be drawn.

I will now provide additional interventions that ethics consultants may want to consider. Some are suggestions; they are offered to suggest the dynamic possibilities that occur in every ethics consultation.

When ethics consultants first meet with patients, they may ask whether the patients want the consultants to share information on patients' possible future outcomes, uncertain though they may be. If patients want to hear about possible outcomes, consultants can say they would like to first discuss the pros and cons, and whether that would be okay. If patients say "yes," consultants can ask how successful patients have been in the past in ignoring potentially worrisome concerns, while still being able to fully enjoy life. Some patients are better able to do this than others, and are more able to deny possible unlikely bad outcomes, so there is a stronger argument to share possible outcomes with them. When patients are less successful at using the defense of denial, sharing possible outcomes may create a risk that they will feel haunted by worst-case scenarios, and feel as though a dark cloud hangs over them. On the other hand, sharing possible outcomes may enhance patients' autonomy, and the transparency of increased sharing may help to make them feel more equal to members of the medical team. Taking this initiative may increase their trust.

Since ethics consultants can't tell which patients might benefit from these interventions, they may need to make them with all patients. Patients who don't need the interventions may find the extra measures tedious. But the interventions are unlikely to do harm. The patients already feel trust. With this trust they are likely to accept that ethics consultants are "going the extra mile" for them, even when they find the interventions to be unnecessary.

ADDITIONAL STEPS

In her article in this issue of *JCE*, Autumn Fiester states that it is critically important to use active listening techniques. In some cases, active listening may be all that we have to offer some patients. But the assistance it provides may be most substantial. For example, as Anthony L. Back, Susan M. Bauer-Wu, Cynda H. Rushton, and Joan Halifax note, "In compassionate silences, clinicians can find that the silence has a moment-by-moment character that patients can experience as a profound kind of being with, standing with, and contact in a difficult moment."⁹ Patients may find it deeply meaningful when ethics consultants simply listen to them. Being and feeling less alone may make patients' suffering more bearable.

In the next section I will describe three additional interventions that may benefit patients: (1) ethics consultants can tell patients what they fear patients may be missing; (2) consultants can ask patients to try to discern hidden, past associations; and (3) consultants can employ humor and laugh at themselves. All of these approaches involve risks that I will discuss.

Tell Patients What They May Be Missing

When patients are ill and feel fear, they may be less able to fully reflect upon, see, and prioritize what it is that they really most want. Ethics consultants may be able to see what some patients most want and share this with them. Some may see doing this as morally obligatory under present models of shared decision making. Others may see doing this as going beyond our present obligations and even as being intrusive and offensively paternalistic. I see doing this as part of giving patients the best possible care.

Jodi Halpern, a psychiatrist and philosopher, provides us with a paradigmatic example. Halpern saw a patient who believed she had no reason to live. Feeling this way, the patient refused lifesaving treatment and died. Halpern writes that she regrets not pushing her patient to explore with her the reasons that the patient might have had to live, but wasn't able to see.¹⁰ A critical question is how and how far "to push" patients: how should we leave space for patients to choose something that seems illogical to us? Simply raising such issues may pressure patients or seem implicitly coercive. Whether this possible coercive effect is warranted by the plausible gain is an additional question to ponder.

I will now provide some examples that support new interventions with patients who are near the end of life. In these cases, imagining what patients may want and sharing those ideas may help patients decide what they truly want. For example, patients at the end of life are often asked to decide whether they want a do-not-resuscitate (DNR) order. Careproviders may tell patients that the chances that cardiopulmonary resuscitation (CPR) will succeed are small, that patients may suffer broken ribs, and that they may not live long after CPR. Consultants may decide to go further. For example, a consultant may know from prior discussions that a patient has saved money for their grandchildren's college education. The patient may say that, in addition to CPR, the patient wants "everything

done.” The consultant might ask the patient to imagine that, after CPR, the patient may linger in a persistent vegetative state (PVS) for years, and the cost of care may deplete the funds saved for the grandchildren to attend college. “Would you want this?” the consultant might ask. This may risk evoking guilt. Some patients may want to be kept alive more than they want to pay for their grandchildren’s college. The possible gain to patients from the consultant’s raising this question may warrant taking that risk.

A second example involves patients who say they “want everything done.” Ethics consultants could ask these patients whether they want to consider the feelings of their closest family members. That is, consultants could describe how patients might end up in a long-term PVS after “everything is done.” On the one hand, family members might find it meaningful to be with the patient in this state, and value being able to touch the patient and speak to the patient, believing the patient is still able to feel them nearby and hear them—and these beliefs may be right.¹¹ Family members might, on the other hand, find it emotionally wrenching for the patient to remain in this state. Or some members of the patient’s family may feel one way, and others feel another. Asking patients whether they want to consider these things may aid their decision making. A risk is the patient may find this discussion haunting and not be able to “go back.”

A third example extends to careproviders’ feelings. Sometimes when staff know that a beloved patient is dying but still wants CPR, they distance themselves emotionally. This may occur unconsciously, as possibly an unconscious effort to lessen anticipatory grief. Consultants may tell patients about this possibility and ask whether they want to consider this.

A fourth example is when patients or their families do not want to tell the other that the patient is dying. This may be a practice in their culture or just the preference of “the family next door.”¹² Ethics consultants could offer to tell the party who wants to keep the secret what they might miss if they keep the secret. Consultants can share that other patients and family members have found that sharing feelings with each other before the patient dies is one of the most meaningful experiences they have had. When patients keep this secret, family members may lose precious opportunities to say “Thank you,” “I love you,” “I forgive you,” “Please forgive me,” and even, “I will miss you dearly, but I

will be okay.” While the last comment may be somewhat open to question, what some patients fear most is that their loved ones will flounder after they die, and so they may find it reassuring when loved ones say they will grieve, but in the long run that they will be okay.

Given these examples regarding patients’ decision making, what is the optimal way for ethics consultants to talk with them about a topic like CPR? There is evidence that *how* a choice is described to us may affect our decisions. George L. Anesi and Scott D. Halpern report:

Choice architecture refers to the different ways in which the same choices can be presented and the environmental conditions under which choices are made. Such context can have dramatic impacts on a broad array of choices, even influencing presumably preference-sensitive decisions such as end-of-life care choices. For example, seriously ill patients’ choices to receive comfort-oriented care in real advance directives are heavily influenced by whether such options are presented as the default. . . .¹³

The authors describe how, in western countries, CPR has become a default intervention, even for patients near the end of life, when it may not always be appropriate, as discussed above. When CPR is presented to patients as a default intervention—that is, that they *will* receive CPR unless they write a DNR order—the designation of CPR as the default can affect their decisions about accepting CPR: it matters that they must opt out.¹⁴ But when the default intervention is changed—for example, to receive CPR, patients near the end of life must *request* it—it can change patients’ perceptions about CPR, and they may change their stated preferences. In light of this, how should careproviders discuss the option of CPR with patients who are near the end of life? Telling patients about Anesi and Halpern’s report—that choices are often made based on what is presented as the default—may increase patients’ autonomy and enable them to better decide for themselves, and this may affect the decisions they make.

Asking Patients to Associate

Past experiences do affect us, sometimes in ways that are wholly outside our conscious awareness. I recall seeing a pregnant woman who refused a cesarian section. She didn’t know why, but she felt, nonetheless, that she must. If

she did not have the cesarian, she and her fetus would most likely die. I asked her about her past and whether she had ever herself had or had heard of other people who had a bad medical experience. At first she said "No." I asked her to recall further, to see if anything more came to mind. She then recalled what at first she hadn't remembered, that her aunt, years before, had undergone surgery and had almost died. This had greatly frightened her, she said, because she was only a child at the time. With this memory recalled, we discussed it. Her fear of having the cesarean diminished. She had the surgery, and she and her infant did well.

Ethics consultants and careproviders commonly already ask patients about such associations. Consultants can perhaps take this further. Asking patients to try to remember and see what, if anything, comes to mind may facilitate this, and, if it does, they can discuss it with patients. These discussions may change patients' decisions, as it did for this woman.¹⁵ A downside of this approach is that it may cause patients to suddenly come in touch with a memory that involves fear, as it did with the pregnant patient. Still, it may be warranted for ethics consultants to push further, and then to remain silent and listen. Ethics consultants should tell patients about these risks beforehand, and ask them, once informed, if they want to proceed.

Using Humor and Laughing at Ourselves

This last intervention involves using humor, and especially laughing at ourselves, because this is safest. In time, the use of humor may become mutual.¹⁶ It may greatly enhance our relationships with patients and even alter them qualitatively. This is because humor may provide what some call "moments of meeting."¹⁷ These moments differ from all other times: they occur spontaneously, outside our usual interactions. They may include a patient's seeing a tear in their careprovider's eye, a shared belly laugh, or a meaningful glance at the end of a consult. "It is no surprise," psychotherapists Lisa Valentine and Glen O. Gabbard write, "that when patients are asked what was helpful in their therapy, they often recall jokes the therapist told or a humorous interchange that departed from the usual format of the therapy."¹⁸ Moments of meeting, the authors conclude, "may be something of a breakthrough" in therapy.¹⁹ Therapy differs from an ethics consult, but closer connections with patients are still a worthy goal.

The use of humor may pose a risk. Humor may, by its very nature, have more than one meaning; its use may risk harming patients who don't tolerate ambiguity well, as considered above. But the likely gain for patients may make it worth the risk, and consultants may lessen the risk by asking patients beforehand whether or not they would welcome it. Consultants can add that they know patients are experiencing a difficult time. Still, humor may deepen their relationship. As Valentine and Gabbard note, it may create within patients a heightened sense of a careprovider's "realness."

Also notable is the view of the renowned psychiatrist Viktor Frankl. The "lightness and laughter" of humor, he wrote, helps patients detach themselves from their suffering.²⁰ It may help them too, he stated, to see their symptoms as "somewhat ridiculous."²¹ It may at this same time, he wrote, help patients to see "the universality of their struggles."²²

AN ETHICS OF IMPERFECTION

Now I will discuss a possibly far-reaching new approach called "an ethics of imperfection," and focus on an aspect that is most relevant to consultants and careproviders: admitting that we share a vulnerability with patients. Patients may feel less alone, and this may help some patients more than anything else we can do. I will explain what "an ethics of imperfection" is and when it might be applied. I will describe a careprovider who had rare success with the hardest-to-reach patients, possibly because he believed in and practiced this approach. He reached patients other careproviders couldn't.

Sharing Painful Feelings

Johanna Shapiro, in "Walking a Mile in Their Patients' Shoes: Empathy and Othering in Medical Students' Education Medical Training," writes, "it is not surprising that patients can evoke feelings of fear, anger, disgust, and horror not only in the non-ill, but also in physicians and trainees, although these are rarely acknowledged."²³ She states that our present emphasis on cognition rather than on feelings has led to a focus on achieving "solutions and restitutions" for patients, but not on patients who do not do so well.²⁴ She posits that careproviders may shift their focus to avoid the pain that the suffering of their patients evokes. Shapiro suggests that we must be more aware of our own painful feel-

ings and share those feelings with our patients.²⁵ This, she believes, will forge our “common bonds of humanity” with patients, a goal Viktor Frankl also held.²⁶ “We might start,” Shapiro writes, by formulating an ethics of imperfection, which “requires role-models who express vulnerability, share mistakes, incorporate not-knowing; who are aware of and transparent about their emotional reactions to patients and about working the edge between intimacy and detachment; and most importantly, who acknowledge common bonds of humanity with their patients.”²⁷

In this, Shapiro is not alone. Mary Catherine Beach and Thomas Inui assert, for example, that “all illness, care, and healing processes occur in relationships.” They write, “Relationship-centered care (RCC) is an important framework for conceptualizing health care and for recognizing that the nature and the quality of relationships are central to health care and the broader health care delivery system.” RCC is, they say, “care in which all participants appreciate the importance of their relationships with one another.”²⁸

Bearing the Least Bearable

If healing takes place in the context of relationships, how might a focus on relationships help patients who bear what is least bearable? In this issue of *JCE*, Gina M. Piscitello, Mark Siegler, and William F. Parker, in “Ethics of Extracorporeal Membrane Oxygenation during Conventional and Crisis Standards of Care,” discuss circumstances that are as heart-wrenching as any in medicine.²⁹ They report that some patients who are on ECMO may undergo a time-limited trial. As Thomas Bein and Daniel Brodie note, these patients most likely know that their life may soon end.³⁰

Piscitello, Siegler, and Franklin emphasize the degree to which they strive to “honor” the preferences of patients who are on ECMO, but that they cannot always succeed. For example, some patients who initially agree that their time on ECMO will be limited, but later change their mind, and want to continue on ECMO, rather than die.³¹ As the authors note, patients may “change their mind at any time.”

What can an ethics of imperfection offer us in such situations? First, as Autumn Fiester recommends in this issue of *JCE*, we can use diagnostic listening techniques. And, beyond this clinical tool, we can share what we are feeling with patients. I think of a patient I saw early on

in my psychiatric training. The patient, a young adult who had worked as a seamstress when she was well, was hospitalized when she was haunted by voices that told her to kill herself. Her father, when he came to the hospital to see her, always asked her how she was feeling. She always told him. He consistently told her what he thought she should do, but that was not what she wanted from him. What she craved was for him to listen and share with her what he felt, so they could bond as two adults, as well as bond as parent and child.

A possible downside of sharing our feelings is that patients who see their consultant or care-provider as hurting may see them as less competent, because they have shared a vulnerability. This risk, though, may be mostly illusory. Sharing how we feel in response to patients’ pain may only add to our credibility. This may enable patients to see us more as real persons who genuinely care about them. Such moments of sharing our vulnerability may be “moments of meeting.” Such sharing furthers what Frankl and Shapiro refer to as careproviders’ and patients’ increased appreciation for the universality of humanity and their shared place within it. This awareness could alter patients’ sense of meaning regarding their illness and could lessen the suffering they bear. I recall a very caring person who affected me in this way. She was a care-provider and was hurting more than anyone I had ever seen after her mother died. I recall feeling while seeing her that there was no one I would rather have caring for my family or me.

Elvin Semrad

Is an ethics of imperfection doable? I find that sharing some of my vulnerabilities with patients since I learned of this approach has evoked increased sharing from them every time. It is as if my patients say to themselves, “Since you shared how you are imperfect, now so can I.” For example, one patient shared how she hurt. I shared how I had felt the same. She shared when she’d hurt more. This outcome, sharing more deeply after every disclosure, due likely to feeling more safe, often happens in other contexts.

To consider again the question: Is an ethics of imperfection doable? To answer, I will describe a care-provider and invite readers to decide. This is a psychiatrist who was known to his colleagues by his last name, “Semrad.” A book of his quotes has only that as its title.³² Those who edited this book, eminent psychia-

trists in their own right, explain that Semrad was a Professor of Psychiatry at Harvard Medical School and Clinical Director at Massachusetts Mental Health Center for more than 20 years. He was a “psychiatrists’ psychiatrist and an analyst’s analyst” and “one of the most important teachers of his generation.”³³ He is known as a careprovider who was able to reach patients no one else could. Patients who were psychotic and wouldn’t speak with others would speak to him. They would suddenly become lucid, only to become psychotic again once they left him. Psychiatric colleagues were “astonished.” He spoke “the language of the heart,” some said, surmising that this might be why he was able to reach these patients.³⁴

How may Semrad have done this? He urged colleagues to keep trying with every patient, even when they didn’t know and couldn’t know whether their efforts would help. This might be the case when we share our vulnerable feelings with a patient who is on time-limited ECMO. Semrad wrote, “We’re just big messes trying to help bigger messes and the only reason we can do it is that we’ve been through it before and survived.”³⁵ He saw the vulnerability to imperfection that he had, as his patients did. With his self-awareness, he was able to convey this non-verbally to patients.

He spoke of the all-importance of relieving, as much as possible, patients’ sense of aloneness. What we all most need, he said, is to be connected with someone: “If patients have one relationship in which they feel comfortable,” he said, “they don’t go crazy.”³⁶ How he would convey this to patients is moving. He would say, “The one thing I can promise you is I will hear you, I will actually with a heart and a half, look to sit with you and really try and have an opportunity to walk with you through this time.”³⁷ His sharing his own vulnerability and painful feelings is demonstrated in the words he used: “a heart and a half.”

CONCLUSION

I have sought to add to Autumn Fiester’s primer on how ethics consultants should listen to patients. I have suggested that, for some patients, consultants should above all seek to gain their trust, and I have suggested some ways we may try to do this. I have suggested three approaches that we may take to benefit patients to the greatest possible extent: tell patients about

concerns that we imagine patients may have missed, ask patients to discover associations they have that might be related to their illness, and use humor to laugh at ourselves. I also have discussed some patients’ intolerance of ambiguity and the importance of choice architecture.

I have discussed an ethics of imperfection. When we use this approach, we may share with patients our vulnerability and painful feelings, such as the pain we feel when we see their suffering. I suggest this is even what we can do when patients agree to a time-limited trial of ECMO and later change their mind about it. I shared, as an example of how effective this approach might be, the work and words of psychiatrist Elvin Semrad, who reached patients that other careproviders could not.

It seems apt to end with Semrad’s words, “there’s one comfortable thought: that two people sharing pain can bear it better than one.”³⁸ Perhaps we, as ethics consultants and careproviders, can be one of those people for our patients.

NOTES

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