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At the Bedside

New Paradigms in Medical Ethics

Edmund G. Howe

ABSTRACT

As new technologies develop, new ethical paradigms may be needed. This article considers several examples, such as stopping venoarterial extracorporeal membrane oxygenation (VA-ECMO), treating patients who are in a locked-in-like state who have awareness, purposefully deceiving patients who have dementia, meeting the needs of transgender persons, showing loved ones patients' wounds, and doing research on controlled substances. I suggest that clinicians should identify the practices underlying their value assumptions so they can alter their assumptions when this might improve the care they offer to their patients.

Physicist and historian Thomas S. Kuhn wrote, in *The Structure of Scientific Revolutions,* that scientific knowledge may proceed in a stepwise fashion, and "the successive transition from one paradigm to another via revolution is the usual developmental pattern of mature science."[1] This may also be said of medical ethics. New paradigms, value priorities, and practices may arise in response to new insights and new technologies.[2] Physician-controlled medicine has given way, for instance, to patient-driven medicine, and new technologies have brought about the startling revelation that many patients whom we had thought were in a vegetative state (VS)—and thus could never think nor feel again—in fact have some have awareness. The changes have in common that they may evoke the kind of revolutions that Kuhn described. The transitions may be stepwise and smooth or hotly contested and later reversed.

In this issue of *The Journal of Clinical Ethics* (*JCE*), there are several such examples that offer new paradigms and challenges to our present thinking. I will add other examples that challenge us greatly at this time. The articles in this issue of *JCE* involve: (1) giving patients and their loved ones more say in stopping VA-ECMO, (2) deceiving patients with severe dementia to maintain their quality of life, (3) showing surrogate decision makers a patient's wounds to enhance the surrogates' ability to make decisions regarding the patient, and (4) doing more research on pain-relieving, but potentially addicting, drugs. Two additional areas I will discuss involve: (5) patients who have disorders of consciousness (DOCs) who are in a minimally conscious state and (6) transgender persons. I will discuss these six areas in three sections, separately categorized according to the ethical value prioritized. These values are (1) respecting patients' and their loved ones' autonomy, (2) furthering equality, and (3) doing good.

In the first section, on new paradigms that would increase the autonomy of patients and their loved ones, I will discuss VA-ECMO and DOCs. VA-ECMO provides temporary oxygenation and perfusion to patients with cardiopulmonary failure so that, hopefully, the intervention will serve as a bridge to another intervention that will maintain the patients' lives. (I will use the briefer acronym ECMO to refer to VA-ECMO throughout the rest of this discussion.) The specific ethical question I will address here is: Who should decide when to stop ECMO when it becomes clear it will not be successful as a bridge?

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This question is similar to other questions that are often asked; as Meltzer and colleagues wrote in 2014,

> Many of the questions regarding the use of ECMO will be familiar. Certainly, similar questions arise with other life-sustaining therapies; however, the general hospitalist may be a bit unfamiliar with ECMO and its unique ethical challenges. For example, ECMO is only provided transiently and generally while patients are in an intensive care unit. Unlike mechanical ventilation, which may be provided long-term via tracheostomy, there is no comparable, enduring form of ECMO. Next, patients requiring ECMO are utterly dependent on the machine for their survival. If they do not recover and are not candidates for transplantation, there are no other therapies to offer. In this scenario, terminal discontinuation is the only option.[3]

In this section I will also consider a new ethical issue noted above—regarding how to better preserve the autonomy of patients with DOCs, who, in the not too distant past, were thought to be in a vegetative state (VS). It is now known, due to new technologies such as fMRI (functional magnetic resonance imaging), that as many as 41 percent of the patients may not lack the capacity to think and feel, but have, instead, some awareness.[4] They may have "islands" of tissue that remain intact within their brain that allow them to have some awareness. New means available now to detect this awareness and to communicate with patients who have it, although to only a very limited extent. In response to clinicians' questions, a patient can imagine a different image to respond "yes" or "no." Instruments can record which image a patient is creating, and, by this means, determine how the patient has responded to the question asked. At present, such detection and communication can take place only in research settings, but the new ethical questions they bring about will probably soon arise in clinical settings. As Meltzer and colleagues note, in regarding ECMO, "hospitalists must be prepared to address questions related to this evolving technology."[5]

In the second section, I will discuss new paradigms that would further the equality of two groups: (1) patients who have dementia and (2) persons who have changed or who want to change their gender. Two articles in this issue of *JCE* discuss dementia. In addition to discussing the articles, I will consider the optimal treatment of patients with dementia, as well as an issue not otherwise raised here, the optimal treatment of transgender persons. Here and throughout this article I will refer to transgender persons as *persons,* not *patients.* This is because, while they may acquire a disorder, their feeling that they are another gender and wanting to change their body to accord with this other gender is not a disorder. This distinction is of immense importance to transgender persons and should be no less important to all, because if identifying oneself with another gender is seen as a disorder, it is stigmatizing and disrespectful to these persons.

In the third section I discuss new paradigms, or at least new ways of seeing patients in certain medical situations, that further the good of patients: (1) showing surrogates a patient's wounds to help them make better decisions, (2) doing more research on controlled substances to better help patients who feel pain, and (3) using a new approach to decide when and whether to adopt a new paradigm, such as the new paradigms presented here. Overall, I will seek to show the gains that clinicians may achieve when they identify the paradigms that underlie what they currently do, and consider whether there are newer, better paradigms that they may wish to incorporate and carry out regularly in their clinical practices.

RESPECTING AUTONOMY

In this first section I will discuss two paradigms that, in different ways, may enhance the autonomy of patients and families, involving ECMO and DOCs. Should ECMO fail as a bridge to longer term treatment, it poses the ethical questions, Who should decide when to stop ECMO? Clinicians? It may be ideal for clinicians, the patient, and the patient's loved ones to make this decision together, as stopping ECMO will result in the patient's death. As the first article I will discuss reports, however, many physicians think stopping the treatment, and starting it, should be their decision alone. This raises the question of whether stopping the treatment should be a shared decision. The clinicians who wrote the article on ECMO in this issue of *JCE* believe that this decision should be shared and explain why.[6]

Earlier, I noted that patients who have DOCs may have awareness. When they do, they may want desperately to communicate with loved ones, and their loved ones will want to communicate with them. Because patients may be in a state that initially looks like a VS, profound questions are raised: When and how often should the patients be tested for underlying awareness? If they are found to be aware and can communicate, what should clinicians do?

There are many ethical questions posed here, including, Who should be tested for awareness and

how often testing should be carried out? What should be done once it is found a patient is aware? If, for example, a patient says "Yes" in response to the question, "Do you want to die?" should we consider this response, if consistent, adequate to stop the treatment? Finally, the resources required to communicate with these patients, that may be necessary to sufficiently relieve their isolated suffering, may be very costly, and needed by others. At what point, we might ask, should limits, if any, be established?

Patients on ECMO who cannot bridge to another treatment and patients who appear to be in a VS raise related ethical concerns, especially how best to respect their autonomy and the autonomy of their loved ones. These patients may have some awareness, and their loved ones may be wholly committed to the patients' continuing to live and continuing to communicate as long as possible. Patients in both of these groups raise new and profoundly important ethical questions.

When patients are on ECMO, they, their loved ones, and their clinicians may together make the decision to stop ECMO, or their clinicians may make this decision by themselves. When patients have a DOC, have some awareness, and are able express themselves, it may be that they should be able to decide whether to continue to live or to die. Alternatively, these patients' capacity to communicate may be so limited that it may be warranted to see them only as having the capacity to validate a prior advance directive. At the same time, these patients may suffer unimaginably should they be aware but not be able to communicate at all. Unless clinicians specifically test these patients, they may remain in a locked-in-like state, in which they can appreciate input from others but can't express themselves, even by blinking. Their capacity for autonomy may not be unearthed, and they will remain locked in because their clinicians have not used, or have not been able to use, the clinical tools now available to enable the patients to respond.

ECMO

In this issue of *JCE,* Ellen C. Meltzer and colleagues, in "A Survey of Physician Attitudes toward Decision-Making Authority for Initiating and Withdrawing VA-ECMO: Results and Ethical Implications for Shared Decision Making," describe how they asked several clinicians who should decide when to stop ECMO when its use as a bridge to another treatment has failed.[7] The authors report that a majority of the clinicians said that they alone should make the decision and should be able to stop ECMO even when a surrogate objects. The authors suggest, based on this and similar findings, that their results might reflect a "widespread reversion to paternalism. . . ." This is not the approach that Meltzer and some of her colleagues use. They ask patients and/or their loved ones to decide when to stop.

In another article, these authors relate how they treated a 40-year-old Hasidic Orthodox Jewish female patient, the mother of four young children, newly diagnosed with large B-cell lymphoma, which encased both her right and left ventricles such that she developed acute heart failure prior to beginning chemotherapy.[8] The clinicians shared the dilemma of whether to stop ECMO with the patient and her family early on, in part to prevent a conflict later. They asked the family to include their rabbi, which they did. With this early discussion, the clinicians hoped the family would better accept the withdrawal of ECMO, should that become necessary. During their discussions, the family said that they would agree to stop ECMO. But, to the authors' surprise, when they felt it was time to stop ECMO, the family did not agree. "Unexpectedly, given the earlier deliberations (although understandably, given the potential for morbid ramifications)," the family "refused to provide consent for withdrawal."

We do not know why the family changed their minds. Perhaps even they didn't know, but primarily responded to their fear the patient would die. That the family changed how they felt illustrates how unsure shared decision making can be. The family's experiences convey the pain all those involved in deciding to stop ECMO may feel, whether clinicians decide on their own or share the decision making. Later, the clinicians and the family agreed to stop ECMO. Notwithstanding the family's about-face, the authors conclude that it is warranted to include patients and families in making these decisions ahead of time: "Importantly, we believe that VA-ECMO should not be withheld categorically from patients whose beliefs may include strong objections to the withdrawal of ECMO. Rather, efforts should be made with regard to the use of preventive ethics to minimize the possibility of a dispute by discussing the potential for terminal discontinuation of VA-ECMO early and often to prepare decision makers for this potential outcome."[9] Thus, the authors offer a new paradigm for such decision making. Should it prevail? This will be discussed below.

The Interests of Patients and Loved Ones

If patients and/or loved ones participate in deciding when to stop ECMO, the pain they experience may be no different from other decisions when

patients decide to stop treatment that results in an earlier death. Since, in some cases, patients could stay alive longer on ECMO and continue their relationships with loved ones, as Meltzer and colleagues convey, the pain of stopping ECMO may be greater.

In trying to imagine the emotional pain that deciding to stop ECMO can cause, I am reminded of a practice carried out decades ago. Patients sometimes came to the emergency room (ER) so badly burned that clinicians knew the patients wouldn't survive for more than a week. The clinicians knew also that the patients would become comatose within hours. Thus, when these patients arrived in the ER, the clinicians on call who had been specifically prepared for this task would come immediately. The clinicians would inform patients that they would soon enter a coma and die. The clinicians would ask patients whether they would want to stay alive in an unconscious state for just a few days or stay alive in that state for at most, perhaps, a week. The clinicians would tell the patients that they would be kept free of pain in either case. The clinicians could give the patients only minimal interventions other than relieving pain and sedating them, or they could give patients all of the life-preserving measures possible, and, by doing this, extend their lives from a few days to several. In either case, after just a few hours, patients would lose consciousness and their capacity to communicate. Thus, the clinicians would ask patients, when they were still lucid, which of these two alternative treatments they wanted.

Why did clinicians do this? Patients were physiologically affected, and, in addition to the psychological trauma caused by their burns, they would be profoundly affected by being told they had only hours of remaining lucidity and only days of remaining life. Ethically, the answer is straightforward: it respected the patients' autonomy to the greatest degree. The clinicians had nothing else to offer.[10]

This also might be the case with patients on ECMO. Clinicians could unilaterally make the decisions in either scenario, but respect may be all that clinicians are able to give, slight though the gift may be. If clinicians engage in shared decision making, they might anticipate the possibility that patients' loved ones may feel guilty that they participated in the decision making. Anticipating this, clinicians may alert family members that this may occur. Clinicians may assure family members that although they may feel guilty, this isn't rational, even though it may be unavoidable. It may help family members cope with the guilt and lessen it, if it occurs. Clinicians could alert family members even further. If family members previously experienced severe guilt, they may be more vulnerable to having their past guilt re-triggered. Clinicians can ask them whether they experienced strong feelings of guilt in the past, without necessarily asking them to share what it was. If family members say that they have, clinicians can alert them to the possibility that their feelings of guilt may increase.

Asking patients and families to share that they have felt profound guilt without relating its content may be a new clinical paradigm. Previously it was believed patients had to share information regarding specific encounters to get better. When we consider clinicians who work with transgender persons, we shall see a particularly important example of this.

Interests of Clinicians

Clinicians may believe that they alone should make the decision to stop ECMO, for many reasons, from wanting to spare patients and families the exceptional pain of making the decision to reasons that are less altruistic. For example, clinicians may want to spare loved ones the risk of feeling guilt, and this could be ethically problematic if it is not what the loved ones would have wanted for themselves. Further, within any group, people are likely to differ. Some loved ones may want clinicians to make the decision for them, but they might not be willing to admit it when they are with other loved ones. There is one reason that Meltzer and colleagues highlight in their study that warrants special comment. A clinician says, "Patients and families most often do not have the medical knowledge to make informed decisions regarding ECMO therapy—considering its complexity and the multimodal specialties involved, there should be deference to the physician teams on whether to initiate or discontinue therapy." The rationale that patients and families lack sufficient knowledge to participate in making decisions to stop ECMO has generally been rejected. It wholly goes against what is assumed regarding participants in research. In research, it is presumed that all would-be participants can come to know all that they need to know to decide whether or not to participate. Members of institutional review boards (IRBs) routinely add to and clarify would-be participants' consent forms so that this presumed capacity to understand sufficiently can be achieved. If the research participants do not know enough to participate, it is presumed that either the researchers have not taught them well enough or that researchers have not taken sufficient time. It is important that participants not only understand discrete pieces of information, but that they can see how the information is relevant to them. Thus it is critical to determine whether the

researchers have discussed the research with potential participants and that the researchers have asked participants questions to make sure that a deeper understanding is in place.

Researchers may seek to do this by using visual aids. Later, I will discuss a new paradigm in which an ethics consultant sought to better inform surrogates by letting them see a patient's wounds at her bedside. Likewise, clinicians who seek to inform families about stopping ECMO could use visual aids.

In the study by Meltzer and colleagues, one clinician's rationale for not involving patients and loved ones in making decisions contrasts strongly with what is more common practice. This raises the possibility that this clinician might use false logic to rationalize away the capacity of patients and family members to understand sufficiently. The clinician may use flawed reasoning for many reasons, but a chief concern is that, like patients and loved ones, this clinician would find it extremely painful to make a decision to stop treatment. Making a unilateral decision to stop treatment may be an attempt by the clinician to reduce this pain in some way—for instance, by being able to feel more in control.

There are two studies that alert us to this possibility, and, by implication, to the greatest pain to which we may all be vulnerable: the pain of seeing and being with loved ones as they die. The pain may be enhanced if we, in some way, believe we have caused this. One study involved nurses who were especially empathic. They came to avoid dying patients early in their training. The authors of the study speculate that this happened because the nurses had not learned yet to manage such exceptional distress. The authors speculate that the nurses may have been able to better manage their distress later on in their careers.[11] Such an overly painful and maladaptive response to too much stress too early in life may occur to any of us. This possibility is suggested by a psychological phenomenon known as "egoistic drift." This human tendency is exemplified by children aged five to 13, who, in one study, were shown videotapes of highly distressing scenes, such as immigration authorities separating a child from parents. The children in this study became increasingly more attentive to the plights of the children they were watching, until their own stress surpassed that of the children in the videos. When this happened, the children in the study shifted their attention and focused on their own needs.[12] Although the study involved children, this egoistic drift also may occur in adults. It may be even that the degree to which people and clinicians care, the more vulnerable they may be to distress.[13]

A woman I was treating for depression was as caring as a person can be. She was a social worker whose job was to assess parents who neglected or abused their children, and, in cases of abuse, to initiate separation procedures. She was exceptionally resistant to both psychotherapy and antidepressants. She stayed significantly depressed. She was able to change jobs and help poor families find better housing. Her depression vanished, almost at once.

What Paradigm Might Be Best?

I won't answer the question of whether those who are most empathic are also the most vulnerable. But I will note that when clinicians reduce families' guilt, they may similarly help relieve their own grief. Ellen Coonan, in "Medical Futility: A Contemporary Review," an article in this issue of *JCE,* suggests that medical professionals who provide treatments that usually would be deemed futile can provide "much needed relief and benefit to a patient's friends and family" by continuing treatment for a longer time, when they can.[14] This may, she asserts, help grieving relatives "through their inevitable emotional upheaval in a kinder and less abrupt fashion." This change from what we often do now, she contends, may alter the definition of futility from a much less patient-centered or physician-controlled approach "to a position that aligns more with the needs of the mourning family," such that the "subsequent decision to either withhold or withdraw treatment can provide more comfort and relief to families." There are clear limitations, including not objectifying patients or adding to their suffering in an effort to better serve the family. These limitation preserve medical resources for others, and in this way further justice.

Early evaluation, Coonan declares, may alleviate the later burdens of making difficult decisions and allow families who are already grieving to "move on" more quickly than otherwise might have been possible. Early, active engagement with patients and families, first as an anchor and then providing updates as they are needed, should be the starting line for all clinical encounters. "Preventive ethics" need not be conceived as episodic, which risks missing patients' and families' ongoing needs and objectifying them as persons to be informed—as a routine. An ethically preferable strategy involves keeping patients and families always meaningfully informed.

Coonan's suggestion for helping families "move on" is intended to maximize their being able to find continued meaning in their lives. To work through grief may be as painful as any task that humans face. And the loss suffered by families will remain.

Notwithstanding these limits, Coonan offers a significant new paradigm for helping families. The paradigm she offers places greater moral weight than we customarily do on benefiting loved ones; "the psychological health of those remaining," she states, "must be taken into account." Her view would apply in all contexts, but it might particularly to loved ones when ECMO must be stopped.

How far and in what contexts, though, should this suggestion be implemented? Should we maintain futile care longer for this reason? And if we believe we should, should we call the care "futile"? Coonan's view serves, in any case, to illustrate the possible gains from considering a new paradigm.

The very word "futile" may have negative connotations for family members. It is intended to convey boundaries and the rationale for these boundaries, but it may assault what family members hope and feel. Its use may seem high-handed to families. Perhaps in clinical care, regardless of the law, it should be jettisoned.

How Sharing a Decision Might Best Be Done

An ethical question not addressed even by Meltzer and colleagues is: What should clinicians do if patients and/or loved ones never agree to stop treatment? It may be that, in time, and sooner or later, hospital authorities would stop ECMO if patients, loved ones, and clinicians won't. Pediatricians have told me than when children have ECMO, clinicians may have more discretion. This possibility, whether true or not, may raise the question of what hospital authorities should do in these instances, and whether they should change their paradigms, especially in regard to adults on ECMO. Since other patients may need ECMO, it may be unjust to leave them without this treatment so patients who will die shortly, in any case, can live a little longer. For these other patients, ECMO may be lifesaving.

Before ending this discussion on ECMO, I would like to briefly share what may be the "state of the art" when parties continue to disagree. The thoughts are Autumn Fiester's, not mine. She is a mediator who has written previously in *JCE*.[15] I will relate a few of her most important, more subtle points.

First, clinicians should attend not so much to the content of what objecting loved ones say, but to the underlying reasons they believe what they do. This involves, for instance, clinicians attending to, listening to, and hearing their concerns and desired outcomes, and to what they value, including what they most fear. If clinicians ask only about "reasons," they risk making this listening too analytically biased. Also, people's capacity to state why they feel what they feel is limited, and it may not be all possible to express some feelings in words, as the care perspective informs us. Clinicians who recognize these realities may overcome them by asking patients and family members to share their feelings, without reasons. Clinicians could say something like, "Please tell me, if you can, about what you are experiencing, what you are feeling, what you fear, and what you imagine and hope." Thus, first of all, clinicians should caringly ask families about their reasons. When clinicians hear them, they should express their agreement. Why? Because families' reasons will always, in some way, be valid. If clinicians miss the validity of the reasons, they have not used their moral imagination richly enough. Here's an example from my own experience. Patient's family: "We are hoping for a miracle." Me: "Of course you are. Because you care."

The approach of searching for loved ones' underlying reasons is one approach, if not the only or best approach, currently recommended when loved ones, based on their religious views, disagree. In a presentation at the 2016 American Society for Bioethics and Humanities conference, Devan Stahl, Trevor Bibler, Myrick Shinali, and Ashley Stephens urged clinicians to explore with patients' loved ones what is most important in their religion, to learn more about their underlying values and to make it more possible that all may come to agree.[16] (Clinicians may use this approach when they discuss with other clinicians the religious objections they have to treating some kinds of patients.) The approach has been found effective in enabling clinicians to come to appreciate views that differ from their own. When we can acknowledge what another person values most, it is more likely that we can become allies. This may clear a path for us to work together.

Clinicians can indicate that they will do all they can to help the loved ones gain what they want—and then do it. I experienced this myself recently, when I told a patient's loved one, who called me, that I would call a clinician on his behalf, in case it might help. I didn't think that it would, but I was overwhelmed at how grateful he was, in response to my having made the offer. I considered it hardly an effort to call a fellow physician to ask what the physician thought, as an expert. The intensity of the thanks seemed wholly disproportionate to my offer. The lesson, for me and others, is to not underestimate the effect our making an extra effort may have—to imagine such initiatives and offer to carry them out, whenever this may be helpful.

It may be possible, when stopping ECMO, to allow patients and loved ones slightly more time, as

Coonan suggests. When this isn't possible, clinicians should express their sorrow and regret that they can't do more, genuinely and emphatically. I did this myself, a few days ago. I suspect it was because I'd just heard about this from Autumn Fiester. I was surprised by the exceptional impact of saying that I felt sorry. A patient wanted pain meds that I couldn't prescribe, because those meds have to be prescribed by a different kind of clinician where I work. She was angry. I explained why I couldn't prescribe the meds, but she was still angry, and I wasn't sure whether her anger was at "the system" or me. "I'm so sorry," I said, truthfully. Her anger, somewhat miraculously to me, seemed to just melt away.

A third point is how clinicians should respond to others' anger. It's important, but not obvious. Many clinicians fiercely set limits. They may say, "This is not acceptable." An alternate approach is to recognize, from a show of anger, that another may feel exceptional stress. They may feel helpless. Recognizing this possibility, clinicians might say, "Wow, I can see from how you feel that I must have really missed hearing what you need. Please let me try again." There is a risk that even when this expression is wholly genuine, patients who are unaccustomed to such candor may misperceive it as patronizing or disingenuous. To be credible, such candor may need to be consistent with how we are at other times. We must not take such anger personally. It is most likely not directed at us. If another's anger is based on a misperception, that can be corrected.

Finally, I offer this clue: We may overly respond because a feeling emerges from within us. In these situations, it can help if we ask ourselves whether we have ever felt something like this in the past. If we have, and this memory emerges, our anger may too, in just a moment, melt away.[17]

DISORDERS OF CONSCIOUSNESS

Advances in neuro-technology have made it possible to detect residual consciousness in patients that, prior to this, we have not been able to detect. Patients who were thought to have been in a VS we now know may be aware. They may be able to communicate.[18] This requires new tools and clinicians who are willing to challenge the previous VS diagnostic paradigm. Patients may be able to communicate only by changing their inner thoughts. For example, they may respond "yes" by imagining that they are playing tennis, and "no" by imagining they are sitting on a couch. These responses, I am told, require considerable interpretation. Given this, some believe that relying on patients' responses to determine whether or not to withdraw life-preserving care is unwarranted, although the patients' responses may have some place, for example, when they affirm that they want their advance directive, previously executed, to be followed.[19] Testing for awareness and responses presently occurs only in research settings. But the question of how much moral weight patients' responses should have—in addition to other important questions—will eventually arise in clinical settings. At that point, especially, new paradigms for helping these patients will be needed.

A first question will be how often clinicians should test patients who are thought to be in a VS. Awareness may come about later, as their brains heal. When patients do have awareness, loved ones may be able to communicate, somewhat, with them. Kathinka Evers has advocated most strongly for these patients. She states, "when these tools for making this diagnosis are available, beneficence suggests that we use them to give all patients the possibility of being correctly diagnosed through them." She believes that beneficence also calls for us to err on the side of "interpretational optimism." This is, she asserts, a "desperate situation." The right to be given the opportunity to communicate should be considered, she says, "a fundamental right that needs no reference to ethical theory to be supported."[20]

Evers reports that now, in many hospitals, clinicians stop checking for the consciousness of patients who are in a coma or VS once certain amounts of time have passed. She hopes this will soon change. The most important and most urgent initial ethical questions we will face will be how we determine whether patients are suffering, and, if they are, what we should do. The patients' inner states may be somewhat like what Dalton Trumbo depicted in his main character in the novel *Johnny Got His Gun,* if they are aware, but their awareness hasn't been detected. The main character in this state asks, "can a man ever be lower can a man ever be less?"[21]

What new paradigms might we adopt to best try to relieve the suffering of these patients? For some, it may be allowing them to die; for others, it might mean providing them with as much opportunity to communicate with loved ones as possible, and as much as they crave. This may pose new questions for loved ones. They may know, rightly, that patients cherish each moment with them and dread their times alone. As Evers points out, patients may find pleasure even in their loved ones' smell.[22] Clinicians who know that this may occur in the loved ones' future may want to help to prepare them for some of the more difficult emotions they may feel. Loved ones may, for instance, know that patients may want

them to be with them as much as they can. Knowing this, patients' loved ones are vulnerable to feeling guilty because they can't do more for patients.

When clinicians discuss this with loved ones ahead of time, it may lessen the extent to which they are vulnerable to feeling guilt. I think of my father, who died after existing for three months, so we thought then, in a VS. As I reflect now, he may have had some awareness. If we had detected this, what would I have felt and done—or not done—differently, I wonder? I might have rearranged my life so that I could be near him and with him as much as I could. If I had done this, would I have resented what I would have given up? I don't know this answer. These are, though, likely the kind of questions that loved ones will ask later, and if clinicians can discuss this with loved ones beforehand, it may help them, and, as a result, the patients, later.

FURTHERING EQUALITY

Patients with dementia may become forgetful, blame others for what they can't find, and become angry and aggressive. Their families may no longer be able to care for them at home. Thus, as a result, patients may lose the source of what is their greatest and even their single joy in life—living at home with their family. To preserve this one way that they can remain "equal," clinicians and loved ones may have to be willing to deceive them. I will discuss this to a greater extent later. Another source of equality with persons who do not have dementia may be the possibility to engage in sex—even though persons with dementia may not know who their sexual partner is. Both purposeful deceit and facilitating sexual relations for persons with dementia illustrate the need for new paradigms when treating patients. Of course there are numerous innovations for these patients that we could pursue here, but retaining some sexual freedom is, perhaps, a particularly clear example we can use to illustrate another new paradigm that we could quite plausibly adopt.

To best illustrate the need for new paradigms, I will turn to a range of interventions we should consider for persons who identify themselves as having a different gender. Our task is to help them, as much as we can, to enjoy an "equal" quality of life. Even though these individuals do not have a disorder, clinicians have an obligation to treat them so that they can live as free from unwanted stress as other persons do. In contrast to patients with dementia, total equality is possible here. It may be, for some transgender persons, that freedom from unwanted stress will mean being able to walk down the street without others noticing them because of how they look. I will give examples of how this may indicate the desirability of these new paradigms.

Patients with Dementia

In this issue of *JCE,* Jenny M. Young and David Unger, in "Covert Administration of Medication to Persons with Dementia: Exploring the Ethical Dimensions," and Robert C. Macauley, in "Covert Medications: Act of Compassion or Conspiracy of Silence?" ask whether clinicians should give patients antipsychotics secretly when, due to advanced dementia, they develop symptoms such as aggression and paranoia.[23] This may leave loved ones no longer able to care for patients in their home, or even for them live in assisted living or a nursing home.

Deceiving Patients for their Own Good

Purposeful deception may be the only way to enable patients to be able to remain with loved ones in their homes, or in assisted living. Young and Unger illustrate this by describing a hypothetical patient with dementia, Mei Ling. She has, they report, for three days, spit out her medications. If she continues to spit them out, she will most likely further decline. She may believe that others are stealing from her, and become aggressive, even physically attacking those she most loves. Macauley considers the case of Mr. Smith, who becomes disoriented when admitted to the hospital for an infection, and won't accept his medication, and whose dementia leaves him agitated and afraid.

I recall such a patient. She attacked her husband after she had been married to him for decades. This behavior is not uncommon among patients with dementia. If, for example, they forget, they may believe another has harmed them and act then in part to retaliate or in an effort to protect themselves. Her husband called me from inside a locked bathroom at a motel where they had been staying. He said she was threatening him outside the bathroom door with a knife. Fortunately, he was able to talk her down. This example illustrates how past trust may not "count" with patients, and thus, to maintain their trust, antipsychotic medications may need to be covertly administered—or as Young and Unger term it, covert administration of medication (CAM). Antidepressant drugs are now initially preferable for these patients, but antipsychotic drugs may be necessary to calm them adequately, even though they may pose an increased risk of sudden death.

Still, as the authors report, CAM occurs commonly, in 43 to 71 percent of nursing homes, and this often includes the administration of antipsy-

chotics. A new paradigm, one that explicitly allows such deceit, may be ethically indicated for clinicians and family in other contexts. Some might argue that giving antipsychotics covertly is ethically preferable and even indicated for these patients if they would otherwise refuse these meds and then become violent or psychotic as a result. The best example is when patients ask after a spouse who has died. Reminding them that their partner has died may cause them the most profound grief. And it may recur minutes later, repeatedly. Clinicians may greatly help patients' loved ones and, as a secondary effect, the patients, by informing loved ones before these situations arise that while honesty is very important, to be compassionate, they may have to lie.[24] The conditions that should be present to indicate this initiative must be carefully assessed and spelled out.

I recall a patient with dementia to whom I prescribed antipsychotics, which, fortunately, she took willingly. They enabled her to overcome episodes of rage, to continue to enjoy a close to equal life, and even, to a most limited degree, to continue to have an experience that once was related to sex. Prior to receiving this medication, she would become angry and, as if in a rage, pound her chest. The medicines enabled her to continue to stay with her care giver, who was much frailer than she. She could also walk with her care giver to a nearby grocery store and to church, which she loved. In time she couldn't recognize either her husband or me. I drove him to the nursing facility to visit, since he could no longer drive. When he would visit, he would kiss her on the lips and she didn't seem to mind. This example suggests another way in which clinicians may help patients be treated more equally.

Helping these Patients Enjoy Sex

Clinicians can increase patients' equality by facilitating their opportunity to engage in sex. As Young and Unger note, treating people equally may mean treating those who are unequal, in some respect, unequally. Thus, with this group we may need to do things we wouldn't do for others. The prevalent belief is that, to adequately protect patients, we should curtail their sexual activity. But paradigmatic change may be warranted here, because while patients with dementia may come to lack the capacity to communicate in other ways, they may have the capacity to experience exceptional pleasure from sex. Alexander A. Boni-Saenz spells out how to best do this, starting in nursing homes. He points out that the most difficult ethical problem may be the concern that a patient's prior self may no longer be who she or he is now. Boni-Saenz solves this objection by limiting the group of patients with dementia for whom he would permit sex, at least initially, to those who have what he calls a "consensus of consents."[25] What this means is that both the prior and present person, as it were, would say that he or she wants to have sex. Boni-Saenz suggests a consensus of consents might best be accomplished by adopting a regular practice of asking patients, when we still can, whether they want to issue a sexual advance directive. Whether the directive should include a specific partner is a question that we should ask, but not one I will address now.

These patients, as all of us, may experience denial. That is, patients with early dementia may not believe that much later they may want to have sex and thus, that a need for an advanced directive exists. Clinicians who want to do this for patients may have to bring up the possibility of issuing a sexual advance directive especially early in a patient's treatment course. Boni-Saenz asserts that long-term care institutions are best equipped to initially enact this change, because they can provide the necessary third-party oversight. He points out, in arguing for this sea change, that sexual expression for the patients is not only one of the few remaining physical pleasures they can enjoy, but also a source of personal meaning and social connection. Pre-planning for patients, he believes, may provide "a forum" through which they and their spouses can "process" singly and together the implicit issues they face that involve "disability and death."[26]

Clinicians may, more generally, help patients and their partners by discussing with them what they would want most in the future regarding sex. Allowing partners to discuss this in advance may help both, profoundly. At later stages of patients' illness, clinicians may have to coach them; that is, as their dementia progresses, patients may forget how to engage in sex and forget what they must do. Coaching may enable patients and couples to do what they want and need, later. Such prior discussions may later help partners who don't have dementia, should their partner who has dementia not know them, and enjoy sex with another person. As Coonan notes, more generally, these discussions should give partners more time to prepare, and, as she says, would give more weight—and perhaps due weight—to helping patients' loved ones to a greater extent.

Transgender Persons

Clinicians may pursue several new paradigmatic changes to help transgender persons. A first paradigmatic change is one I mentioned earlier: that clinicians, as well as our greater society, become

committed to doing what is necessary for transgender individuals to be treated equally, even though they do not have a disorder. Transgender persons may become depressed or have another psychiatric disorder. If these persons haven't changed their body to fit with their gender and feel depressed or anxious, their depression and anxiety may remit once they have this change. Their needs may go beyond what many clinicians now recognize. For example, transmen—persons born female but who feel that they are male—may, after other interventions involving male hormone treatments, need their chest recontoured so that they may engage with others without their appearance interfering in their social interactions. Likewise, transwomen may not look as they want and need after they have had female hormones. Consequently, they may need and want, in addition, breast implants.

These may be the best examples to illustrate the new paradigms that may be needed for these persons. There are a host of others. The few examples I use here are, at this point, not well established but nonetheless among the key interventions that are currently taught. I am using them not to convey these edge-of-the field practices, but to illustrate the paradigm shifts that may be required to enable these persons to achieve the "equal" quality of life that they want. Clinicians may be accustomed to assuming, for example, that they are warranted in expecting all their patients to be wholly open and forthcoming. When these are transgender persons, this may not be the case. These patients may want to keep to themselves, for example, whether or not they have in the past had what is sometimes now referred to as "bottom surgery," that is, surgery below the waist. In many medical contexts, there may be no need for clinicians to know this. Thus, clinicians should respect these persons' wish to keep this information to themselves.[27] Clinicians who see these persons should, as with all patients, take the initiative to learn what they need to know to be able to inform these persons what they may medically need to consider, rather than be educated by these persons. All too often, this is now reportedly the more common case.[28] When clinicians provide hormones to these persons, for instance, clinicians should review with them whether they feel they might later want to have children. If they might, clinicians should advise them that they may need to freeze their sperm or eggs if they plan to continue taking hormones for more than a year.

The last new paradigm is of overriding importance, and it may go wholly against readers' and our society's usual cultural views. We highly value respect for religion and religious beliefs. Currently, some clinicians will not treat transgender persons because changing one's gender goes against the clinicians' religion and religious beliefs. This objection may be seen as ethically equivalent to clinicians who are not willing to treat a patient on the basis of race; the current objection is based on persons' gender. I will not address what is or isn't justifiable. I will, however, describe how some clinicians, including me, have approached clinicians who have this religious view. If a clinician is open to discussing this, the approach that Fiester urges can be used, which I presented earlier. One can ask these clinicians what, aside from what they believe their religion says, they believe a refusal to treat most stands for and the values it most prioritizes, underlying all else. Those who have talked with physicians tell me that often the physicians, although initially opposed to treating transgender persons, in response to this kind of inquiry, change their mind.

I recall one such clinician. I was situated ideally in the discussion because he had taken the initiative to present his religious objection to me as his problem, and asked me what I thought he should do. We discussed first some basic concepts, such as whether ethically he should tell a transperson, before starting treatment, about his religious beliefs. I said that perhaps the best way to overcome such views is to get to know such persons better. I asked him to role play. What turned out to be the transformative point for him was when he, in the role of clinician, was trying to decide whether initially to tell me that he viewed my wanting to change my gender as wrong. He recognized at this moment that he might change his view if he treated me and came to know me. He realized that if he told me his view initially, he might never get the chance to know me. He decided that to respect transpersons who come to see him for treatment, he should inform them initially that he has this view, but add that he hoped very much that despite this, the persons would allow him to treat them, as least for a short while, because the clinician hoped that by doing this, his religious views would change. He has not yet, however, had transpersons come to see him for treatment. Thus, he hasn't found out, as of now, how he or they will respond.

SURROGATES AND RESEARCH

In this last section, I will explore two new paradigms described in articles in this issue of *JCE* that may be exceptionally far-reaching. The first article describes clinicians showing surrogate decision

makers patients' wounds. It could be that ethics consultants might want to do this with some frequency to better inform surrogate decision makers. The second article explores whether researchers should do more studies on controlled substances than they do currently. This may involve investigators and those who are responsible for approving research that involves human subjects to rebalance competing priorities, so that we can find new, safer ways to relieve patients' pain without the risks of addiction. The authors report how different persons who were asked to assess the research question came to change their views in a very short time. The process the authors used may be useful to clinicians who are trying to decide whether they should adopt a new paradigm, such as those presented here.

Inviting Surrogates to See a Patient's Wounds

In "Cases from the Cleveland Clinic Foundation: What's Knowledge Got to Do with It? Ethics, Epistemology, and Intractable Conflicts in the Medical Setting," Bryan Kibbe and Paul J. Ford report a case in which they took surrogate decision makers to an incapacitated patient's bedside to see her decubitus ulcer.[29] They did this in response to a request by family members who hoped to enhance their knowledge of the patient's state, so that they could make the best decision for her. This is an uncommon practice, and may be seen as a new clinical paradigm. The ethics consultant who took this rare course did it because the views of the medical team and of some family members differed. The team was "more and more convinced that Ms H. would not survive her current medical condition and would not benefit from various medical treatments," whereas most of the family members disagreed, and felt stopping treatment might be akin to murder.

In making the case for taking surrogates who are willing to see a patient's wounds, Kibbe and Ford offer this thought-provoking analogy: "During a magician's performance, the audience 'sees with their own eyes' someone disappear, as if by magic, even though this is not what actually occurs. Similarly, the very strong visual display of wounds or other injuries might lead away from understanding, if not provided in a responsible framework or context that gives greater meaning and clarity to what is seen." They discuss what clinicians, and particularly ethics consultants, might do to help insure that surrogates who view a patient's wounds acquire greater clarity, rather than have a bad end result.

As the consultants who chose to do this were aware, it may have had bad results. Clinicians who want to impose their own views but who need surrogates' consent could use such "super-informing" to try to effect the result they believe is the best one.

Perhaps the most important advice the authors give is to prepare surrogates adequately for the distressing nature of patients' conditions or wounds. The gains from preparing loved ones mirrors the suggestions of Meltzer and colleagues regarding ECMO, and Coonan, more generally.

As it happened in the case described by Kibbe and Ford, the majority of the patient's family members remained fixed in their view that they did not want to withdraw medical treatment. Still, what remains particularly noteworthy in this case is how the family members who willing to "go and see" the patient's wounds wanted the ethics consultant to go with them. This aspect of ethics consultation is, to me, the greatest accomplishment—for those conducting any consultation, regardless of its outcome—to keep all relationships trusting and caring, especially when there are highly aggrieved parties. The consultant in this case clearly did this.

Should other clinicians suggest this same intervention with their patients' family members? In response to this question I think of a natural disaster that occurred that left a young boy with a wound in his leg so badly infected, the leg needed to be amputated if he was to survive. His mother refused to give consent. His surgeon knew it went beyond standard policy to show the mother her son's wound, but he did. She, duly shaken, consented. The surgeon operated, and the boy lived.

Seeing may also change staffs' views. A case in which I was involved is one example. A child had Werdnig-Hoffman's disease, a genetic condition that causes ascending muscle paralysis until the child dies, usually at the age of two or three. At two years, this young girl acquired pneumonia due to the weakness in her lungs. The staff had treated her successfully with antibiotics, but, being appropriately proactive, the staff asked the ethics committee to meet to help them decide whether they should place the child on a ventilator, if needed, the next time she came in. The staff assumed that if they did, she would need it permanently. The members of the ethics committee did not see the child in person, but imagined that her family was deeply despairing, because they knew that within months their daughter, whom they loved so dearly, would soon die. Pediatric respiratory specialists added that if she was on a respirator, she wouldn't be able to understand why, the suctioning would painful, and, due to the respirator, she would not be able to hug her family. The majority of the ethics committee decided to say "no"—if she came back in with pneumonia, she should

not be placed on a respirator. The harm versus gain would just be too great.

I felt unsure, so I went to the child's hospital room. I stopped outside her door, because I was surprised by what I heard from inside her room: peals of her laughter. This was wholly different from what the ethics committee had imagined. I thought of trying to reconvene the committee, but did not. I may have been wrong in not contacting them. The parents, to my knowledge, never returned. This example illustrates a key point Kibbe and Ford wish to make—that there may be an important difference between knowing by verbal testimony and "knowing by direct perception."

This ethics committee did not, however, know—they believed, and their belief may have reflected primarily their bias. My belief may have reflected my own bias. Seeing is then, as the ethics consultants fully realized, fraught with peril. "Buyers" clearly must beware. Still, this additional intervention may be a new, even lifesaving intervention.

Doing More Research on Relieving Patients' Pain

In this issue of *JCE,* an article by Evelyn Rhodes, Michael Andreae, Tyler Bourgiose, Debbie Indyk, Rosamond Rhodes, and Henry Sacks, "Stakeholders' Views on Barriers to Research on Controversial Controlled Substances," is the last article that I will discuss.[30] The authors ask why we don't do more research on controlled substances. They believe that we should. As they indicate, the research is clearly needed. As use of oxycodone has decreased, the use of heroin and deaths from it have increased. There is, at this same time, no greater reason for doing research than to find better ways of relieving patients' pain. Pain, like dementia patients' aggression, may wholly destroy the quality in their lives. When patients are in pain, they may feel they need to use drugs that may be addicting—and they may. But they also may not. Depending on the type of pain the patients have, the drugs may not, over time, be effective, and, still more importantly, patients' need for these drugs may become, for them, their only need, and it may come to replace all other interests they previously had in their lives. Thus, clinicians struggle with whether or not to prescribe these drugs. They may fear the outcome of addiction so much that, rather than take this risk, they choose to leave patients feeling pain. Ironically, as I will share shortly, this may be, in the longer run, for many patients, in their best interest. This is another example of new paradigms that may be needed.

Research is essential to determine how clinicians best can treat pain, but fears, including a fear of addicting participants, may spill over to fears of doing research. These authors ask, "Do the risks of physical harm associated with controlled substances constitute an insurmountable barrier to research on their medicinal value?" Why is this research so critically important? Because, in addition to other well-known factors, what is best for patients is, it appears, not well understood. Glenn Jordan Treisman, a professor of psychiatry and behavioral sciences at Johns Hopkins Medicine, is an internationally recognized expert on addiction. He states that pain relief for certain kinds of pain is not helpful in the long run. Thus, at the chronic pain clinic he co-runs at Johns Hopkins, he often seeks to help patients whose lives have fallen apart, due to these drugs, to learn to go on without them. They can regain the quality of their lives. They can, for example, work and become available once more to their loved ones. The success he achieves helping these patients, he says, is in the range of 30 percent. He, too, calls for much more research on the best approaches, so that this figure can become much higher.[31] His approach to not use the usual drugs is a different and uncommon paradigm. When patients come to him in pain, pleading for him to help them, he tells them they have come to the wrong person. If they want to see him but continue to take pain meds that won't help them, he will, he says, only "yell at them." He tells them that he is committed to their long-term quality of life, and he will not participate in destroying it, although they may find other clinicians who will.

Finding Answers

In their article, Rhodes and colleagues ask whether the risks of physical harm from the controlled substances used in research outweigh their medicinal value. In pursuing an answer, they gathered clinicians, members of IRBs who must approve these studies, and people with HIV and AIDS. At the beginning of the survey, the authors asked all of the stakeholders whether or not they thought the risk of physical harm posed too much of a barrier to such research. One participant initially responded wholly in the affirmative: "They [are] going to become addicted. Then they're going to be bootlegging and stealing out the stores. And 125th Street is going to be on fire." (125th Street is in the heart of Harlem in New York City.)

Another shared this story: "Listen, we know someone who did this study. . . . She went in. She did the study. She sat there. They gave her all the crack she wanted. . . . But when she came out—. . . she was so messed up that she immediately went to a long-term rehab. Long-term." This last anecdote

describes the outcome that Treisman fears and opposes so strongly. What is most surprising, and, perhaps, promising about the study by Rhodes and colleagues is that, in 90 minutes, even after hearing the above reports, both clinicians and IRB members came to recognize what they had not seen before: that they had had unsupportable beliefs that affected their previous attitudes, such that they had overly-inflated the risks of providing heroin in research.

The authors say, "Ultimately, nearly all of the clinicians and IRB members reached the conclusion that, with appropriate study design and considerable caution, the risks of physical harm involved in studying heroin or marijuana as a possible treatment for HIV symptoms were surmountable." They conclude that focus group discussions (FGDs) can produce a convergence of views: "Our finding is remarkable because all eight of our FGDs reached the same conclusions on a set of related issues." "Seeing this transformation in group after group," they say, "was unanticipated, startling, and encouraging." This is only one study, but its results suggest that, as in this instance, using new paradigms, such discussions may allow clinicians and others to change their initial views. Clinicians' main task may be to imagine new paradigms so that others can consider them.

CONCLUSION

I have discussed new paradigms and other ethical innovations raised by articles in this issue of *JCE.* I added a few more of examples of my own. The optimism implied when finding new paradigms may be misleading, because the advances may make it appear that more gains are possible than actually are the case. Medicine is often limited. When used as a bridge to longer term treatment, ECMO may not succeed. Patients with DOCs may not get better. Patients with dementia continue to go downhill.

To balance such an overly optimistic emphasis, I would like to end this article with a suggestion of what clinicians may do when treatments may not help: they can listen. Even when clinicians can listen to only a limited degree, the degree to which this can help is suggested in the following essay by Norman Quist, "How Homer Foreshadows the Therapeutic Relationship and Psychoanalysis: 'Tell Me that We May Know It Together . . .' " on Achilles's interaction with his mother in Book I of *The Iliad.* I have abstracted key parts of the essay. Direct quotations from *The Iliad* are in italics.

> . . . we find Achilles weeping over the loss of Briseis: *"Looking out upon the boundless waste of waters,"* Achilles *"raises his hands in prayer to his immortal mother. 'Mother,' he cried, 'you bore me doomed to live for but a little season; surely Jove, who thunders from Olympus, might have made that little glorious. It is not so. Agamemnon, son of Atreus, has done me dishonor, and has robbed me of my prize by force.' " . . .*
>
> Whatever we might say about the circumstances of Achilles's prize and his plea, his suffering is clear, *"looking out upon the boundless wastes of waters."* And so is his vulnerability, as he *"raised his hands in prayer."* What makes this instance of praying different is that Achilles is praying to his mother to intervene, to consider or feel again his circumstances, the occasion of his fate. Her responsibility, if not complicity, is assumed. Achilles's appeal is one we might all imagine making to our mothers, to our parents. . . .
>
> Achilles looks to his mother, as all infants first turn to their mother, for it is she that gave him life; she that bore him, nurtured him. . . .
>
> What is of primary interest here, for Achilles and for us, . . . is his mother's response to his prayer.
>
> When his mother heard him, *"Forthwith she rose as . . . a grey mist out of the waves, sat down beside him as he stood weeping, caressed him with her hand."* She continues, *"'My son, why are you weeping? Keep it not from me. . . .'"* A response that we might imagine, if not predict, of every good enough mother. [The "good enough mother" is a well-known concept of the child psychoanalyst D.W. Winnicott.]
>
> But Achilles's mother seems to know something more, to possess a heightened awareness and sensitivity to suffering and love, for she says, *"'. . . but tell me that we may know it together.'"*
>
> This is the language of a wise parent, even as she is a deity; but it is also the motivating language that is the heart of the therapeutic relationship and psychoanalysis: *"'. . . but tell me that we may know it together.'"*
>
> With this *"Achilles drew a deep sigh and said, "'You know it; why tell you what you know well already?'"* Is this not also what every analysand [patient] imagines and resists, and what Lacan cautions, and why analysts like Bion and Ogden begin each encounter as if for the first time: *"'why tell you what you know well already?'"* Rather: *"'tell me that we may know it together.'"*[32]

NOTES

1. T.S. Kuhn, *The Structure of Scientific Revolutions,* 3rd ed. (Chicago: University of Chicago Press, 1966).

2. Examples include the new the questions posed

regarding DOCs. These discoveries were made possible through innovations such as fMRI.

3. J. Fins, J. Illes, S. Hossain, and J.P. Bishop, "True or False: Neuroethics Deserves an Exception," presentation at the 18th Annual Meeting of the American Society for Bioethics and Humanities (ASBH), in Washington, D.C., 7 October 2016; K. Evers, "Neurotechnological Assessment of Consciousness Disorders: Five Ethical Imperatives," *Dialogues in Clinical Neuroscience* 18 (2016): 155-62, 155; D. Kondziella et al., "Preserved Consciousness in Vegetative and Minimal Conscious States: Systematic Review and Meta-Analysis," *Journal of Neurology, Neurosurgery and Psychiatry* 87, no. 5 (May 2016): 485-92.

4. Evers, "Neurotechnological Assessment of Consciousness Disorders,"see note 3 above, p. 155.

5. E.C. Meltzer et al., "Extracorporeal Membrane Oxygenation as a Bridge to Chemotherapy in an Orthodox Jewish Patient," *Oncologist* 19 (2014): 985-9, 986; E.C. Meltzer et al., "Extracorporeal Membrane Oxygenation in Adults; A Brief Review and Ethical Considerations for Nonspecialist Health Providers and Hospitalists," *Journal of Hospital Medicine* 9, no. 12 (December 2014): 808-13.

6. E.C. Meltzer et al., "A Survey of Physicians' Attitudes toward Decision-Making Authority for Initiating and Withdrawing VA-ECMO: Results and Ethical Implications for Shared Decision Making," in this issue of *JCE,* 27, no. 4 (Winter 2016).

7. Ibid., 988.

8. Meltzer et al., "Extracorporeal Membrane Oxygenation as a Bridge to Chemotherapy," see note 5 above.

9. Ibid.

10. S.H. Imbus and B.E. Zawacki, "Encouraging Dialogue and Autonomy in the Burn Intensive Care Unit," *Critical Care Clinics* 2, no. 1 (January 1986): 53-60.

11. E. Stotland et al., *Empathy, Fantasy, and Helping* (Thousand Oaks, Calif.: Sage, 1978), 199.

12. J. Strayer, "Children's Concordant Emotions and Cognitions in Response to Observed Emotions," *Child Development* 64 (1993): 188-201, 199.

13. J.M. Flury, W. Ickes, and W. Schweinle, "The Borderline Empathy Effect; Do High BPD Individuals Have Greater Empathic Ability? Or Are They Just More Difficult to Read?" *Journal of Research in Personality* 42 (2008): 312-32.

14. E. Coonan, "Medical Futility: A Contemorary View," in this issue of *JCE,* 27, no. 4 (Winter 2016).

15. A. Fiester, "Learning the Skills of Conflict De-Escalation for Challenging Ethics Consultations," presentation at the 18th Annual ASBH Meeting, 9 October 2016.

16. D. Stahl, T. Bibler, M.C. Shinali, and A. Stephens, "Responding to those Who Hope for a Miracle: Conceptual Resources and Practical Responses for Clinical Ethicists," presetation at the 18th Annual ASBH Meeting, 8 October 2016.

17. M.J. Redinger, "Countertransference and the Clinical Ethics Encounter; What, Why, and How We Feel During Consultations," presentation at the 18th Annual ASBH Meeting, 8 October 2016.

18. Evers, "Neurotechnological Assessment of Consciousness Disorders,"see note 3 above, p. 155.

19. J. Illes, E. Racine, K. Kreitmair, and N. Martinez, "Toward a Nonreductive Approach to Integrating Neuroscience in Law, Practice and Policy," presentation at the 18th Annual ASBH Meeting, 7 October 2016.

20. Evers, "Neurotechnological Assessment of Consciousness Disorders," see note 3 above, p. 158.

21. D. Trumbo, *Johnny Got His Gun* (New York: Bantam, 1970), 179.

22. Evers, "Neurotechnological Assessment of Consciousness Disorders,"see note 3 above, p. 160.

23. J.M. Young and D. Unger, "Covert Administration of Medication to Persons with Dementia: Exploring the Ethical Dimensions," and R.C. Macauley, "Covert Medications: Act of Compassion or Conspiracy of Silence?" both in this issue of *JCE,* 27, no. 4 (Winter 2016).

24. C. Oppenheimer, "Ethics in Old Age Psychiatry," *Psychiatric Ethics,* 4th ed., ed. S. Bloch and S.A. Green (New York: Oxford University Press, 2009), 417.

25. A.A. Boni-Saenz, "Sexual Advance Directives," *Alabama Law Review* (Fall 2016): 1-48, 5; see also P. Simpson et al., "The Challenges and Opportunities in Researching Intimacy and Sexuality in Care Homes Accommodating Older People; A Feasibility Study," *Journal of Advanced Nursing* (27 July 2016), epub ahead of print.

26. For these patients, sex may be an "enduring source of gratification at a time when pleasures are becoming fewer and fewer." Boni-Saenz, "Sexual Advance Directives," see note 24 above, p. 18, note 85.

27. L. Buckman, "Assessment and Evaluation From Initial Assessment to Recommendations for Medical Interventions/Transition; Significant Factors Such as Transition Options/Paths, and Fertility Issues," *Caring for Transgender Persons in a Changing Environment,* presentation at the Walter Reed National Military Medical Center, 13-14 September 2016, Bethesda, Md.

28. K. Tetzlaff, R. Kling, and E.S. Swirsky, "Panel on Trans and Gender-Diverse Bioethics," presentation at the 18th Annual ASBH Meeting, 8 October 2016.

29. B. Kibbe and P.J. Ford, "What's Knowledge Got to Do with It? Ethics, Epistemiology, and Intractable Conflict," in this issue of *JCE,* 27, no. 4 (Winter 2016).

30. E. Rhodes et al., "Stakeholders' Views on Barriers to Research on Controversial Controlled Substances," in this issue of *JCE,* 27, no. 4 (Winter 2016).

31. G.J. Treisman, "Chronic Pain and Addictions—A Behavioral Perspective," presentation at the Academy of Medicine of Washington D.C., 5 October 2016.

32. N. Quist, "How Homer Foreshadows the Therapeutic Relationship and Psychoanalysis: 'Tell Me that We May Know It Together . . .' " unpublished. Readers may obtain the text from the author at *Quist@clinicalethics.com.*

I am exceedingly grateful to Norman Quist for sending me this essay and for his numerous helpful comments and references throughout my article. Listening together may be, in itself, a new paradigm. This essay conveys the gains that patients and others can have from being able to share their stories with clinicians, even when their clinicians have nothing else to offer. Clinicians may gain from the interaction.