

Edmund G. Howe, "New Ways to Cut through Ethical Gordian Knots," *The Journal of Clinical Ethics* 28, no. 4 (Winter 2017): 257-68.

At the Bedside

New Ways to Cut through Ethical Gordian Knots

Edmund G. Howe

ABSTRACT

Clinicians and ethicists routinely encounter complex ethical dilemmas that seem intractable, which have been described as ethical Gordian knots. How can they best assist patients and surrogate decision makers who are entangled in struggles around the capacity to make life-or-death treatment decisions? In this article I describe unconventional and unorthodox approaches to help slice through these dilemmas.

It is common that clinicians and clinical ethicists encounter complex ethical dilemmas. In 1995 in this journal, Bruce E. Zawacki, MD, MA, described the debate about futile interventions as an ethical Gordian knot,¹ referring to the legend of a fantastically complex knot tied by King Midas in the city of Gordium in the southern Balkans. An oracle had prophesied that the one who untangled the Gordian knot would rule all of Asia. Alexander the Great sliced through it with his sword. In his article, Zawacki proposed a way to slice through this seemingly intractable debate.

In a similar way, two articles in this issue of *The Journal of Clinical Ethics (JCE)* offer new, better approaches to resolving ethical Gordian knots. In

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"Comparativism and the Grounds for Person-Centered Care and Shared Decision Making," Anders Herlitz discusses how clinicians can help patients with full cognitive capacity make better treatment decisions.² Herlitz describes how clinicians can help patients make rational choices when there is no one treatment that is better than another.

In the second article, "Incapacitated Surrogates: A New and Increasing Dilemma in Hospital Care," Karen L. Smith, Patrice Fedel, and Jay Heitman provide new criteria that clinicians can use to decide when they should oppose decisions made by a patient's surrogate decision maker, when the surrogate appears to be incapacitated.³ The two-step process the authors suggest includes making a best guess about the patient's most likely outcome.

I will consider patients who have a surrogate, but who differ from most other incapacitated patients: while these patients currently lack capacity, they may be able to regain it.⁴ There is a good reason to help patients in this group regain their capacity, if and when possible: if they do regain capacity, they will become able to choose what they want for themselves.

Therefore, I will consider how we may best help these patients regain capacity, and I will do so in three sections. First, I will describe the patients and discuss how it may be that they become able to regain capacity. Second, I suggest what I see as the three most important principles in treating these patients that are likely to bring about improvement in their capacity. Third, I discuss why it may be ethically justified for us to make some exceptional interventions for these patients. In this regard, I refer not only to the extra time these exceptional inter-

ventions may take, but to sometimes making personal sacrifices that we otherwise wouldn't make.

Some of the interventions I will suggest are counter-intuitive and controversial. In part, this is because they are unconventional and not commonly practiced. Those who have pioneered these approaches have used them to reach and successfully treat incapacitated patients when others couldn't help them using any of the more usual ways. These approaches may be effective in other contexts as well. Thus, I will indicate how the approaches may be effective in the contexts discussed by Herlitz and by Smith, Fedel, and Heitman.

WHO ARE THESE PATIENTS? HOW CAN THEY REGAIN CAPACITY?

Who Are These Patients?

I will begin to answer this question by referring to a patient described by Sarah Lytle, Susan J. Stagno, and Barb Daly in an article they published in *JCE* in 2013.⁵ In "Repetitive Foreign Body Ingestion: Ethical Considerations," the authors report the case of a 19-year-old patient who swallowed knife blades repeatedly. I use this case as a paradigmatic example of a patient who initially may lack capacity but who later may regain it. In discussing this patient, the authors cite a study that reported on 33 patients who ingested foreign objects; 79 percent of these patients had psychiatric disorders.⁶ The disorders included problems in impulse control, malingering, borderline personality disorder, pica (the persistent eating of nonnutritive, nonfood substances, inappropriate to the developmental level of the individual), and psychoses.⁷ Despite having different diagnoses, the cause of patients' repeated ingestion of foreign substances was sometimes the same. Patients may experience similar psychological processes although they have different emotional disorders. The study cited by the authors reported, for example, that patients' ingestion of foreign substances might be motivated by anger, impulsivity, entitlement, aggression, dependency, ingratitude, and the desire to manipulate. As these causes suggest, these patients may evoke highly negative feelings, including even hate.⁸ I will discuss later how clinicians who want to help these patients may have to cope—and can best cope—with their own negative feelings.

A more specific emotional pattern that these patients may experience is having increased feelings of tension, followed by ingesting a foreign substance, and then obtaining relief.⁹ This pattern may occur in other behaviors. A common example is self-cutting, as Lytle, Stagno, and Daly reported in their article. Later, I will discuss self-cutting when I re-

late how to most help all patients in this group who can regain capacity. Patients who lack control over self-cutting may be regarded as incapacitated. When they gain greater control of self-cutting—as they may in response to therapy—they regain capacity because they can choose, to a greater extent, whether or not to cut themselves when they have the urge. Lytle, Stagno, and Daly say one way to understand these repeated behaviors is to regard them as an addiction. In discussing this view, they state that the literature suggests that when patients are addicted to alcohol or drugs, they may not be able to control their use of these substances. I would concur. Under some circumstances, the urge to drink or use drugs may be so strong that even if patients use all of the coping resources they have to block the urge, it is not enough. A key rationale for this belief is that patients may be vulnerable to cues that trigger overwhelming urges to drink or use drugs. Thus, they may, at best, use medications and psychosocial interventions in the hope of reducing their cravings when the cravings are triggered.

This model is useful in understanding why these behaviors reoccur. Lytle, Stagno, and Daly suggest that patients who repeatedly ingest foreign substances may, like patients who misuse alcohol and drugs, have lost their autonomy to choose to not ingest foreign objects. The authors state, though, that in assessing whether these patients have capacity for autonomous decision making, it may not be clear whether what patients do is "irresistible or merely unresisted."¹⁰ This speaks to our inability to discern the extent to which people can exert control under different circumstances. Patients' impulses to use these substances may not, the authors assert, be irresistible. The impulse may be merely stronger than any other motivation at the time. The authors, in regard to self-cutting, raise the same question: Is this behavior "irresistible" or "merely unresisted"? To determine, assess, and even imagine whether a patient has capacity is difficult and ultimately, in some circumstances, may be most uncertain.

Anorexia nervosa is an example illustrating why it is so difficult to determine the capacity of patients with addiction-like disorders. Because it is so difficult, it's not clear it's ethically justifiable to feed patients against their will when they reach a predetermined low weight. Patients engage in these behaviors because the behaviors, in part, give them a positive feeling that they find hard to resist, or because the behaviors help them to avoid feeling negative emotions that they experience as being close to unbearable. Thus, not eating may be a behavior that patients feel they cannot resist. They may not eat, even when they know they may die. Their capacity

to choose to eat is seen as being so impaired that research involving deep brain stimulation is being carried out with these patients, to see whether physically altering their brain has a beneficial effect.¹¹

Lytle, Stagno, and Daly discuss dissociative disorders as another example of when patients' capacity is difficult to determine. The most extreme dissociative disorder was known as multiple personality, but is now called dissociation identity disorder. When a person experiences such dissociation, one part of the brain seemingly becomes cut off from other parts, such that the patient lacks access to the parts that record memories. Consequently, the patient does things he or she does not remember later. Dissociative disorder can be envisioned as occurring along a spectrum. At one end of the spectrum might be so-called "highway hypnosis," a state of inattention while driving a long distance that could cause one to miss a highway exit. But at the extreme other end of the spectrum is having no memory of one's actions. When a person has such a lack of memory and two or more distinct personality states, he or she has dissociative identity disorder.¹²

Such dissociation may be one cause of self-cutting, and may cause other self-harming behavior. As Lytle, Stagno, and Daly state, "People who self-harm may experience dissociated states when under stress, possibly secondary to a history of childhood abuse, trauma, or neglect." They go on: "When a patient is able to function competently in the world and then finds herself cutting her wrists and overdosing over some trivial disappointment, she struggles to maintain her dignity, denying the seriousness of her recent behavior and accusing helpers of humiliating her." In determining the capacity of these patients, Lytle, Stagno, and Daly assert that patients' inability to control self-harming behavior, in and of itself, does not render them incompetent, but, rather, "it is only the *act* that is non-autonomous."¹³

This is based on the notion that persons may have moments when they lack control, and at other times regain capacity. How many non-autonomous acts make a patient incompetent? The difficulty of answering this question shows how hard it can be to determine competency. One patient I saw particularly illustrates the difficulty of assessing the capacity of patients who dissociate. This man had just escaped death after he crashed his motorcycle into a tree. He, like those who ingest foreign substances or cut themselves, had done this before, escaping death seemingly just by luck every time. Each time he came to the hospital after an accident, he had no memory of why or when he had gone off the road. This presumably was because he had been in a dissociated state. Another part of him had "taken over,"

as it were, just before each crash, ramming him into a tree intentionally.

Self-destructive behavior of this sort, and the harm it causes to others, is not uncommon among persons with a full-blown dissociative disorder. Frequently, the patients were severely abused during childhood, as Lytle, Stagno, and Daly note. It is now thought that these patients cope by psychologically locking away or compartmentalizing their feelings of hurt and anger, particularly if they have the mental capacity, enabling them to not react with fear and anger when they are beaten. If they cannot compartmentalize in this way, but express anger, they may be beaten even worse. In response to a provocation years later, the pent-up anger may suddenly emerge and not be softened by opposing emotions. While in this "pure anger" state, they may harm someone else—or if they are angry at themselves, harm themselves. Thus, when I was able to talk with this patient's "other self," I asked whether he knew that he might die from this kind of crash. Without pausing, he said that he would not die. He said he had existed before he came in the other man's body, when the other person already was nine. He had existed before this, he said, without having or needing this body. Thus, he would exist as well, he said, if and after this man was dead.

This explanation of "another personality state" may not make sense, but the people in this state may not be concerned about what is not possible. Contradictions don't bother them. This also can happen when a person is in a deeply hypnotic state. In response to a suggestion while hypnotized, a person may hallucinate to see the second version of a person in the room. "There are two of this person?!" you might exclaim. "So?" they might respond, without being at all perturbed.¹⁴

We might ask ourselves if the patient who repeatedly ran his motorcycle into a tree and had no memory of it had capacity, and if he was in the hospital and declined a lifesaving operation, whether we should respect that decision. I would not. The inference would be too strong that he lacked capacity to choose to not save his life. Ironically, though, it could be that if he got better—as he might in response to therapy—he might "competently" decide to end his life. He might not want to live with the other states sometimes taking over.

There are many other kinds of patients whose capacity is difficult to determine. The goal is to help them regain capacity. It may be best to see these patients as neither having nor lacking capacity, but rather as existing in a kind of limbo. The task is to try to nudge them into a state in which they can have the capacity to make decisions for themselves.

If capacity is envisioned as existing on a spectrum, at one extreme end would be patients who are in a minimally conscious state who may have no capacity at all, but who may possibly acquire capacity if their brain heals. We used to believe these patients could neither think nor feel, and that they would always be in a persistent vegetative state (PVS). We now know that many of these patients have “islands” within their brain that are sufficiently intact to give them some awareness, or when they don’t, that their brain may heal, and later they may acquire some areas that are intact. Many in this group regain some or full capacity, especially with caring interactions. Joseph J. Fins describes a patient, “Maggie,” in whom, he believes, this occurred.¹⁵ (Fins and colleagues have another article published in this issue of *JCE*.¹⁶) Maggie suffered a massive stroke during her senior year at Smith College. She made cognitive progress, Fins believes, in response to the caring interactions she received over six years. Magnetic resonance imaging indicates, Fins relates, that structural and functional reconstructions can take place in an injured brain, and this can enable even a “grievously injured brain” to heal itself. This process bears a strong resemblance to typical brain development, Fins reports. This suggests to him the importance of giving patients ongoing, loving engagement.¹⁷ Maggie could communicate only by moving one eye, and said, in regard to herself, it was “enough to have a life, even a small life.” This, she said, was because she had “things that many people didn’t have—relationships, friends and family who loved her.” This suggests what other patients might be able to experience, if they retain some degree of awareness; that no matter how physically impaired they may be, like Maggie, they may feel that they gain from others’ caring, and gain so much that, to them, they have a meaningful quality of life.

A core question posed here, more precisely for our discussion, is the extent to which we can help patients acquire improved cognitive capacity for decision making, and, if we can, how. Some broad conceptual leaps have been made here, from patients who ingest foreign objects, to patients who experience dissociative states, to patients who are in a minimally conscious state. But all involve the risk of prematurely determining that a patient lacks capacity. How can we help these patients? It is this question to which I now turn.

How Can Interpersonal Caring Help Patients Regain Capacity?

Our critically important clinical goal is to help patients regain their capacity, so that they can make the decisions they want for themselves. Ethics con-

sultants and committees are often called in to help with these patients.¹⁸ Sometimes they are called in because the patients’ outcomes seem so bleak. Their loved ones and clinicians may feel that they have done all that they could—and have failed—such that the patients continue to suffer so much they would be better off dead. Thus, family members and clinicians call in ethics consultants or committees to consider the option they see as the only compassionate one. These cases, I expect, do occur often. Colleagues have brought them to my attention from time to time.

When helping patients seems hopeless and their suffering continues, clinicians, family, and ethicists sometimes feel that since their extreme emotional pain is unrelieved, the patients would better off if clinicians gave them only palliative care, if they have a life-threatening illness, and allow them to die. I describe two such cases shortly. In these cases, especially, the approaches I discuss are likely to be uniquely effective. Some patients regain capacity solely or primarily with the help of medication, but what is less recognized and appreciated is that some may respond better, and uniquely, to the right kind of interpersonal intervention. The examples I present are mostly among patients who ingest foreign objects, self-cut, or who have addictions and dissociative disorders, but these approaches also may help other patients who are psychologically worse-off. These approaches may even be necessary.

Those with substance abuse problems may respond better—or only—to group interactions such as Alcoholics Anonymous (AA). Patients with dissociative disorders may do well with psychotherapy, but not respond at all to psychotropic medications. It is not uncommon for patients with these conditions to do well and regain capacity. According to one study, 78 to 99 percent of patients who ingested foreign bodies or who had a borderline personality disorder got better.¹⁹ As these figures convey, borderline personality disorder can now be treated most successfully. That these patients, despite their highly diverse emotional disorders, responded well to caring interpersonal interactions with others should not be surprising. In the practice of psychotherapy, it is well acknowledged that the single most important factor in determining how well patients will do is the quality of the patient/therapist relationship.²⁰

Why might this be? At the scientific level, this may occur because what we say to each other can change our brains; imaging studies have shown changes to patients’ brains after psychotherapy.²¹ This is one among numerous new understandings that contribute to the perception that our brains have “plasticity.”²² Such changes can occur, sometimes

even quickly. This has taken place even when patients have a thought disorder that is so severe they are out of touch with reality; what clinicians would regard as psychotic. I heard of this case from a colleague. A man who was African-American had been a resident for some time on a psychiatric ward for delusional thinking. What precipitated this irrational state remains unclear, but the patient had been thinking clearly before he was hospitalized. The medical staff on the ward was entirely White. A psychiatrist on the ward who was working late one night began talking with a custodial worker, also working late. The worker was African-American. He shared with the psychiatrist that when he talked with the patient, he seemed “just as normal” to him “as he could be.” On receiving this information, the psychiatrist arranged for the patient to be transferred to a hospital with African-American clinicians. The patients’ thought disorder resolved and he left the hospital within a very short time. Presumably, the greater sense of safety and comfort he felt when with others who were African-American caused him less stress, and to regain his rational capacities.

The same response may occur in patients with schizophrenia, although generally it takes much longer for them to substantially recover. Loren Mosher, a psychiatrist known for his expertise in treating these patients, reported on studies he conducted in which some patients with schizophrenia were housed in a small group home and not given meds, and a matched sample group were given antipsychotic meds and hospitalized on an inpatient ward, as was more usual then. The first group received only around-the-clock supportive care. In some ways they did as well or better, over a period of months, than those in the second group.²³

Thus, patients’ emotional state can radically change, with caring support. This occurs regularly in patients who don’t have a psychotic illness, in a very short time, in some cases a matter of minutes. The rapid transformation may not last, but illustrates the profound, almost magical and immediate calming effect that responding in the right way can have on patients who are highly distraught. Patients occasionally may find an insight that changes them profoundly and permanently. It may sustain them when they feel suicidal. It may be like a light that promises hope in what had previously seemed to be wholly dark. In my own experience, patients have come to a psychotherapy session feeling and believing they are genuinely homicidal or suicidal. In response to being listened to and understood, they don’t feel the same way at the end of the hour, and are even able to laugh. This may be the reverse of a dissociative disturbance: such support may elicit an

emotionally healthy, underlying response. Regardless, these examples indicate what we may be able to help patients to accomplish for themselves—if we don’t prematurely judge that they lack capacity, but instead, we seek to better understand them. The prognoses and potential for recovery for each of the patient groups we have considered greatly differ. Thus, the general guidelines I outline leave the specifics to be tailored to each patient.

As I have argued above, we may miss an opportunity to help patients when we are too quick to assess their capacity, rather than work with them over a longer time. Similarly, when we seek to help patients resolve an ethical conflict, we may achieve a radically better outcome when we refrain from making quick judgments. In working to address an ethical conflict, we may—meaning to do this or not—succumb to the temptation to point out to the other parties involved why our logic is superior to theirs. The other parties may be patients or surrogates. They may, in response to being told their logic is inferior, respond in unproductive, possibly even self-harming ways. This is one, not uncommon, way that efforts to resolve an ethical conflict can go awry.²⁴ How can this be avoided? Primarily, I believe, by staying longer in a “seeking-more-to-understand mode,” which I describe next. This is the mode that therapists use to enable patients who appear to be genuinely homicidal or suicidal to move to a different emotional state, in which they can warmly relate.²⁵

I will present approaches that I find are the most likely to help patients to regain capacity. There are standard ways to assess patients’ capacity, and although they may be optimal, I will not review them here, but rather suggest that whenever patients are in an incapacitated state, we should ask whether their capacity could change. The approaches I will discuss may help us in ethical conflicts when the other parties are potentially volatile. The approaches are much the same as those presented previously. This should not be surprising because people, when stressed, tend to respond in ways that are similar.

Approaches to Restore Decision-Making Capacity

Here are three ways we can most effectively restore patients’ capacity to make decisions. The possible sources of the patients’ gains are diverse. For some patients, the “fight or flight hormones” that flood in, in response to stress, may recede. Other patients may gain insights or new tools to cope with stress. Whatever the reason, patients’ capacity to function—and to make choices for themselves—may improve. The first two approaches are to help patients feel safe and to start with patients from “wherever they are.” A third approach may, however, be

necessary with the kinds of patients we have been considering. That is, some patients, like those who swallow foreign objects, may need additional evidence that their clinician genuinely cares for them. Put simply, when we treat these patients, we may need to jump at every opportunity to indicate we care, when this is possible.

All three of the interventions may go against more conventional practices and even the usual theories. They are necessary because these patients may have more deeply seated problems than other patients. They may be initially more vulnerable in some way, and/or have experienced greater trauma in their past. Accordingly, we may need greater and different interventions to reach and help them.

Helping Patients to Feel Safe

There are few ends to which we should not go to try to help these patients to feel safe. This is a first step we should always take, and it is especially necessary when patients have experienced any profound trauma. These patients are likely to feel great, intense, underlying fear. When people feel such fear, physiological changes occur that can wholly interfere with their ability to listen and respond in ways that will help them to help themselves. Most likely they enter a fight-or-flight mode that we humans have acquired over time to help us survive.²⁶

Some specific examples. One key to helping patients feel safe is not being, or conveying, that we are judgmental. Merely raising an eyebrow or scowling in response to something patients say, rightly or wrongly, may be perceived as a judgment, and may drain patients' trust in an instant. After trying not to convey a negative response, the next task is to be alert to any changes patients show that suggest they may feel offended.²⁷ If we see this, we can ask, "You looked to me just now especially concerned. Were you? If you were, was it something I did or said?" Hopefully, patients will say what it was they thought they saw and give us the benefit of the doubt.

We should be cautious about giving patients too much unsought advice. Giving patients too much advice may connote, rightly or wrongly, that we believe that we know better than they do what is best for them. This also risks draining patients' trust in an instant. For example, should a patient say, "Based on the phase of the moon, I think I should. . . ." our silence may be golden. Our best hope, hard though this may be, is that patients know, at some level, what is best for them. Our choice is how to respond in a less harmful way. We must trust that, in any case, if we can help patients feel most safe by remaining silent, it is more likely that they will be

come more aware of their own underlying, more insightful knowledge.

This same principle may be useful to follow when we try to help patients with capacity to make rational choices when there is no one treatment that is better than another treatment. In his article in this issue of *JCE*, Herlitz describes such discerning as "an act of willing." He writes, "I suggest that an appropriate response to the non-determinacy problem is not to simply pick an alternative among the alternatives . . . , but to rather *create* a reason that, when applied to the situation requiring a choice, can establish an alternative that is better than the other(s). . . . Both a lack of understanding and too much impact of stress risk undermining the validity of reasons that arise from acts of willing."²⁸

Simply listening to patients can increase their feelings of safety and convey that we care. The latter is true especially because patients know that we have limited time. Thus, our spending additional time listening, and trying to understand, is a first example of how we may help patients by making a sacrifice we may not usually make. Doing so helps patients and respects them as persons directly, regardless of the additional, secondary gain to our relationship with them. With these patients, a secondary gain—gaining their trust—may be even more beneficial because it may enable them to stop behaviors like ingesting foreign objects, as noted above. The ethical justification for our doing this is probably already apparent. Still, I will discuss this further in the last section of this article.

A model from psychotherapy. Laura S. Brown, who practices feminist psychotherapy, provides what may be as good a model as any to emulate when we try to create feelings of safety for patients. In this kind of therapy, Brown says, a therapist "uses analysis of gender, power, and social location as a means of understanding the emotional distress and behavioral dysfunctions that trouble people who enter psychotherapy."²⁹ Whether or not the causal assumptions underlying this therapy about how gender, power, and social location affect people is correct, the use of this understanding can help to maximize patients' feelings of safety. That is because, based on this understanding, patients' problems are often due to outside factors and, if they are, we cannot blame patients for being at fault in their problems. How Brown implements this is instructive:

The no-coercion rule applies from the start. Although we want to gather a complete personal history from clients, we empower and equalize power by acknowledging the essential absurdity of the request that personal information be

shared with a complete stranger on demand simply because of our job titles. The client-as-expert rule also applies immediately; if a person is yet unable to know what her goals are, the job of the feminist therapist is to create conditions under which her client can come to know those goals, rather than imposing her own.³⁰

How much more applicable could a model be in creating feelings of safety in patients who lack capacity, or for the various parties involved in an ethics consultation? This approach can be used to create feelings of safety in patients who have full capacity who would like to “create a reason,” as Herlitz puts it.³¹ Brown illustrates this approach with one of her patients: “It took the better part of 3 months of meeting weekly before Heidi decided to tell me some details about her childhood and the abuse to which she had been subjected.”³²

Many of the patients we have been considering have been, as we read in the article by Lytle, Stagno, and Daly, subject to such abuse. The importance of the uncommon approach of *waiting* to the extent that Brown does warrants restating: she will not press patients to “share with a stranger,” whom she recognizes includes herself, before her patients feel that they are ready and want to share. The fear these patients feel may not be rational. It may reflect only their prior experience. That doesn’t matter, because a therapist—or clinician, or ethicist—is, at least initially, no more than *another* stranger.

I caution medical students when they take psychiatry rotations to not press patients for information about themselves too hard, for this same reason. If the students push too hard, it risks traumatizing patients even more than they may already have been traumatized. Yet students usually need to get patients’ information to pass the rotation. I therefore advise students to inform the patients they will interview, prior to taking their history, of the ethical bind that both of them may be in. Students must put their efforts into doing solely what their patients need. Patients may have aspects of their past history and feelings that they don’t want to share, but may feel some obligation to give students the information the students need—if, for no other reason, because the patients care for the students as persons.

Feelings of counter-transference. An important and difficult challenge for clinicians who want to help patients feel safe has not yet been discussed. This may be dealing with the negative, counter-transference feelings that patients may evoke. It may be worth it to pause for a moment to imagine working in an emergency room when a patient comes in for

the third, fourth, or fifth time, after swallowing a foreign object. This may help us to better to imagine how intense these negative feelings may be. Such negative feelings may arise in all areas of medicine. For example, patients with diabetes who don’t take their medicines and go off their diet repeatedly, with the result that they require multiple and ever higher foot and leg amputations. Only the best interpersonal interventions—that may seem very unusual—may reach these patients and help them change their behaviors when other, standard interventions won’t.

The most successful route in many contexts may be person-to-person, perhaps because caring interventions can mirror early parent-child relationships. When patients’ early relationships are scarred or absent, a relationship with a clinician may, to a degree, provide patients with what they lack, and meet unmet needs still within them. From this experience of caring, patients may become able to care more for themselves. This may be require time, although it may require less time than other high-quality interactions. Caring, ongoing inquiries may move and inspire patients more than drawn-out efforts.

One approach to use to erase or control negative feelings about patients is one used by psychologist Noel Larson. She is known for successfully treating patients with profound personality problems whom other therapists aren’t able to help. For example, these patients may harm children. Larson, or any therapist who wants to treat these patients, must be able to handle negative feelings toward the patients. Larson imagines the horrors that the patients went through when they were children.³³ I will refer to her and her work again later.

Starting Where Patients “Are”

We must start whenever our patients “are.” This approach feels very safe because it is nonthreatening, and it is necessary to help patients progress. An example is how to best intervene with a patient addicted to alcohol who is willing to go to an AA meeting, but is unwilling to go alone. It may be that the only way the patient initially would attend an AA meeting is if we find someone the patient will accept to go with him or her. Or we could accompany the patient. Conventionally, this would be (rightly) seen as contraindicated, because going this extra mile in this instance could be seen as “rescuing” a patient and even “enabling.” Such rescuing or enabling may “deprive” a patient of the opportunity to acquire the capacity to take more responsibility for him- or herself.

But an unconventional approach may be needed. Going the extra mile for patients may be the only

way they can move from where they are, to where they hope and want to be. We should start not from where we think patients should be, but from where the patients think they are. If we don't start where patients think they are, even when we do know more than they do about what they *could* do, telling them this and/or pressuring them to do what we think they can do risks shaming them, and, in this way, even in an instant, halting their progress.

As an unintended result, an effort to move patients to do what we think they could do may create a glitch in our relationship. Such glitches may decrease patients' capacity to do what they want and need to do. There may be an even worse outcome: pressured expectation may evoke within these patients a reflexive oppositional or defiant reaction that they do not want. These responses may "take over," and patients may have no control over them; similar uncontrollable urges may underlie some patients' repetitive behaviors such as ingesting foreign substances or "choosing" to cut themselves.

Other interventions that have been used to help patients who do not respond to standard approaches may help convey the wide range of approaches that may be used with the patients, or in "stuck" ethics consultations. I present some examples that were pioneered by therapists.

Noel Larson. I described Noel Larson's approach to negative counter-transference feelings above. Among the patient groups Larson has specialized in treating are those who cut themselves. An approach she has used, that exemplifies starting where patients are, is to, in groups, encourage patients to cut themselves with their other, nondominant hand. Why would she do this? She believes that this gives patients an additional option, a first step in acquiring other, additional options thereafter. The end goal sought is for the patients to be able to put their pain into words so that, when they are hurting, they can respond by talking with another person, rather than cutting themselves. Larson informs and acknowledges to these patients that she knows they are doing the best they can with the coping skills they have at the time. Thus, patients feel safe with her and not judged, which leaves them more able to progress. Prior to doing this, however, Larson takes precautions, so she is less likely to undergo avoidable, unwanted, personal repercussions. She tells appropriate persons, such as patients' parents and the local authorities, in advance that she will be doing this.³⁴

David Mee-Lee. Another therapist who has had success beginning where patients are is David Mee-Lee, a psychiatrist at Harvard. He was concerned when his schizophrenic patients wouldn't take the antipsychotic medications that he believed would

most likely help them. The law generally allows patients to choose not to take medications, even when, as a result, they continue to have highly disordered thinking. Mee-Lee wanted to find a way to help his patients be able and willing to help themselves. Starting where they are, he tells them he agrees that they *may not* need medication. But, he adds, maybe they do. He asks patients whether they are willing to work with him and experiment together to see whether they do better on or off meds.

He suggests that patients go without meds for a time and see how they do, but if they don't do well, they will agree try the meds. If a patient agrees to try this, Mee-Lee asks, "How long do you think we should try your going without meds for us to best see whether or not you need them?" If, during the trial, the patient has more problems off meds, the patient may be more willing to take the meds, and, after this, also more willing to work with Mee-Lee.³⁵ Like Larson, Mee-Lee takes precautions. He tells his colleagues before proceeding that he is doing this and why. Otherwise, if a patient, off meds, becomes psychotic and needs inpatient hospitalization, staff may ask, "How could you tell this patient that it was okay to not take medications?"

Milton Erickson. The therapist who has probably most encouraged and pioneered the approach of starting wherever patients are is Milton Erickson, a psychiatrist who practiced before most psychotropic meds were available. Reportedly, mental health clinicians throughout the United States sent him patients with whom they had failed. It appears that Erickson most often succeeded. Most importantly, he wrote how and why he did what he did with his patients, in detail. Here is just one example to suggest how he first provided safety, and started where the patient was. In this case example, Erickson didn't risk evoking stress in the patient by mentioning the reason for the consultation.³⁶ The patient was a 10-year-old boy who "still" wet his bed. His parents routinely whipped him when he did, and made him wear a sign, "I'm a bed wetter." These interventions hadn't worked. They brought their son to Erickson. After the parents left the boy with Erickson and the office door was closed, the boy screamed. Then Erickson screamed. The boy looked surprised. "It was my turn," Erickson said. "Now it is your turn."

Erickson knew from a prior conversation with the parents about the boy's prowess at baseball. Thus, Erickson focused exclusively on that, at every weekly session. After having met once a week for four weeks, the boy told Erickson he no longer wet his bed! How might this have happened? Erickson believed that the boy generalized his prowess in

baseball to stopping his bed wetting. This was why Erickson talked with him only about his prowess in baseball. In light of the multiple successes Erickson brought about, he well may have been right.

These examples hint at the range of nonstandard practices that may reach patients who lack capacity, or to have the best possible outcome when intervening in an ethical conflict. These two principles—regarding patients' feeling of safety and starting where patients are—are essential. I will provide representative examples of a patient who lacked capacity and a surrogate decision maker who was likely to have a bad result. And, as mentioned above, there is a third principle: Going the extra mile and making a sacrifice to help patients, when necessary.

Going the Extra Mile and Making a Sacrifice

Patients like those who repeatedly swallow foreign objects may feel so alienated and isolated from others that they need additional "proof" that their clinicians truly value them. Patients need to know this to be able to trust their clinicians. Patients can suspect and fear that their clinicians may be just "doing their job." To overcome this belief, we may have to make extra efforts we otherwise might not make. These efforts might include making a personal sacrifice. I already have given a paradigmatic example of going with a patient to an AA meeting. But there are no limits to what can be done.

We may, for example, offer to go with patients to a court or other hearing that they fear. We may do this even when our presence may not help. We may take the initiative to offer to help, since patients may be too hesitant to ask us to do this themselves. As another example, patients who feel suicidal may fear that they will feel more suicidal if they are admitted to a psychiatric ward. They may be right. Thus, they may be adamantly opposed to being admitted, even voluntarily, to a psychiatric ward. They may agree gratefully, however, to their clinician's calling them several times, as many as three or four times, initially throughout the next day and early night. This may be close to safe for patients in the short run, and even safer over the longer run, in part due to the ongoing patient/clinician relationship that this may help cement. Moreover, it may be the only route, over the longer run, for patients to do well.

Other sacrifices may be substantially smaller. For instance, a patient calls on Friday night, saying he or she has run out of sleep medication. We could take time with the patient to find a pharmacy still open, so we can prescribe a medication so the patient can sleep that night. As a further example, after prescribing the sleep medication, we could search the internet for another preparation of the medica-

tion that could help the patient more. If we find one, we could call the patient at home to indicate what we found, and offer to prescribe it. Such sacrifices exist in all fields. We could call a patient during our lunch break to inform her or him immediately after we receive biopsy results, to say the biopsy that could have shown cancer is benign. We could call a patient, likewise, after a procedure to ask how she or he is.

Some sacrifices may go so far as to be ethically controversial, for example an intervention that challenges our moral conscience, an intervention that take us farther than we want to go. Examples exist in all fields. We may consider giving a patient a diagnosis that is not the one that we would first choose, but is medically sound and would benefit the patient to a much greater extent; for example, a psychiatric diagnosis that would allow a patient's insurance to give him or her more outpatient visits.

These interventions involve gaming the system. Some believe we should do this for patients;³⁷ others do not. The general consensus is that rather than game the system, we should try to change it. Ethically, it may be that, regardless of how we come out on gaming the system, an argument to go the extra mile may be stronger, because it might not be possible to achieve positive results with these patients in any other way. I end this section with the example of a patient who might benefit—and might only benefit—from the use of these approaches. As is often the case, ethics consultants were involved.

The patient had repeatedly injured himself. Each time, lifesaving surgery repaired the wound, so he would not die of infection. Between injuries, he did marginally well. He was cognitively challenged due to a prior brain injury, and he had depression that waxed and waned. When I met him he had recently been referred to a residence where the staff would help look after him. He said that he would like to stay there. Most importantly, there was a senior staff person there he said he felt very close to. He "really liked" her. Not long after, before arrangements could be made to place him in that residence, he became depressed and gave himself a life-threatening injury, as he had in the past. He would die from infection without surgery, but he refused it. It was unclear whether he had the capacity to make this decision. Because he had suffered so much throughout his life and no treatment had been successful, his loved ones and many of his clinicians believed the most caring approach would be to consider him competent and to respect his decision. If we apply the three principles presented above, what might this patient's clinicians best try to do for him? Perhaps they could go outside the hospital system and seek to bring in

the senior staff member the patient had said he really liked. I use this example to make the point that our caring might be the best way—or the only way—to reach such a patient. I do not know his outcome.

The Use of These Approaches with a Surrogate

Smith, Felice, and Heitman, in their article in this issue of *JCE*, present two cases involving surrogate decision makers who seemed to have questionable capacity to make decisions for the patient. The authors point out the criteria that the surrogates' decisions should meet, and they discuss alternatives that clinicians may take when the criteria aren't met. In the first case, a surrogate decision maker believed that the patient, his elderly brother, would recover faster at home, where he would be able to sleep on the floor and eat his favorite foods. In the second case, a patient was hospitalized in an intensive care unit for four to six weeks longer than her medical condition required, at least in part because the hospital staff was not able to work with the patient's son, her surrogate decision maker, "in an effective manner." The authors present a two-pronged framework they find helpful in determining when a hospital system might be justified in pursuing legal action to remove an incapacitated surrogate.

On the other hand, one way to avoid pursuing legal action may be to use some or all of the three approaches I have outlined above. Here is an example in which the hospital staff thought the patient should be released from the hospital. The patient's lucidity waxed and waned, due to her medical conditions, and so the staff considered her husband to be her surrogate decision maker. The problem with releasing the patient from the hospital was that she required ongoing medical attention. Her husband did some research online, and found that even if his wife went to a nursing home with the best medical facilities, the medical attention his wife would receive there would be less than she received in the hospital. He feared that the reduced attention in the nursing home would increase the risk that she would die. The staff would not acknowledge his concern. As a result, he became fearful of being confronted by them. To avoid this, he visited his wife only during the evening, when the staff whom he feared wouldn't be there. The staff saw this behavior as grounds for dismissing him as a surrogate, and debated whether they should. I don't know how the conflict was resolved.

The question here is how the staff might have avoided this conflict and possibly gained a better result. In general, just as there are patients who ingest foreign objects, there are surrogate decision makers who respond in much the same way to stress.

The exceptional measures outlined here may then help in this context too.

How? We can prioritize helping the surrogate feel safe. In the above case, the staff could acknowledge the logic of the husband's concern. Starting where the surrogate was, following Mee-Lee, staff might have explored with the husband what the risks of less attention (if any) would be, and seek a course that would not increase the risk of death. This might require staff to go the extra mile. For instance, they could offer to go with the husband to the patient's bedside to determine exactly what care she was receiving, and then go to the nursing home to see what level of care the patient would receive there. The husband might see that the greater risk to his wife that he feared didn't exist. Or he and staff might find the nursing home did pose a greater risk. If so, staff might help the husband seek another, better arrangement. And staff could have told the husband they would do this when he first expressed concern.

Finally, as suggested by the cases from Larson, Mee-Lee, and Erickson, there are alternatives for working with the kinds of patients we have been considering, and there are experts at resolving escalating conflicts who may be of help. I think particularly of John and Julie Gottman's pioneering work. What do they do, and what do they recommend? The husband and staff in the case above were in conflict; the Gottmans say that the kind of negativity displayed in this case "spills over," and they call this the Quicksand Effect.³⁸ That the patient's husband would only visit at night might be an example of this effect. What do the Gottmans recommend? They emphasize that such difficulties can be the result of a failure to be able to "repair." This is a challenge I referred to earlier, when clinicians may raise an eyebrow or smirk without knowing.

There are two critical, reparative responses the Gottmans recommend. First, one party (in this case, the staff) must not respond defensively. This response may be useful when clinicians experience negative counter-transference feelings, as described above. Second, most importantly, both parties (the staff and the husband) must recognize that underneath what the other party does, each has a *positive need*.³⁹ Both parties must try to see this, and then respond. The Gottmans recommend a third step, "building gratitude," in which both parties try to meet the other party's positive need, on a continuing basis.⁴⁰ This third step may be seen as going the extra mile. As suggested above, the staff might go the extra mile by going with the patient's husband to the patient's bedside to determine her precise needs, then visit the nursing home, and then compare how each facility could meet her needs.

GOING THE EXTRA MILE AND MAKING A SACRIFICE MAY BE ETHICALLY WARRANTED

Why might it be ethically justified to take the time to go the extra mile, and even sacrifice our own interests for patients and surrogate decision makers? Here are three principal reasons. The first is from Nel Noddings. I believe that she would support doing what we feel we must do, simply because we care. She argues that we should not limit ourselves in how far we go to care, even when there are abstract ethical principles that would argue against doing so.⁴¹ Noddings grounds her view in the relationships that persons have with each other. Such an exceptional commitment based on caring would generally be strongest for family members. It might be that we should extend the view and moral priority Noddings espouses to the kinds of patients we have considered here, like patients who swallow foreign objects, cut their skin, have addictions, and dissociate; and to surrogate decision makers.

The patients we have been considering may be among the most helpless. When we offer our services to these patients, we should rightly see this as requiring more than what we offer to most patients. The most penetrating rationale for these exceptional interventions is offered by Fins, and his views regarding Maggie. He acknowledges the realities. Our initial responsibility is to get the diagnosis right, and then pursue what the patient needs. There are rare exceptions: some patients may receive a diagnosis with feelings of fear they will not be able to erase. For example, they may have a genetic disease such as Huntington's and not want to know. But when we consider whether to make an exception, we must make sure there is a good reason. Fins acknowledges medicine is now "at a time of fiscal scarcity." Considering our ethical responsibilities to patients in a minimally conscious state, he says, "one might see the surrounding politics as untenable and reasonably seek to spend resources elsewhere." Fins argues it would be a mistake to view our responsibilities so narrowly; that this is a fundamental question of basic civil rights and of not leaving conscious individuals isolated and abandoned.⁴² This is the one consideration that should move us beyond our usual, professionally defined boundaries. Maggie's words are memorable. She said she had "enough to have a life, even a small life," because she had "things that many people didn't have—relationships, friends and family who loved her." Fins says, "Now that we know this, we can't look away. When we restore voice to these patients we bring them back into the room and the conversation."⁴³

CONCLUSION

I primarily have discussed three ways that we may optimally reach and restore the capacity of patients whose capacity is uncertain. I have suggested that these same approaches may succeed, in some cases, when ethical conflicts arise. Cutting through these ethical Gordian knots is more likely to be possible when we give our overriding attention to first establishing and then maintaining as mutually caring and trusting a relationship with patients as possible. This particularly is the case when patients ingest foreign objects, or surrogates are concerned that a loved one may unnecessarily lose his or her life. The three approaches I urge involve helping patients feel safe, starting where patients are, and, when possible, taking extra measures. These approaches may ethically be most required when a patient or surrogate would otherwise remain alone. The goal is, in the end, as Maggie said. To provide enough, even if it is only a small life.

ACKNOWLEDGMENT

I would like to thank Norman Quist for his careful reading and insightful comments on this article.

NOTES

1. B.E. Zawacki, "The 'Futility Debate' and the Management of Gordian Knots," *The Journal of Clinical Ethics* 6, no. 2 (Summer 1995): 112-27.
2. A. Herlitz, "Comparativism and the Grounds for Person-Centered Care and Shared Decision Making," in this issue of *The Journal of Clinical Ethics*, volume 28, number 4 (Winter 2018).
3. K.L. Smith, P. Fedel, and J. Heitman, "Incapacitated Surrogates: A New and Increasing Dilemma in Hospital Care," in this issue of *The Journal of Clinical Ethics*, volume 28, number 4 (Winter 2018).
4. "The boundaries between different categories [of capacity] are often arbitrary, but once some arbitrary boundary exists, we forget that it is arbitrary and get way too impressed with its importance." R.M. Sapolsky, *Behave* (New York: Penguin, 2017), 6.
5. S. Lytle, S.J. Stagno, and B. Daly, "Repetitive Foreign Body Ingestion: Ethical Considerations," *The Journal of Clinical Ethics* 24, no. 2 (Summer 2013): 91-7.
6. R. Palta et al., "Foreign-body Ingestion: Characteristics and Outcomes in a Lower Socioeconomic Population with Predominantly Intentional Ingestion," *Gastrointestinal Endoscopy* 69 (2009): 426-33.
7. Although these actions may seem volitional, they may stem from a dysfunctional personality disorder; 25 percent of primary care patients may meet criteria for personality disorder. M. Fiddle, T. Meeks, C. Alvarez, and A. Dubovsky, "When Personality Is the Problem: Managing

Patients with Difficult Personalities on the Acute Care Unit,” *Journal of Hospital Medicine* 11, no. 12 (2016): 873-8, p. 873.

8. J.E. Groves, “Taking Care of the Hateful Patient,” *New England Journal of Medicine* 298, no. 16 (20 April 1978): 883-7.

9. Lytle, Stagno, and Daly, “Repetitive Foreign Body Ingestion,” see note 5 above.

10. The pattern of building tension followed by relief may include sexual assault. People have come to emergency rooms when they feel such tensions mount, asking for help before they act on these impulses. *Ibid.*

11. J. Pugh, H. Maslen, and J. Savulescu, “Ethical Surgical Placebo-Controlled Trials of Deep Brain Stimulation for Treatment-Resistant Anorexia Nervosa,” *Lancet Psychiatry* 4, no. 6 (June 2017): 441-2.

12. M.T. Orne, D.F. Dinges, and E.C. Orne, “On the differential diagnosis of multiple personality in the forensic context,” *International Journal of Clinical Hypnosis* 32, no. 2 (April 1984): 118-69.

13. Lytle, Stagno, and Daly, “Repetitive Foreign Body Ingestion,” see note 5 above, p. 93.

14. Suomen Akatemia (Academy of Finland), “A hypnotic suggestion can generate true and automatic hallucinations,” *ScienceDaily*, 13 August 2013, www.sciencedaily.com/releases/2013/08/130813101014.htm.

15. J.J. Fins, “The Civil Right We Don’t Think About,” *New York Times*, 27 August 2017, <https://www.nytimes.com/2017/08/24/opinion/minimally-conscious-brain-civil-rights.html>. The capacity of patients who have brain damage from trauma or a stroke also may be difficult to determine. T. Chen and B.B. Worrall, “Capacity, Consent, and Country in Acute Stroke Research,” *Neurology* 89, no. 13 (September 2017): 1406.

16. M.W. McCarthy, D.R. Asua, and J.J. Fins, “The Rise of Hospitalists: An Opportunity for Clinical Ethics,” in this issue of *The Journal of Clinical Ethics*, volume 28, number 4 (Winter 2017).

17. Fins, “The Civil Right,” see note 15 above.

18. See, i.e., P.L. Schneider and K.A. Bramstedt, “When Psychiatry and Bioethics Disagree about Patients’ Decision Making Capacity,” *Journal of Medical Ethics* 32, no. 2 (February 2006): 90-3.

19. In the study, 10 to 36 percent of patients got better, but then regressed. Lytle, Stagno, and Daly, “Repetitive Foreign Body Ingestion,” see note 5 above, p. 94.

20. M. Leszcz, C. Pain, J. Hunter et al., *Psychotherapy Essentials To Go* (New York: W.W. Norton, 2015), 11.

21. “Psychotherapy has evolved through empirical research during the last century and is used not only to modify behaviors, but also to modulate the neural circuit, as detectable with functional magnetic resonance imaging.” K.-Y. Choi and Y.-K. Kim, “Plasticity-augmented psychotherapy for refractory depressive and anxiety disorders,” *Progress in Neuro-Psychopharmacology & Biological Psychiatry* 70 (2016): 134-47.

22. *Ibid.*

23. L.R. Mosher, S.J. Keith, “Research on the Psychosocial Treatment of Schizophrenia: a Summary Report,” *American Journal of Psychiatry* 131, no. 5 (May 1979): 623-31; J.R. Bola and L.R. Mosher, “Treatment of Acute

Psychosis Without Neuroleptics: Two-year Outcomes from the Soteria Project,” *Journal of Nervous and Mental Disease* 191, no.4 (Apr 2003): 219-29.

24. When we advise patients on what they should do, we may risk infantilizing and demeaning them. That is, we may imply we believe they are not able to help themselves on their own. Patients who were greatly infantilized previously may “hear” only this when we try to help by giving advice. Thus such efforts may make them worse.

25. It is difficult to not feel terror when patients say they feel like killing another person or themselves. It may be possible for patients to genuinely agree and conclude this would not be what they most want to do. The best route, if possible, may be to allow them to discover this on their own, rather than telling them this directly.

26. “When a person’s heart rate is above 100 beats a minute, or their oxygen is below 95 percent, they can’t listen very well. They can’t empathize. . . . In the consulting room this means stalled progress.” T. Real, “The Long Shadow of Patriarchy,” *Psychotherapy Networker* 41, no. 5 (September-October 2017): 34-41, 58, p. 47.

27. For example, when saying we are sorry, we should say we are sorry for what we did, not, “I am sorry you felt this way.” This may imply that we believe the patient is at fault for responding as he or she did. D. Forrest, “Frontline: Teaching Affect recognition to Medical Students: Evaluation and Reflections,” *Journal of the American Academy of Psychoanalysis and Dynamic Psychiatry* 39, no. 2 (Summer 2011): 229-41.

28. Herlitz, “Comparativism,” see note 2 above.

29. L.S. Brown and T.C. Bryan, “Feminist Therapy with People Who Self-Inflict Violence,” *Journal of Clinical Psychology* 63, no. 11 (November 2007): 1121-33.

30. *Ibid.*, 1127.

31. See Real, “The Long Shadow of Patriarchy,” see note 26 above.

32. Brown and Bryan, “Feminist Therapy,” see note 29 above, p. 1127

33. N.R. Larson, “Finding Compassion for Clients Who Do Horrible Things,” <https://www.psychotherapynetworker.org/author/bio/2381/noel-larson-ph-d-msw>.

34. Larson shared this at a course on helping patients with severe personality disorders that I attended.

35. David Mee-Lee has pioneered therapeutic approaches for patients with addictions, see <https://www.changecompanies.net/blogs/tipsntopics/>.

36. *A Teaching Seminar with Milton H Erickson*, ed. J.K. Zeig (New York: Brunner/Mazel, 1980), 110-112.

37. D.H. Novack et al., “Physicians’ attitudes toward using deception to resolve difficult ethical problems,” *Journal of the American Medical Association* 261, no. 20 (May 1989): 2980-5.

38. J. Gottman and J. Gottman, “The Science of Togetherness,” *Psychotherapy Networker* 41, no. 5 (September/October 2017): 42-47, 59, p. 45.

39. *Ibid.*, 47.

40. *Ibid.*, 59.

41. N. Noddings, *Caring* (Berkeley: University of California Press, 2003), 95.

42. Fins, “The Civil Right,” see note 15 above.

43. *Ibid.*