

Edmund G. Howe, "Going from What Is, to What Should Be, to Care Better for Our Patients and Families," *The Journal of Clinical Ethics* 28, no. 2 (Summer 2017): 85-96.

## *At the Bedside*

# Going from What Is, to What Should Be, to Care Better for Our Patients and Families

*Edmund G. Howe*

### ABSTRACT

This piece discusses ways in which clinicians may go beyond their usual practices. These include exploring the limits of old laws, consulting with colleagues and ethics committees earlier and more often, and giving patients' family members new choices they didn't have previously. This could include asking patients and family members whether clinicians should prioritize staying in the single, unconflicted role of serving patients and families, even when this might preclude simultaneously serving another interest, for example, that of a hospital.

A primary goal of research and writing in medical ethics is to improve how we treat our patients and their family members. In this introduction to *The Journal of Clinical Ethics (JCE)*, I discuss three articles in the current issue that particularly exemplify this effort. Each article suggests, implicitly at least, how to move from what we mostly do now, to what we should do. This distinction, between what *is* and what *should be*, is ever present in ethics.

The first article I will discuss, "A Patient (Not) Alone," describes how a medical team worked to provide the end-of-life care that their incapacitated patient would have wanted, even when it seemed

the law would not allow it.<sup>1</sup> The second article I will discuss, "How Do Healthcare Workers Feel about Family Presence during Cardiopulmonary Resuscitation?" intends to give more family members a new option that many would want.<sup>2</sup> The third article, "Development of a Clinical Ethics Committee *De Novo* at a Small Community Hospital by Addressing Needs and Potential Barriers," reports on survey results indicating that nonphysicians would utilize an ethics committee at a greater rate than physicians.<sup>3</sup> One implication of this may be that physicians should consult ethics committees more often.

I will discuss these articles in three sections. First, I will describe how careproviders who work together as teams may more consistently achieve better results. Second, I will describe strategies that will allow careproviders who work alone to do better. Finally, I will present an unprecedented approach that may benefit patients and families maximally. More than anything, this approach may increase the degree to which patients, families, and careproviders can emotionally bond.

### HOW TREATMENT TEAMS CAN DO BETTER

Lauren Sydney Flicker's "A Patient (Not) Alone," in this issue of *JCE*, describes how one team of careproviders struggled to give their patient, Ms E, the best end-of-life care possible, even though it initially appeared that the law opposed this. The success they achieved was singular. This team models the imagination and courage to which we should all aspire. Ms E was 83. She had an intracranial bleed and was unconscious. She had been on a ventilator for a week, and she needed a tracheostomy and a PEG

---

**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 or assertions contained herein are the private views of the authors and are not necessarily those of the AFRRI, USUHS, or the Department of Defense. The funders had no role in study design, data collection, and analysis, decision to publish, or preparation of the manuscript. Conflicts of interest: none.

(percutaneous endoscopic gastrostomy) to survive. The medical team thought she would never again become conscious. She had no family. She had friends who felt certain that she would not want these additional interventions, and that she would want to die with dignity, but her friends were not willing to be her surrogate decision makers. The team agreed with Ms E's friends that she would not want these interventions, but the team feared that legally there was no way they could carry this out. How they resolved this I will leave readers to enjoy.

The team's efforts illustrate two critical points. First, their efforts exemplify how vigorously we must try to meet patients' needs when we think we know what they are; their needs may ultimately be uncertain, but we should pursue them nonetheless.<sup>4</sup> The second point is more ominous: the obverse implication of Flicker's article is that, should a medical team not pursue patients' needs, the end result may be most negative. That is, what would have occurred if Ms E's team had not been as committed and gifted as it was? She most probably would have remained alive and unconscious indefinitely.

These kinds of results, we know, are not uncommon. Alisa Carse and Cynda Rushton, in the last issue of *JCE*, for example, reported a case in which nurses and doctors had to continue to treat a "catastrophically brain-injured child," which the team experienced as cruel and unconscionable.<sup>5</sup> Ms E's team sought and found a new solution, as we should, for our patients. Thus, the thrust of this first section is: How might we best do this? We must, of course, first be open to considering unprecedented options, and second, willing to take on the extra effort of imagining them. Both involve risks of straying too far from what seems to be a more sound *status quo*.

Initially I shall discuss how we might best work with our colleagues who are lawyers. Next I will present how we might pursue the best possible results as a team, with or without an ethics committee. Finally I will discuss how, as a team, we might best bring our views to hospital administrators. The approaches discussed may help only a small number of patients, such as Ms E or the brain-injured infant mentioned above, but the benefits to these few patients may be enormous. We need only think of these two patients to appreciate and remind ourselves how important such extra effort may be.

### **How a Team May Work Best with their Lawyers**

Clinicians and ethics committees often readily defer to hospital attorneys when the attorneys say, from a legal perspective, what they should do. Often, this deferring makes the most sense. Ethically, for example, deferring to the law is the approach

our society has approved for resolving many disputes. The law, whether ethically right or wrong, also requires extensive procedural requirements that, as we shall see throughout this discussion, may lead to better results. Sometimes, though, this deferring may occur too readily. Lawyers may interpret the same law differently. Some lawyers, for instance, take what the law *says literally* more than others. Other lawyers may give greater weight, for example, to what the law *intends*.<sup>6</sup>

When a hospital lawyer interprets an applicable law differently than another lawyer might, if we defer to that interpretation too early, it may lead to a biased result that reflects only one lawyer's view, when there may be others. Thus, a hospital lawyer must make it clear when his or her view is only one among several possible views. If a lawyer does not do this, patients and families may unnecessarily suffer. Many patients and family members have encountered differing interpretations from hospital lawyers, and from others, when advance directives are read. One lawyer may say, for example, "This is what this advance directive literally says." Another may say, "But this is what I think this patient means."

The possibility that there may be differing legal interpretations leads to a first practice that medical teams should routinely carry out: they should ask lawyers with whom they are working whether what the law requires is absolutely singular in its meaning, such that they have no discretion whatsoever, or whether the law is subject to differing interpretations, only one of which is their own. When there is more than one interpretation of the law, teams may have some discretion. An example is the one Flicker reports. The law required the medical team to do what was medically "standard." Ms E's team imagined a deeper interpretation of what was standard, allowing them to go a new and unprecedented way. That the members of Ms E's medical team believed that they had discretion was critical, for example, to their being able to imagine the solution that they then followed. There are, of course, risks to being too "inventive," and in every such case, there is, of course, a renewed need for legal sanctioning. A next step for team members is to determine the limits of their discretion. This will be addressed next.

*Discerning the extent of discretion.* In discussing the case of Ms E, Flicker notes that legal requirements can result in suboptimal ethical outcomes, and she states how this may occur: "Occasions arise when it may initially appear that following the letter of the law would require physicians to act in a way that may be ethically inappropriate." She spells out the possibly ominous implications of this. The "definition chosen by institutional policy, or in the

absence of such a policy, chosen by a physician's own value set," she declares, "could have *drastic implications*." (Emphasis added).<sup>7</sup>

The clinical implications are compelling. If following the letter of the law may result in suboptimal ethical outcomes, we should do all we can to try to do better. Ms E's team did this. They looked to the law and found ambiguity. Flicker reports, "although pervasive in the hospice and palliative care literature, 'imminence' of death is rarely defined." That the team saw this ambiguity enabled them to find a legally acceptable interpretation and resolution to what, on a first reading, might have been interpreted as being prohibited.

When a law's meaning is open to question, what should we do? Flicker provides guidance. Using Ms E's legal situation as her example, she states, "The statute as it currently reads not only invites, but requires physicians to use their own clinical judgment." She identifies the challenge that faces teams like Ms E's: "There are many clinical situations that are extralegal—circumstances in which the law provides no guidance, and clinicians must instead seek guidance from hospital policy, professional association guidelines, or use their own judgment."

To use one's own judgment, even in a team, takes courage, because when there is legal discretion, it may not be clear where this discretion ends. Thus we may be at risk of acting outside the law. Still, we may best serve our patients by first trying to discern what discretion we have, if any. We should ask ourselves what, within the legal limits, is the best we can do for our patients. The attorney we contact may need to consult the appropriate legal authority to be able to decide whether he or she can approve a team or ethics committee's recommendation.

#### *Discerning whose interest lawyers represent.*

There is a second question that team members should ask lawyers: Are they providing advice as attorneys for the hospital, or on the behalf of the patient? This distinction may make a profound difference in the outcome of a patient like Ms E. This is because the legal risk to the hospital may be small, but a lawyer working for the hospital may feel obligated to represent his or her hospital nonetheless. The risk to the patient, however, may be extremely likely and profound in its negative effects. An example is Ms E. The risk of suit from allowing her to die under these conditions was presumably minimal. Her loss of dignity if she was kept alive indefinitely was absolute. Ethically, there may be little question regarding what the medical team should work for in such cases: what is best for the patient.

Ideally, hospital lawyers will point out this distinction and make clear whom they represent in

what they say, when it is relevant. They may say, for example, "As an attorney representing the hospital, I would advise the hospital to take the least risky course, even though the risk here is small." They might add, "This risk is extremely unlikely." They may then add, "The medical team clearly should take this risk, for the benefit of the patient, and I shall convey this to the administration if this is what you decide you would want to do."

Hospital lawyers may have a good reason to recommend what is best for a patient, even if it poses some legal risk to the hospital: the law, put broadly, has a general interest in clinicians doing what is best for patients, as opposed to doing what they know is worse for patients, in the hope of protecting themselves legally. Thus, it may be what appears to be in a hospital's interest initially, in that it accords with the law literally, may, on deeper inspection, not be. Judges and juries may be loathe to approve a hospital's putting its interests first, above interests that are unequivocally the patient's. Clinicians, accordingly, may explicitly bring this up for consideration with lawyers when these questions arise.

The potential benefit of taking this course for patients like Ms E is illustrated in the following real case. (All of the cases I report from my own experience have been altered to protect the identities of those involved.) A woman had severe brain damage, so severe that her nurses and doctors believed that she would not only remain comatose, but would soon die. Like the members of Ms E's medical team, they wanted to preserve some dignity for the patient, by allowing her to die, rather than keeping her alive in an unconscious state indefinitely. The patient had no advance directive. She had, though, a surrogate decision maker designated by the law: her husband. It was he, however, who had put her in this state. He had, it was quite convincingly known, given her several severe, repeated blows to the head. He had not yet been convicted. He had not, actually, even been found. Her primary physician, the hospital's lawyer, and I (representing the ethics committee) went to the hospital's chief administrator, who had the authority to approve the team's allowing the patient to die. We told him that we all thought that he should approve our stopping the patient's life-prolonging care. Our hospital lawyer, who was also a member of the ethics committee, said that stopping the patient's life-prolonging treatments could put the hospital at slightly increased legal risk, since her husband was legally still her surrogate decision maker. He added that, *as a member of the ethics committee*, however, he thought that ethically there was no question: the administrator should accept the team's request.

The administrator said, “If this is what all the nurses, doctors, and ethics committee members think is best, this is good enough for me.” The team stopped the medical interventions, and the patient was allowed to die. I don’t know the outcome of her husband. This is hardly a typical case. Under circumstances less clear, this might be the kind of case in which hospital lawyers consulting with the appropriate higher legal authorities may be necessary.

### **How We Might Get Better Results on Our Wards**

Careproviders each have their own, greatly different, ethical views. These views may make an enormous difference to a patient when only one view among several—even when all of the views are equally sound—tends to prevail. This may be likely to be the case in many clinical contexts. The moral view of the attending physician may prevail. He or she may impose her or his moral views, even unintentionally. This may occur for many reasons. For instance, the members of the attending’s team may see the attending as having moral views that are more insightful than their own. This may be so, but is always open to question. Medical expertise and experience don’t necessarily carry over into ethics.

A less ethically admirable reason might be that team members may disagree, but are unwilling to express their dissent. Recognizing this may be a key to achieving better outcomes: when a team member does not speak up, regardless of the reason, it may harm a patient. We need merely recall Ms E, or the brain-damaged child mentioned above. The main goal for attendings is to establish an environment in which all persons with concerns feel safe voicing them. Attendings may even ask team members individually if they have conflicting ethical views.

Why it is so important for all team members to express any dissenting view? The case of Ms E is a paradigmatic example. Suppose her attending thought her life should be maintained. The harm this would cause her is evident. The reverse may also occur. For example, at an ethics conference, a clinician described an attending on her hospital’s oncology ward who believed that if a patient was expected to die in two weeks or so, any intervention would be death-prolonging, not life-prolonging, and any intervention should probably be stopped. But to patients and loved ones, a patient’s last moments can be precious. If a treatment that could help the patient live slightly longer is “prematurely” stopped or not initiated, the patient and family could feel bitter. This bitterness might stay with members of the patient’s family throughout their lives.

Other careproviders might oppose the view that continuing treatment under these conditions is

merely prolonging death.<sup>8</sup> In either case, if team members don’t speak out when they disagree, a patient’s outcome may be suboptimal. In the last section of this article, I will describe how the views of team members may affect how they interact with patients, and how it may be all-important for team members to be able to continue to be as intimate as possible with patients and family members until the end of the patients’ lives. This is just the opposite of the “14-day rule” just described.

Members of a medical team may feel strong social pressure not to disagree with the moral views of their attending—and even the moral views of other team members—or, at least, too strongly. Team members and others, after all, will continue to work together, in the future, day after day. Agreeing with each other may be further fueled on an unconscious level, as team members may identify more with their colleagues than with their patients.

This tendency is illustrated by the case related to me by a colleague, of a woman who came to the emergency room insisting on seeing a female doctor. She had a pain in her lower abdomen. The doctor next in line to see her was male. He was deeply insulted. His colleagues fully supported him. They favored, consequently, telling the woman that they wouldn’t treat her unless she accepted being seen by a male doctor. A female doctor ended up seeing the patient, regardless, but the doctors brought this case to the ethics committee, hoping it would help them adopt a policy that they wanted, in the event that they would again confront such a patient.

The ethics committee viewed the situation differently. Its members imagined that the patient might have been previously harmed by a man, even perhaps raped. If so, they thought, the past history of such a patient should clearly be taken into account. The committee also considered more theoretically the question of whose interests should count more—patients’ or clinicians’. They concluded that, in general, patients’ interests should prevail, since patients are the ones who have a problem that brought them to the hospital. Raised more widely, these kinds of questions are increasingly complex. What if, for example, a patient objects to being treated by a care-provider because of his or her religion or ethnicity? Should the arguments be the same?<sup>9</sup>

Thus it may, for many reasons, be difficult for members of a treatment team to speak up morally and oppose their attending, or each other. Accordingly, attending physicians and all team members should be committed to insuring that they always speak up, or at least raise their doubts. Attendings can later ask team members who have raised doubts whether their concerns have changed, one way or

the other, after additional discussion. How else can attending physicians and staff best do this? One way is for attendings to tell all staff this initially, before they discuss patients on rounds: if a staff member has a dissenting view regarding an ethical issue, the staff member should express it. Attendings should repeat this to staff periodically. The effect of an attending saying this should not be underestimated. It is equivalent to the initial speaker at a conference telling participants there are no stupid questions. These kinds of statements, especially when made by a person in authority, may well make the difference in whether team members will speak up.

Chairs of institutional review boards (IRBs) regularly remind IRB members regarding their need to recuse themselves if they have a conflict of interest, for a similar reason. Team members, likewise, may encourage their colleagues to speak up, even when their attending doctor doesn't. Team members may, for example, ask colleagues if they have a different view if and when they look doubtful—or even when they don't. If these measures are followed, and some team members continue to dissent, it may be that the team's best course would be to refer the dilemma to their ethics committee.

Regarding referring team members to an ethics committee: it's better to do this early, rather than be too late. Referring to an ethics committee may have several advantages; for example, it is more likely that ethics committee members will discuss their dissenting opinions. It is, after all, their understanding that it is their purpose to fully air and express their differences. Team members on rounds, in contrast, focus on providing clinical care to patients. Ethics committees, said simply, also have more time. Still more importantly, perhaps, the memberships of ethics committees are typically more diverse, and their members feel, or should feel, more empowered to fully dissent. These differences may result in nonphysicians, such as nurses, having greatly increased voices. It may wholly change patients' outcomes if these kinds of discussions can occur on the ward. But this is much less likely to happen, and the greatly increased richness of contributions by nonphysicians may only be able to fully come out during meetings of an ethics committee.

An example of this richness, and the difference in outcomes it may allow, is suggested in the article by Carse and Rushton, mentioned above. They relate how an attending had residents practice cardiopulmonary resuscitation (CPR) on a dying patient in the emergency room while the patient's family waited outside. Those being taught apparently had no problem learning in this way, or, if some did, they did not say so. This latter possibility may reflect the

difficulty of dissent referred to above. Their learning was challenged by a nurse, but her speaking up didn't stop the lesson, and neither did her physical intervention.<sup>10</sup> In an ethics committee, the nurse would have been heard, and her dissent, and that of others, would, in contrast, have been expected. At the very least, she would have been supported in raising such an objection, whether or not others on the committee agreed with her. Power imbalances may occur even in ethics committees. In principle, the primary task of an ethics committee is to air all relevant moral concerns, and so this may be less likely to happen in an ethics committee than it would in another group. Leaders and participants should take initiatives to bring out dissent: "You seemed to look doubtful. Do you have a concern?"

This example does not stand alone. In this issue of *JCE*, Alicia Pérez Blanco's "How Do Healthcare Providers Feel about Family Presence during Cardiopulmonary Resuscitation?" also makes this case.<sup>11</sup> In her article, she reports how nurses' and physicians' views, relative to each other, differ in regard to whether close relatives should be allowed to be present when careproviders perform CPR. She reports that the nurses she surveyed were more in favor of having family members present during CPR than the physicians she surveyed were. The difference in the sample sizes was small, but the differences in the qualitative content of Pérez's study may be most revealing. It may be most important to a patient's family to be with their loved one at this time. At a minimum, this study raises new questions to be explored: What do families, and, I would add, *patients*, want? How should this be decided?

I am reminded of reports from ambulance drivers. Some families insist CPR be done, even when a loved one has been dead for some time. Family members express relief and gratitude to the drivers, as though their trying to resuscitate, in and of itself, gave the family needed closure. We can imagine that, for family who want CPR performed, no matter what, this might have a most positive emotional impact. The nurses in Pérez's study, more than the doctors, saw this, and gave the positive impact greater moral weight. This extended example illustrates the possibly profound ethical difference that increasing the participation of nurses may bring about. The outcomes of doing so may be qualitatively different.

A similar conclusion is suggested by Bonnie H. Arzuaga in this issue of *JCE*, in "Development of a Clinical Ethics Committee *De-Novo* at a Small Community Hospital by Addressing Needs and Potential Barriers."<sup>12</sup> Arzuaga reports on nonphysicians' and physicians' differing views regarding when they should refer cases to an ethics committee.

Arzuaga found that a higher percentage of non-physicians than physicians said that they would use an ethics consultation service if their hospital had one. When asked if they would have initiated an ethics consultation in the past year, if they could have, a majority of nonphysicians answered in the affirmative. A majority of the physicians said that they would have not. Why did they respond in this way, and what, if anything, was lacking for the physicians, such that others would seek an ethics consult before the physicians would? The answers to these questions may help guide which way we should go. It may be that nurses, doctors, and other clinicians, whether members of ward teams or of ethics committees, may do better at speaking up when their group has a more varied membership when they confront ethical questions regarding their patients. Groups with more-diverse memberships may have more important differing views, and members of the group may feel safer speaking up in a group with greater diversity. As Grunstein-Amado put it, “professional authorities (for example, the college of nurses and the college of physicians and surgeons) need to work together to address the issue of the construction of a new framework to which both groups are committed and which is consistent with both the nurses’ and doctors’ ethical codes.”<sup>13</sup> Entrenched practices take time to change. Still, we can start work on making changes, and this is happening now, in some contexts.

### **Seeking a Referral from Another Ethics Committee**

Ethics committees may, as noted above, have a more extensive process for reviewing ethical dilemmas than medical teams do when they discuss ethics on the wards. These more extensive procedures may, over a large number of cases, bring about better outcomes, in the same way that required procedures, such as the right to cross-examination, may lead to better end results, overall, in a court. Ideally, studies should be conducted to help us better determine which ethics committee procedures lead to better end results. The best ethical outcomes of the deliberations may be difficult to determine, but it may help us know how better outcomes—such as more persons speaking up—may best be achieved.

This advantage, and the other advantages of ethics committees that were noted above, does not mean that an ethics committee’s final judgments will always be better than the final judgments of medical teams.<sup>14</sup> Since members of ethics committees may find it easier to dissent, it may be that, when the members of an ethics committee find themselves at an impasse, they may not be able to work beyond it. When this happens, members of ethics committees,

like members of treatment teams, can refer an ethical dilemma to another body. Asking another ethics committee may be an ideal choice. Aside from providing an additional and outside opinion, the members of another ethics committee may bring new and different gifts to the table. Such consultations have been carried out, and most ethics committees should welcome this. An important question may be what kind of referral—if any—an ethics committee should not accept. In an instance known to me, for example, an ethics committee was asked to review a conclusion reached by an IRB, even though the IRB had much greater research expertise. Is this kind of request for a second opinion appropriate?

Like the members of Ms E’s medical team, members of another ethics committee may come up with new resolutions that the initial ethics committee hadn’t imagined. If, on the other hand, members of an ethics committee feel stymied by a legal concern that they fear ties their hands, they can consult with not only a lawyer, but with a legal authority. The authority may be willing to offer a legal opinion that is not binding.

An ethics committee I am on has found this most useful in many cases. An authority’s opinion may leave committee members feeling free enough to offer a recommendation they otherwise wouldn’t have made. Further, even though the authority’s opinion is informal, it may be most helpful should the committee later bring a request to an administrator. Having an authority’s opinion may leave the administrator able to approve the committee’s request when he or she would not have approved the request otherwise. If the ethics committee is turned down by the hospital’s chief administrators, it may be able to appeal still higher. It could seek a remedy through a court. In the next section, I will describe an instance in which I participated in such a case.

The core justification for a committee’s decision to go even higher is, in theory, ethically clear. If a patient’s need is substantial and certain, no step to try to meet this need should be regarded as going too far. If an ethics committee could go further, for example, by trying to see if an attorney would go to court on a patient’s behalf, the committee should tell their administrator, prior to asking for a meeting, that this is possible. Doing so is necessary, to be even just minimally respectful. But they should go beyond this. The committee should explain that they would do this only because, to them, the patient’s interest is morally compelling. Examples would be that of Ms E and of the brain-damaged child whose continued care violated the child’s careproviders’ consciences. The ethics committee might explain, in addition, that it understands that, by its saying

this, the administrator may feel some pressure. They can note they deeply regret this, but they know no way they can avoid this unwanted secondary effect.

An inpatient hospice staff did this when a patient requested terminal sedation, and the staff wanted to comply. The local hospice authority turned down the patient's request. The hospice staff went to a higher hospice authority. This authority gave the staff the permission that they sought. The outcome of this case has an instructive, if paradoxical, outcome. The staff gave the patient the sedation for a few days, then withdrew the sedation to see whether the patient wanted the staff to continue its administration. The patient did not. He had had a change of mind. From that point on the staff strove to give the patient a meaningful end to his life, as they did for their other patients.

### **What Criteria to Use When Seeking a Referral?**

A critical last, unanswered question applies to both members of medical teams on the ward and to members of ethics committees asking themselves if and when they should seek out a consult or go even higher: What criteria should be used in making a decision? One approach, that might rightly be considered the highest ethical approach, would be to refer their dilemma to others, if even only one member continues to disagree. This approach might be warranted if a member of the group, when questioned later, continues to disagree strongly. This rule may be optimal for those who serve as the chair of an IRB. When an ethical question arises, the chair may consult on it with the IRB's administrative staff. If the members of the administrative staff have differing views regarding the best resolution to the question, the IRB chair may then refer the question to the full IRB. Even if only one administrative staff member disagrees with the views of the other staff, the chair may refer to the full IRB. The rationale for doing this is ethical and straight forward. The research decisions of an IRB may determine patients' outcomes. If even just one administrative staff member disagrees with the others, it may be that a majority of the IRB board agrees with the lone administrator about what would be best for patients.

Careproviders who seek to use this criteria—or any other—for deciding whether to seek a referral may find uncertainty distressing. Not only may they not know whether to seek a referral, but they may be asking about whether to refer because they don't know what would be the best thing to do. It may be particularly tempting under these circumstance to opt for a less radical position. In the case of Ms E, for example, this might have been to make a decision to keep Ms E alive.

A recent Maryland case may be particularly instructive. A patient had an advance directive. She made clear the conditions under which she wanted to be allowed to die. Her careproviders violated this directive. But she then made "a remarkable recovery."<sup>15</sup> She is now 86, has dementia, lives at home, recognizes her family, and is taken to church on Sundays. But, she asks "Why am I still here?"<sup>16</sup>

Historically, when clinicians feel doubt about how best to proceed, they err in maintaining a patient's life because death is irreversible. Family members now, however, have begun to bring suits against clinicians who violate patients' advance directives. These court clashes over advance directives as of now, however, hardly represent settled law.<sup>17</sup>

The core point of this first section is for members of medical teams and members of ethics committees to not be overly influenced by what the law might require, but rather to have what is clearly what the patient wants, or is in the patient's best interest, be their guide. The smaller the group, the more likely it is that the group members will have similar values. Thus, when confronting an ethical issue, teams, as a team, should work to increase and include more of their less directly involved members. This should, in many cases, reduce the likelihood that a medical team can miss an optimal intervention, or that the team will allow its decision making to be affected by unrecognized bias. Medical teams may do better by referring dilemmas to an ethics committee, earlier and more often. Sometimes ethics committees may do better by referring their ethical dilemmas to another ethics committee.

### **HOW TO DO BETTER WHEN WE MAKE ETHICAL DECISIONS INDIVIDUALLY**

In the above section I have discussed how clinicians who work in teams can seek to care better for their patients, as Ms E's team did for her. In this section I will discuss how clinicians may do better when they are making ethical decisions individually.

### **The Paradigm: Assessing Patients' Capacities**

In the section above, I used Ms E's team's response to her as a paradigm for exploring how clinicians who are working as a team might achieve the best results for their patients. In this section I will ask how clinicians may improve their ethical outcomes when they are working individually, using a different paradigm: determining patients' capacity to consent to treatment. Clinicians making this assessment do not need to consult with a psychiatrist. Ganzini and colleagues argue that patients' capacity can be assessed "by any clinician familiar with a

patient's case."<sup>18</sup> If clinicians see a patient as lacking capacity, they may go to a court, which may or may not declare the patient legally incompetent. Judges usually base their decisions on what the patient's clinicians believe. Judges know that the clinicians can assess capacity better than they can.

Clinicians may consult a psychiatrist or other mental health expert. Therefore, the question analogous to those just considered is: When to consult? This is especially critical to clinicians who seek to determine capacity, because capacity can't be determined empirically. That is, bacterial infections can be verified by viewing bacteria under a microscope or growing them in a petri dish. Determinations of capacity lack such means of independent, external verification.

Consider this example. A woman is driving a car carrying her husband and children. The car is in a head-on collision. Everyone else is killed. She is conscious and paralyzed from the neck down. She needs to be placed on a respirator. She is lucid and says, "No. Turn off the respirator." She says she does not want to live on in this way. If consulted, a psychiatrist might conclude that the patient should be allowed to refuse, since she fully understands her alternatives. Another psychiatrist might disagree, saying, "No. She cannot but be affected by most profound grief. Her family, just hours ago, were alive. She may feel somehow that she is at fault. And she also has just learned that she will be paralyzed from her neck down her whole life." Even psychiatrists may, in some cases, not be able to agree, and clinicians are not required to consult them. How can clinicians who are making an assessment not risk making a decision that reflects their own clinical biases and values? This is the core question I will address here. In this section, I will initially indicate the full extent of this clinical dilemma by considering determinations of capacity in three kinds of cases. Then I will discuss how clinicians may best approach this and similar ethical conundrums.

### **Three Ways Individual Moral Views May Unduly Influence What We Decide**

Different clinicians may attribute differing weights to the same signs and symptoms. They may place differing weights on different factors, as in the case of the woman in the head-on collision. Another example was presented in a recent issue of *JCE*: a patient who loved to dance ballet fell asleep while practicing yoga. She was sitting on her ankles and cut off the blood going to her feet. Tragically, she needed both feet amputated if she was to survive. She refused.<sup>19</sup> A first question for her primary care-provider would be whether to consult a psychiatrist.

A second question for the primary or her psychiatrist might be phrased as "How to err?" as every possible answer includes ethical difficulties.

Beyond this, a patient's primary and psychiatrist might have views that differ from those of other primary careproviders and other psychiatrists, and even different than one another, not because they have different clinical knowledge, but because—whether they know it or not—their values affect how and what they weigh what they see.

Different clinicians may, for example, place different values on the degree to which a patient may still be in shock, such as the woman in the car accident. Depending on their values, clinicians may differ on whether or not they use a "sliding standard" or "sliding scale" to assess a patient's capacity to make decisions. A sliding standard allows clinicians to adjust the threshold used to determine whether a patient has the capacity to make decisions: a lower threshold of capacity is required when a proposed treatment presents little risk of harm and a high likelihood of benefit; a higher threshold is required when a treatment presents higher risk and less gain.

There seems to be general consensus that a sliding standard should be used when determining capacity. The highest moral road may be that whenever clinicians make a capacity assessment alone, they should consider consulting with others whenever they can imagine that their judgment may be affected by their values. Only by consulting with others may clinicians be able to significantly reduce the risk that what happens to their patient will reflect not the patient's needs, but the clinicians'.

The ways in which clinicians weigh-in other factors, such as the passage of time, also may vary. One example is from a case published in a previous issue of *JCE*.<sup>20</sup> A family asked the medical team to posthumously remove and preserve the ovaries of their loved one, so that they could attempt a surrogate pregnancy in the future, should the technology evolve to make this possible. Shortly before her unexpected death, the woman had visited a fertility clinic to discuss surrogacy, but she had not consented to the removal and preservation of her ovaries. Ethics consultants met with the woman's life partner and family, and advised them that the European Society of Human Reproduction and Embryology recommends a one-year waiting period before posthumously collected reproductive materials are used. The rationale for this recommendation is straightforward: those who want to use the sperm or eggs of a deceased loved one shortly after the death may change their mind after a year's time.

Another example is the recommendation of the World Professional Association for Transgender

Health, in its “Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People,” that time may be a critical factor that transgender persons, and their careproviders, consider prior to irreversible genital surgery.<sup>21</sup> Time is not a sign or symptom, but it is a factor in which a clinician’s personal values may play a role.

Clinicians may feel they need to improvise. It may be that, for the treatment of some disorders, the optimal criteria for determining patients’ capacity haven’t yet been established. This may currently be the case for traumatic brain injury caused by a blast, typically caused by explosive devices used as weapons in Afghanistan and Iraq. In the past, brain injuries were caused much more often by direct trauma to the head, as from a car injury. The damage to the brain resulting from an explosive device may cause a wholly different kind of injury. The blasts may cause multiple, tiny injuries throughout a person’s brain, and these injuries leave the person still able to reason logically, but, emotionally, often most subtly, the person is significantly impaired.

This injury might raise new questions regarding how decision-making capacity for these individuals should best be determined. Suppose, for example, a service member who has such a brain injury needs lifesaving surgery, such as the amputation of an injured leg, but refuses. The patient may literally understand that, without the surgery, he or she will die. This may, using standard measures of capacity, be sufficient for clinicians to judge the patient as having the capacity to refuse the surgery. But more extensive psychological testing may reveal numerous, more subtle ways in which the patient’s cognition and feelings are impaired. It may be that the best standard for determining the capacity of these patients has yet to be developed.<sup>22</sup> Clinicians who seek to use current standards to determine capacity for these patients may be somewhat on their own in deciding what relative weights they should place on different factors. This is another way in which clinicians may, knowingly or unknowingly, determine a patient’s outcome based, in part, on the clinician’s own personal moral beliefs.

### **How Might We, Acting Individually, Do Better?**

The key to making optimal choices when acting individually may be much like those outlined above, for medical team members. When we recognize that our own moral values may be affecting our decisions, we may choose to involve others in the process. One somewhat counterintuitive context in which it may be more likely that we are responding to unconscious bias is when we feel exceedingly certain. As in the cases I present above involving capacity, there may

not be a clearly right answer. Teams who face such concerns may refer their questions to ethics committees. Likewise, when we are assessing a patient’s capacity individually, we may seek out the responses of others. They may be our nonpsychiatric colleagues, psychiatrists, or members of an ethics committee. These options are common knowledge, but when we are making assessments individually, it might be optimal to use these options earlier, and more often. Others may alert us to our own biases and be able to provide us with additional ideas that go beyond our own.

When we are working individually to assess a patient’s capacity, we might first consult a colleague, ideally one who has moral views that we know can be different than our own. To assist in this type of consultation, institutions could survey clinical departments, and, based on the survey responses, the departments could know and inform clinicians regarding which colleagues on their service would most likely have a different view. Institutions could assess clinician’s values by using cases, such as decision making for Ms E, the child with brain trauma, the mother who had been in the car accident, and the ballet dancer.

Or, we could consult a psychiatrist or other mental health expert—ideally, one who is most likely to have a different opinion than our own. If the expert’s view differs from ours, what should be done? As opposed to accepting the expert’s opinion, we could consult with the members of our institution’s ethics committee. As I outlined in different context above, when we consult with an expert, we should tell the expert, in advance, that we might next consult with an ethics committee, so it will not take the expert by surprise, if we do. And, as described above regarding when a medical team can’t come to an agreement, when we consult with an ethics committee and we can’t come to an agreement with the committee, we may consider going beyond the ethics committee. We may ask to consult with another ethics committee, a legal official, or a court.

The most difficult ethical decision in taking such exceptional options may be deciding what criteria we should use to determine when to proceed further, and how far we should go. The highest moral road might be to go further whenever we have significant doubt, or, on the other hand, when we feel most certain and have no hint of moral distress. As is obvious, these options require extra effort. Making the extra effort, though, may make a profound difference in a patient’s outcome, as illustrated by the following case. An elderly, indigent patient refused to have an amputation that her medical team assumed she needed to survive. It was initially de-

termined that she was incompetent when she refused to have the amputation, and thus the surgery was scheduled to take place without her consent. The patient had already had one foot amputated, so she had some idea what it would be like to have no feet. In some ways she had distorted views of reality, but she remained clear that she didn't want the surgery. There were significant obstacles to arranging for the further legal actions and medical examinations necessary to challenge the initial judgment that the patient was incompetent, and thus should have surgery against her will. Her attorney, Barbara Mishkin, had to get legal backing to even just get on the ward to see the patient. The patient's outside geriatrician (Joanne Lynn) and psychiatrist (me), called in to consult, could not examine the patient or review her chart for several days, because the ward nurses were not informed about the court order.<sup>23</sup>

The court accepted the patient's refusal, and she lived for several months. She died, not from foot gangrene, but from an unrelated circulatory problem. Her medical course and outcome exemplify the extensive effort that may be required for careproviders to pursue what they believe is right. Achieving a preferable end for a patient may sometimes require substantial additional time, with no fee. The overall theme here is to go from the *is* to the *should*, that is, from what we currently do now, to what might be optimal for our patients.

The examples I have given are all specific. They are intended to represent the myriad ways that we can follow the model provided by the members of Ms E's medical team.

#### **PATIENT AND FAMILY: OUR CORE CONCERNS**

The two sections above primarily discuss ways that members of medical teams, and clinicians who are acting alone, can make the best decisions for a patient when their own values may affect what they decide. What has been left out is how team members and clinicians can best take into account the specific needs and wants of a patient and family. The predominant—or at least emerging—view is that, whenever possible, decisions should be shared. When possible, we should consider going beyond this: in some cases, we can go further than we do now to allow a patient and family to make choices wholly on their own. Pérez's example of families being able to decide for themselves whether to be with a loved one during CPR is one such example.

Here are two more examples pertaining to the situations discussed above. They involve respecting the patient and family, and their autonomy, to a somewhat new perhaps even radical extent, by ask-

ing them to choose whether they want us, their clinicians, to be involved in end-of-life decisions or determinations of capacity. The examples are geared to the two specific clinical decisions discussed above, but are intended to represent other scenarios as well. The patient and family may prefer to share decision making with us, rather than having us leave decision making to them. In this last section, I will discuss why a patient and family may want to choose whether their careproviders should be involved in decision making, and I will address how we might practically best implement this.

#### **Why a Patient May Not Want Our Involvement**

A patient may want those closest to him or her to not be a surrogate decision maker. The persons closest to the patient may not want this, as well. Why? Both may foresee, accurately, how knowing that a loved one will take on this role may affect each of them. Future surrogate decision makers may, in anticipation, distance themselves from the patient. The patient, in turn, may pick up on this and become more distant in response. This may occur outside the parties' awareness and control. Each may be affected more deeply by nonverbal cues than by what is said. This may happen especially when an interaction has exceptional meaning, for example, in discussions of whether the patient should continue to live, or whether the patient has the capacity to refuse a lifesaving intervention. In such critically important moments, neither the patient nor the clinician want any distancing to occur.

On the other hand, a patient and family may want the clinician who is closest to them to be among those making treatment decisions. A patient and family may believe—most likely rightly—that their clinician knows the patient well, and thus may be the patient's best advocate. Given the common absence of advance directives, and the reported discomfort some clinicians have in carrying out these kinds of conversations, whether we can really *know* a patient this well is open to question. We may have accumulated knowledge through sharing decision making. Some patients may trust us to speak for them, and respecting their preference may be warranted. It is possible that a clinician may truly be a patient's best ally. A clinician may be so committed to being a good ally that she or he may work to try to effect what the patient wants, even if this means going against what the clinician personally believes is best for the patient. Prior to serving as a patient's advocate in this way, a clinician should discuss her or his differing views with the patient.

Joanne Lynn, an eminent gerontologist and ethicist, describes examples of several practices that she

has adopted, often on her own, to most benefit her patients: “Nothing was beyond our scope, so long as I served a patient. We arranged baptism by immersion for a tracheostomy patient; we got airlines to donate tickets so that patients could go home; . . . we learned to let people eat despite bowel obstructions; we covered reflective surfaces so that disfigured people would not have to confront their losses; in short, we did whatever was humanly possible to make the end of life rewarding and comfortable.”<sup>24</sup> These examples are exemplary—they epitomize what careproviders can do with exceptional effort and humane sensitivity. These examples, like that set by the members of Ms E’s medical team, may go beyond what many of us may ever achieve. There are, though, some ways in which we can all, most likely, do better. A description of these ways follows.

### **What to Do When We See the Risk of Distancing**

The patient and family may have different preferences regarding whether they want their primary careprovider to be among those making life-or-death decisions, or to determine the patient’s capacity to make treatment decisions. When we can see that this may be a possibility as we care for a patient, and thus can anticipate it, we may ask the patient and family whether or not they would want us to participate in decision making or judging capacity.

Asking in this way respects, to a greater extent than we usually do now, the autonomy of patients and family members. We can explain why they may or may not want us to be involved, and we can add that our most important consideration is to become and remain as emotionally close to them as possible, if this is what they want, for as long as they want. We can indicate how we regard our patients in a way that approaches the closeness between family members by how we behave toward them, and by what we say. We can show our concern and availability to patients and families and talk about our relationship with them in an open and authentically caring manner. This may include letting ourselves show the pain and concern for our patients that we sometimes feel as we speak with them.

This may be the most that we can do when questions arise around the care of patients like Ms E, the ballet dancer, and others described here. Patients and families may see this, too. The ethical priority is to seek to maintain our relationship with patients and families, to convey our willingness to be with them, to the extent that they would want this, even in the most dire circumstances. Preserving these relationships must take precedence, even over the approaches and many guidelines presented here.

Often, patients and families look and listen most attentively to their careprovider’s every gesture and word, to discern any hint of what he or she may be thinking or feeling. One eminent psychoanalyst, Robert Langs, refers to this proclivity as the “me-not-me interface,” and to “the patient’s unconscious sensitivities to the therapist’s countertransferences,” or feelings toward the patient.<sup>25</sup> An example of this sensitivity is a dentist, who, after repairing a tooth, might remark, “This looks pretty good.” But a patient may respond to this not with relief, but with fear. The patient may worry, “What is wrong? Why didn’t the dentist say it looks perfect?” (This worry may be the consequence of a deficit in communication—the outcome might be better, for instance, when conversations like this include more detail.)

Accordingly, when a careprovider anticipates that he or she may later need to make a life-or-death treatment decision or judgment about capacity that may go against a patient’s or family’s wishes, the careprovider, patient, and family may be emotionally affected by it. Careproviders may emotionally distance themselves, unconsciously, to help steel themselves in case they later have to make a decision or judgment about a patient, in addition to caring for the patient. The patient, in turn, may detect the distancing, and respond by becoming more emotionally distant, too.<sup>26</sup> On the other hand, though, if careproviders do not distance themselves emotionally, they may feel more sorrow, and even weep, when a patient is very ill. This may be painful for a patient to see. Much more than this, however, a patient may be deeply moved, seeing how much the clinician cares.

Clinicians may find a way to bear and convey the pain they feel without becoming harmfully distant. As mentioned above, clinicians may reveal heartfelt emotions nonverbally. For example, they may allow themselves to grimace as they speak with a very ill patient. Doing this may convey genuine empathy, and may allow clinicians to show they feel such emotions, inside, *with* a patient, rather than feel apart from a patient, and hiding or repressing their emotions.

### **CONCLUSION**

Clinicians usually know the best clinical practices. In this piece, I have emphasized how we may do even better. We can ask what is best for our patients and their families, and seek to do it. Ms E’s careproviders did. Pérez urges this also. This means we must recognize the profound risk that we may unwittingly impose our own moral views, and that

we may lack the imagination that others may have that could enable us to do better. The byword is separating the *is* from the *should*.

A core, practical point is that we should consult and refer, more often and earlier. The most important point is that patients and families may want us to be as close to them as possible at critical times. It is often said that clinicians may not always be able to heal, but can always care. If patients and families can have nothing else, it may be that they can at least have us with them. To be able to do this may mean just as much to us.

#### ACKNOWLEDGMENT

I would like to thank Norman Quist for his careful reading and suggestions of improvements in the text. Any errors in this piece are my own.

#### NOTES

1. L.S. Flicker, "A Patient (Not) Alone," in this issue of *JCE*, volume 28, number 2, Summer 2017.

2. A. Pérez Blanco, "How Do Healthcare Workers Feel About Family Presence during Cardiopulmonary Resuscitation?" in this issue of *JCE*, volume 28, number 2, Summer 2017.

3. B.H. Arzuaga, "Development of a Clinical Ethics Committee *De-Novo* at a Small Community Hospital by Addressing Needs and Potential Barriers," in this issue of *JCE*, volume 28, number 2, Summer 2017. The composition of the two survey groups is reported in this article. The physician group included physician assistants and nurse practitioners.

4. S. Saxen, "Untangling Uncertainty: A Study of the Discourses Shaping Clinical Ethics Consultation as a Professional Practice," *The Journal of Clinical Ethics* 27, no. 2 (Summer 2016): 99-110.

5. A. Carse and C.H. Rushton, "Harnessing the Promise of Moral Distress: A Call for Re-Orientation," *The Journal of Clinical Ethics* 28, no. 1 (Spring 2017): 15-29, 19.

6. Flicker points out that "legislation at the State and Federal level often has a subsection for definitions in order to explicitly spell out how words should be interpreted, so that the law may be applied uniformly." Flicker, "A Patient (Not) Alone," see note 1 above.

7. See, in this regard, J. Lynn and C.O. Gregory, "Regulating Hearts and Minds: The Mismatch of Law, Custom, and Resuscitation Decisions," *Journal of the American Geriatric Society* 51, no. 10 (October 2003): 152-3.

8. M. Agha Barary and N.N. Dehghan, "Medical Futility and Its Challenges; A Review Study," *Journal of Medical Ethics and History of Medicine* 9, no. 11 (October 2016): 1-13, 1.

9. See, i.e., S.H. Bahman, "Young Doctor; Angry Patient: Culture Clash," *Washington Post*, 11 April 2017, E1.6.

10. Carse and Rushton, "Harnessing the Promise of Moral Distress," see note 5 above, p. 17.

11. Pérez Blanco, "How Do Healthcare Workers Feel,"

see note 2, above.

12. Arzuaga, "Development of a Clinical Ethics Committee *De-Novo*," see note 3, above.

13. R. Grundstein-Amado, "Differences in Ethical Decision-Making Processes Among Nurses and Doctors," *Journal of Advanced Nursing* 17 (1992): 129-37, 137.

14. R.L. Holmes, "The Limited Relevance of Analytical Ethics to the Problems of Bioethics," *Journal of Medicine and Philosophy* 15, no. 2 (1990): 143-59.

15. P. Span, "The Patients Were Saved: That's Why the Families Are Suing," *New York Times*, 10 April 2017.

16. *Ibid.*

17. *Ibid.*

18. L. Ganzini et al., "Ten Myths About Decision Making Capacity," *Journal of the American Medical Directors Association* 5 (2004): 263-7, 266.

19. S. Napier, "When Should We Not Respect a Patient's Wish?" *The Journal of Clinical Ethics* 25, no. 3 (Fall 2014): 196-216.

20. L. Guidry-Grimes, "The Case of Ms D: A Family's Request for Posthumous Procurement of Ovaries," *The Journal of Clinical Ethics* 27, no. 1 (Spring 2016): 51-8, 53.

21. G. Selvaggi, C. Dhejne, M. Landen, and A. Elander, "The 2011 WPATH Standards of Care and Penile Reconstruction in Female-to-Male Transsexual Individuals," *Advances in Urology* (2012): 1-13, 3. See also the World Professional Association for Transgender Health, "Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People," 7th ed., 2011, <http://www.wpath.org>.

22. J.M. Goeke, "Postconcussion Syndrome: Neuropsychological Evaluation and Management," *Psychiatric Annals* 47, no. 2 (February 2017): 92-6, 94. See also C.L. MacDonald et al., "Detection of Blast-Related Traumatic Brain Injury in U.S. Military Personnel," *New England Journal of Medicine* 364, no. 22 (2 June 2011): 2091-100; G.S. Owen, F. Frevenhagen, W. Martin, and A.S. David, "Clinical Assessment of Decision-Making Capacity in Acquired Brain Injury with Personality Change," *Neuropsychological Rehabilitation* 27, no. 1 (January 2017): 133-48; K. Davis, "The Brain Defense," *American Bar Association Journal* 103, no. 3 (March 2017): 60-5.

23. B. Mishkin, "Determining the Capacity for Making Health Care Decisions," *Advances in Psychosomatic Medicine* 19 (1989): 151-66, 163.

24. J. Lynn, "Reliable Comfort and Meaningfulness at a Sustainable Cost," *Journal of Palliative Medicine* 10, no. 3 (January 2007): 660-64, 661.

25. R. Langs, *The Listening Process* (New York: Jason Aronson, 1978), 231.

26. L.F. Dillen, L.T. Harris, W.W. van Dijk, and M. Rotteveel, "Looking with Different Eyes: The Psychological Meaning of Categorisation Goals Moderates Facial Reactivity to Facial Expressions," *Cognition & Emotion* 29, no. 8 (2015): 1382-400.