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At the Bedside

- 257 New Ways to Cut through Ethical Gordian Knots
Edmund G. Howe

Features

- 269 Comparativism and the Grounds for Person-Centered Care and Shared Decision Making
Anders Herlitz
- 279 Incapacitated Surrogates: A New and Increasing Dilemma in Hospital Care
Karen L. Smith, Patrice Fedel, and Jay Heitman
- 290 Measuring Instrument for Ethical Sensitivity in the Therapeutic Sciences
Alida Naudé and Juan Bornman
- 303 Make It Plain: Strengthening the Ethical Foundation of First-Person Authorization for Organ Donation
James L. Benedict

Cases from the Cleveland Clinic

- 308 Incarcerated Patients and Equitability: The Ethical Obligation to Treat Them Differently
Lisa Fuller and Margot M. Eves

Clinical Ethics Consultation

- 314 Ongoing Evaluation of Clinical Ethics Consultations as a Form of Continuous Quality Improvement
Rebecca L. Volpe
- 318 Moral Distress, Ethical Environment, and the Embedded Ethicist
Donna Messutta

Medical Education

- 325 The Rise of Hospitalists: An Opportunity for Clinical Ethics
Matthew W. McCarthy, Diego Real de Asua, and Joseph J. Fins

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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 reconnections 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

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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.*

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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.*

Anders Herlitz, "Comparativism and the Grounds for Person-Centered Care and Shared Decision Making," *The Journal of Clinical Ethics* 28, no. 4 (Winter 2017): 269-78.

Features

Comparativism and the Grounds for Person-Centered Care and Shared Decision Making

Anders Herlitz

ABSTRACT

This article provides a new argument and a new value-theoretical ground for person-centered care and shared decision making that ascribes to it the role of enabling rational choice in situations involving clinical choice. Rather than referring to good health outcomes and/or ethical grounds such as patient autonomy, it argues that a plausible justification and ground for person-centered care and shared decision making is preservation of rationality in the face of comparative non-determinacy in clinical settings. Often, no alternative treatment will be better than or equal to every other alternative. In the face of such comparative non-determinacy, Ruth Chang has argued that we can make rational decisions by invoking reasons that are created through acts of willing. This article transfers this view to clinical decision making and argues that shared decision making provides a solution to non-determinacy problems in clinical settings. This view of the role of shared decision making provides a new understanding of its nature, and it also allows us to better understand when caregivers should engage in shared decision making and when they should not.

Person-centered care and shared decision making are popular in medical ethics in general, and in clinical ethics in particular.¹ Typically, it is argued that person-centered care is important because it generates better medical outcomes,² and because it better meets important values in bioethics such as autonomy and consent.³ In this article I provide a different argument in favor of shared decision making in clinical settings that lays out the view that shared decision making ensures the possibility of rational choice, such as conceived by *comparativists*.⁴ Comparativism is the view that a rational choice is a choice based on the comparative merits of the alternatives. Since comparative value-theoretical non-determinacy is prevalent in evaluations of clinical options, we need to invoke shared decision making to enable rational choice. Ascribing this role to shared decision making, I suggest, brings some clarity to the complicated issue of how some disagreements between physicians and patients should be solved by prioritizing the view of patients.

The core idea of person-centered care is that, rather than applying the traditional model in which caregivers embody a paternalistic attitude toward patients and their health needs, caregivers should allow the characteristics, desires, and beliefs of patients to have a significant impact on decisions regarding what treatment to apply, by involving patients in the decision process. Advocates of person-centered care suggest that this should be done by

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the application of a series of more specific practices. Ekman and colleagues, for example, have argued that it is important to initially invite patients to express their personal views of their illnesses and symptoms, and their impact on the patients' lives, to encourage caregivers and patients to engage in shared decision making and to decide on a clinical approach to medical problems together, and to document patients' narratives in order to make the interplay of caregivers and patients transparent and to facilitate the continuity of care.⁵

In this article I focus on shared decision making. I present an argument of how to justify person-centered care and shared decision making in light of value-theoretical problems and the desire to make rational choices, and I discuss what this justification might tell us about how to understand what the practice of shared decision making ought to look like, an issue that is contested.⁶

The structure of the argument is this:

- Premise 1: *Comparativism*: A decision is rational if it tracks the comparative relation between alternatives so that an alternative that is *best* (that is, at least as good as every alternative) is chosen.
- Premise 2: There are non-determinacy problems in many situations involving clinical choice so that sometimes no alternative is best in the light of given reasons.
- Premise 3: When, and only when, no alternative is best in the light of given reasons, created reasons that are grounded in the will of individuals who are involved in the decision can determine a best alternative.
- Conclusion: In situations that are characterized by non-determinacy problems, shared decision making should be used to form created reasons, so that a best alternative can be determined and a rational decision made.

This article is structured in the following way. Throughout, I make the assumption that comparativism is a sound view. In the first section, I argue that comparative, value-theoretical non-determinacy (not to be confused with epistemic problems determining the relation between alternatives in light of what matters) is prevalent in clinical settings. That is, often, given values that apply to situations involving clinical choice fail to fully determine a course of action that is better than, or equal to, every other course of action. The argument focuses on the ideal of health promotion, and I argue that, in a large number of clinical cases, it is not determinate which course of action best promotes

health, even if we have perfect information about all of the relevant facts. This means that in so far as we accept comparativism and want clinical decisions to promote health, we face a serious problem: often, treatment alternatives cannot (even in principle) be ranked with respect to how well they promote health. In the second section, I introduce a solution to the problem of comparative, value-theoretical non-determinacy that has been suggested in recent research on practical reason, namely that we can *create* reasons in light of which a best decision can be identified when *given* reasons fail to do so. I argue that, for clinical settings in which a professional caregiver provides care to a patient, this solution is best implemented as shared decision making. In the third section, I discuss what this means for how we should understand the nature and role of shared decision making and argue that it gives us a reason to give priority to the views of the patient over the views of the caregiver when there is non-determinacy and disagreement.

COMPARATIVE NON-DETERMINACY

Consider a clinical situation in which a caregiver identifies a serious ailment in a patient; let us say a complicated type of cancer. Untreated, the patient will live for an additional five years with significant physical disabilities. The caregiver sees two distinct treatment alternatives for the ailment and is, we assume, also able to correctly predict the exact outcome of the treatments. Either (A): the patient can be provided certain medication that will not cure her or him, but radically reduce the amount of physical disability that she or he will experience. Given this treatment, the patient will be able to live the remaining five years of his or her life with a high quality of life. Or (B): the patient can be provided a different treatment that will significantly prolong her or his life, but at a significant cost in terms physical disabilities. If this treatment is chosen, the patient will live for another 10 years, but the 10 years will be spent with significantly reduced quality of life due to physical disabilities. Prolonging someone's life contributes to the goodness of a treatment in light of health promotion, and improving the quality of life by mitigation of physical disabilities contributes to the goodness of a treatment in light of health promotion. Both alternatives are alternatives that promote health, but they do this in very different ways. Is one alternative necessarily better, worse, or equal to the other alternative with respect to health promotion? Otherwise put, is health promotion an objective that is *complete* so that we, in case we have

perfect information, in all situations that require a choice, can order all alternative treatments in terms of how well they promote health? Below, I argue that this is not the case.

In this section I will use the so-called small improvement argument (which has been used to challenge completeness axioms in value theory, by pointing to how very small improvements in one of many dimensions do not change comparative relations) to argue that occasionally it is not possible to determine what a *best treatment* is, in clinical situations, in light of health promotion. Instead, I suggest that we must accept that it is possible that no treatment is at least as good as every alternative treatment in light of health promotion. That is, the trichotomy <better than, worse than, equal to> does not exhaust the set of possible relations between alternative treatments. The argument relies on a stylized situation that requires a choice, and I will start by introducing this. All of the simplifications that are needed to define the stylized situation that requires a choice are arguably unrealistic. I will, for example, discuss only physical disabilities and longevity when I discuss health promotion, and I will assume that we can fully predict the effects of alternative treatment options. In real situations that require a choice, decision makers will also need to take psychological disabilities and distress into account, and uncertainties are ubiquitous. Yet, since the simplifications enable us to identify a core aspect that is ubiquitous in clinical settings, they are warranted. We should expect that the complications that are here removed from the discussion will support the conclusion, since they introduce additional aspects that decision makers must take into account and weigh against the aspects presented below. For example, taking also psychological disabilities into account means that we also need to compare alternatives along this dimension, and this entails another possible non-determinacy.

To model well-defined clinical situations that require a choice, let us first assume that there is only one single value at stake: health promotion. In other words, let health promotion be the “covering value” in the situation.⁷ By stipulation, health promotion is what matters to the choice—the value in light of which alternatives are evaluated and compared—similar to how monetary returns might be the covering value for an investor who considers alternative investments, or to how national security might be the sole concern for individuals in the national security sector. Health is, of course a deeply complicated concept, but most of us can agree that one can promote health in at least the following two

ways. Everything else being equal, health is promoted by decreasing the amount of physical disability (for example, difficulties walking, physical incapacity to engage in intimate relations, decreased pulmonary functioning) an individual involuntarily and unavoidably experiences, and it is, everything else equal, promoted by prolonging the life expectancy of an individual (at the very least up to a normal level). We improve health by improving the mobility of someone who has difficulties walking, and we improve health by prolonging the life expectancy of someone who is expected to die very soon. That health is promoted by decreasing the amount of physical disability that an individual involuntarily and unavoidably experiences as well as by prolonging the life expectancy of an individual (at least up to a normalcy level) is not controversial.

If we, furthermore, assume that we can represent both how good an outcome is in terms of prolonging a patient’s life and how good an outcome is in terms of decreasing physical disability with numbers, we can characterize the choice between treatment A and treatment B in the following way:

Outcome A: 5 LY; 1 P

Outcome B: 10 LY; 60 P

Let LY represent life years, the more the better, and let P represent average physical disability during these years, the less the better. In light of health promotion and health promotion only, the question is: is it better to create an outcome where a patient lives for five years with very little physical disability, or an outcome in which the patient lives for 10 years with physical disability amounting to 60 on a scale of 0 to 100, or is no outcome better than the other?

A standard way of thinking about comparisons in which two alternatives are to be evaluated in terms of a defined covering value such as health promotion is to hold that the alternatives will bear one of the following three relations to each other: A is better than B, B is better than A, or A and B are equally good. This has been called the “trichotomy thesis.”⁸ Below, I will argue that the trichotomy thesis does not hold true for alternatives that are compared in terms of health promotion such as this has been defined above, and I will suggest that this is just the tip of an iceberg of comparative non-determinacy in clinical situations that require a choice.

Consider that there is an indefinitely large set of (theoretically) possible situations of the particular type introduced above, in which one alternative does relatively better in terms of LY, and the other does relatively better in terms of P. In the example

above, significantly decreasing physical disability stands against prolonging life by five years. Other possible situations will involve a conflict between decreasing physical disability and prolonging life by more than five years, and still other possible conflicts will involve decreasing physical disability and prolonging life by less than five years. If the trichotomy thesis were true for comparisons of alternatives within this set so that in light of health promotion it is true for every pairwise comparison within the set that one alternative is better than, worse than, or equal to, the other, there must be a pair of alternatives in this set that are equally good.⁹

Supposing that the trichotomy thesis holds true; let us select a pair of alternatives, X and Y, that are deemed equally good in light of health promotion, and consider whether that is plausible. X is not better than Y, and Y is not better than X. To make the exposition simpler, let us furthermore assume that this pair is the same as the pair introduced above, that is, treatments A and B. Thus: in light of health promotion, let us assume that it is not worse to provide the patient with a treatment that predictably gives the patient five years of life with almost no physical disability than to provide the patient with a treatment that predictably leads to 10 years of life with physical disability amounting to 60 on a scale 0 to 100, and vice versa. A is not better than B, and B is not better than A.

Now, imagine that a mistake was made when the caregiver assessed the options; there is a third treatment available that the caregiver had previously overlooked: A'. Implementing A' will lead to 5.0001 LY, and 1 P. Treatment A' has the same good effects as A in terms of reducing physical disability, but it will also prolong the patient's life by a tiny amount. Obviously, A' is better than A. It is not worse than A in any way, and it is clearly better than A in terms of LY ($5.0001 > 5$). But is it really reasonable to hold that A' is better than B? If A and B really are equally good, if the trichotomy thesis is true, and if A' is better than A, then A' *must* also be better than B. Treatment A' cannot be equal to B, since "equal to" is a transitive relation, and so if A' was equal to B, it would be equal to A, which it clearly is not. And A' cannot be worse than B. It is false that A is worse than B, and it is false that A' is worse than A, which again in virtue of transitivity indicates that A' cannot be worse than B. If the trichotomy thesis is true, and better than, worse than, and equal to are the only possible relations between A' and B, treatment A' must be better than treatment B. Yet, how can the additional fraction of a day that the patient will be able to live if A' is chosen make such a large differ-

ence to the comparative relation of the alternatives? Accepting that a fraction of a day makes a difference when everything else is equal is one thing; this is why A' is clearly better than A. But when two alternatives are contributing to the goodness of an outcome in such radically different ways, how can a small improvement in terms of one factor change the comparative relation? Together with Ruth Chang, I assert that it does not.¹⁰ It is true that A' is better than A, but it is not true that A' is better than B, and this is because the trichotomy thesis does not hold true in this context. Although A is not better than B, and B is not better than A, treatment A and treatment B are not equally good. The relation between a treatment that prolongs the life of a cancer patient, who is predicted to live with significant physical disabilities and to die in five years, and a treatment that significantly decreases the patient's physical disabilities but does not prolong the patient's life, is non-determinate, in the sense neither is better than the other, and they are not equally good, either.¹¹

Objections can be raised against this particular example on various grounds. It could be held that the example is poorly designed because it is unreasonable to hold A and B to be the pair that is equally good. This might be true, but it does not address the core problem. I invite readers to select whichever pair they see fit as candidates for X and Y, and make the same thought experiment. The point is not that the particular pair {A; B} is problematic, but that a small improvement in one factor cannot make a decisive difference when two alternatives contribute to the overall goodness of an outcome in such different ways. Some will question why the argument is confined to improvements in life expectancy. This is for reasons of space. The exact same point can be made by contemplating the introduction of B', for example, 10 LY; 59.9999 P. B' is better than B, but is it better than A? And finally, some might object to the selection of the factors life expectancy and involuntary, unavoidable physical disability. I contend that the exact same problem arises whichever factors we bring out. Alternative treatments often meet the overall criterion of health promotion in radically different ways (some promote health by prolonging life, some by decreasing physical disabilities), and many clinical choice situations will be such that the feasible set of choices contains alternatives that are good in different ways. By comparison, assuming that neither Michelangelo nor Mozart is better than the other with respect to artistic genius, the comparative relation would not change if we discovered that Mozart had written another sonata. The small improvement argument illustrates that we must

abandon the assumption that there will always be one alternative in the feasible set of choices that is better than or equal to every other alternative.

One can draw different conclusions from this type of problem. A radical approach that has been suggested by Larry Temkin is to conclude that the mistake lies in accepting the transitivity of the better-than relation.¹² If we accept that the standard relations are not transitive, then of course A' can be both equal to B and better than A. John Broome has argued that the problem lies in non-semantic vagueness.¹³ Ruth Chang, in turn, introduces the potential of a fourth value relation, *parity*, and Derek Parfit claims that there can be what he calls *imprecise equality*.¹⁴ I will not defend or dismiss any of these proposals, but rather suggest that from the perspective of the issue at hand, the possibility of rationality in clinical decision making, it suffices to note that there is comparative non-determinacy, and, more generally, a non-determinacy problem. Occasionally, it is impossible to establish a single course of action that is better than, or equal to, every other alternative in terms of health promotion. And this is not because we lack knowledge about the situation; it is because the trichotomy thesis does not hold true for the comparisons.

Comparative non-determinacy of the kind illustrated above poses significant problems for the very possibility of rational choice. If we are unable to identify an alternative that is either better than or equal to every other alternative, we are unable to actually make a decision that is rational, in so far as we believe it is rational to select an alternative that is best in light of given purposes and facts.¹⁵ We can, it should be noted, also, in the face of non-determinacy, identify alternatives that are *ineligible* in the face of non-determinacy. Of the options A, A', and B, it is clear that A is an ineligible alternative, because there is an alternative that is clearly equally good or better in every respect: A'. Yet, if we hold an alternative to be ineligible if and only if it is worse than some alternative in *some* respect and worse or equally good in all respects, the alternatives that remain when all of the ineligible alternatives have been removed will not necessarily be rational. The fact that both A' and B remain in the set of choices once we have removed the alternatives that are ineligible (that is, A) does not mean they are both rational choices.

CREATING REASONS

In this section I argue that the paradigm of person-centered care and, in particular, shared decision

making, provides a very good framework for dealing with the non-determinacy problem outlined in the previous section. Again following Chang, I suggest that an appropriate response to the non-determinacy problem is not simply to pick an alternative among the alternatives that are not ineligible, 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). Below, I first introduce Chang's idea of how we can deal with non-determinacy when it comes to practical reasons. Thereafter, I indicate how this can be reinterpreted and applied to a clinical setting by invoking shared decision making.

Dealing with non-determinacy is easy in practice but hard in theory. Comparability problems like the ones outlined above can be addressed, and are often addressed, by superimposing a degree of comparability that is not warranted by the relevant given factors. Also, in a situation in which the relation between alternatives is non-determinate, we *can* evaluate them as if it was not.¹⁶ In the example above, one could, for example, pick a way of weighing life expectancy and physical disability that is complete in the sense that it ranks all possible alternatives in accordance with the trichotomy thesis. This is similar to what the concept of DALY (disability-adjusted life year) does at population level.¹⁷ I contend that this, in clinical settings, is a huge mistake, but it is important to accept that it is still *practically* possible. Practitioners could embrace an evaluative model of health promotion according to which A' is better than B and follow this in their practice. However, if A' is not better than B, this practice would lead to treatment decisions that are not justified. We need to settle on a treatment, and, if nothing else, this means that we at least implicitly rank the alternatives. The puzzle is, then: if we cannot simply pick an alternative that is not ineligible, which should the grounds for such a ranking be?

Chang, who first argued for the possibility of parity using the small improvement argument,¹⁸ has outlined a promising way in which to deal with situations when the comparative relation between alternatives is non-determinate. Rather than simply picking an alternative, based on the reason that none of the alternatives is determinately worse than the other, she suggests that, in situations such as these, we can rely on *created* reasons. The problem arises, according to Chang, because the reasons that are *given* sometimes fail to fully determine what we ought to do, and when we face this problem we need to turn to a kind of reason that has a different origin. In the argument above, the given reasons available

to us are: prolong the life of the patient and minimize the amount of involuntary, unavoidable physical disability. These reasons, occasionally, fail to fully determine what one ought to do, all things considered.

Relying on a rich voluntarist philosophical tradition that dates back to Duns Scotus, Thomas Hobbes, and Immanuel Kant, Chang argues that, apart from given reasons, there are reasons that agents can create through an *act of willing*.¹⁹ This largely overlooked tradition can be contrasted with the views that are more common in contemporary philosophy, regarding the nature of reasons: externalism and internalism. According to externalism, reasons are grounded in facts “outside” of us, for example, that something is painful provides reasons to avoid it.²⁰ According to internalism, reasons are grounded in facts “inside” of us, for example, that I desire to avoid pain gives me reason to avoid it.²¹ Both of these theories, Chang holds, provide explanations of *given* reasons, such as “prolong life” and “minimize physical disability.” However, since these reasons fail to fully determine what we should do, we need to accept a different kind of reason, which can be explained by the *voluntarist* theory: reasons can be grounded in our *willing* and *commitments*, for example, that I will to live a life with minimal amounts of physical disability provides reason to minimize physical disability.²² These reasons are not given; agents themselves create them.

To will something, it is important to note, is not the same as to desire something. Rather, it is to be understood as an activity constitutive of the very agency of someone, as decisive of what and who someone is. Desires, Chang suggests, are passive. They are mental states toward which we are largely passive. To will something is different from desires, in that it is an active state. Chang invites us to make a comparison to divine command theory. According to this view, God could create reasons for us not to eat hooved animals by willing it, which is different from God desiring that we do not eat hooved animals. Likewise, Kant can be seen as suggesting that rational agents can lay down laws for themselves. Again, these are not supposed to be passively desired.²³ More mundanely, there is a difference between me desiring to sleep as a result of being tired and me willing to sleep because I want to be a person who sleeps during certain regular hours.

Having recognized two different types of reasons (given reasons and created reasons), Chang suggests that the reasons should be given different importance and different roles. Since we are able to will anything, and since the very structure of rationality it-

self relies on reasons, it is imperative that we recognize that given reasons take priority; a caregiver cannot create a valid reason to purposelessly harm patients through an act of willing, and I cannot create a valid reason to believe that $2+2=5$ through an act of willing. Created reasons, grounded in acts of willing and commitments, Chang holds, only apply to situations when given reasons fail to fully determine what we ought to do.²⁴ It is only in situations when there is comparative non-determinacy, cases such as the one outlined in the previous section, that created reasons become at all relevant. However, in these situations, the role of these reasons is indispensable: they enter to settle hard cases in which we otherwise cannot establish an alternative that is better than or equal to every other alternative.

Contrary, then, to merely picking an alternative within a set of not ineligible options, choosing a rational option by first creating a reason through an act of willing involves making a commitment to a specific value. In the example above, the patient can, for example, enable a rational decision in this manner by committing to living to see her or his children grow up, and thereby create a reason in favor of selecting the alternative that gives the longest life expectancy, in the example B. Or the patient could enable a different rational decision by committing to “living life to its fullest” and maximizing life at full functioning, and thereby choose A (A’ in the expanded version), because it maximizes the time the patient has left not being impaired by physical disability.

First of all, we can see that this provides a solid ground for the general idea that healthcare should be person-centered in the quite broad sense that treatments should be decided upon based on the particular circumstances of the patient: appropriate solutions to non-determinacy are dependent on the persons who face the non-determinacy. Given reasons are universal, and whatever given reasons tell us to do in a clinical setting, they tell us to do it regardless of who the patient is. Created reasons, on the other hand, are actualized in particular situations by the individuals involved in the situations in question that require choice. Therefore, if clinical situations require that we deal with non-determinacy, and if non-determinacy is best dealt with by invoking reasons created by acts of willing, clinical practice should be person-centered at the very least to the extent that it is person-centered created reasons, and not general reasons provided, for example, by policy makers, that guide decisions when non-determinacy problems arise. Importantly, this ground for person-centered care is unrelated to ethi-

cal and medical reasons to embrace person-centered care. Such reasons might exist, but in addition we have a reason here to embrace person-centered care because it enables rational choice.

Second, it provides a ground for shared decision making that is different from other medical and ethical reasons to engage in shared decision making. Chang proposes that individuals can rationally solve situations in which they face reasons that fail to fully determine what one ought to do by creating reasons through acts of willing. It is problematic to directly transfer this to clinical settings, in the sense that we ought to simply let the patient make a commitment. Clinical decisions typically involve large amounts of highly complicated, but doubtlessly relevant, medical aspects. Furthermore, there is a large risk that patients will experience high amounts of stress in situations that require a difficult choice. Both a lack of understanding and too much stress risk undermining the validity of reasons that arise from acts of willing. A commitment that is formed either without a proper understanding of the situation, or as a result of stress, is not a valid ground for a created reason because it can be questioned whether patients really committed to what they believe they committed to. In other words, in clinical decision making, in which created reasons are invoked, it is, first, important that medical competence is involved in the decision process. This at least raises the likelihood that the commitments, the acts of willing, that generate created reasons actually are based on a good understanding of the complexities of the situation. Caregivers can play an important role in making sure that patients actually understand the specifics of a situation. Second, some medical conditions create large amounts of stress. Having a second party taking part in the decision process can prevent some of the influence that this stress might have on the final decision. If we accept that an appropriate way of dealing with comparative non-determinacy is to invoke reasons that are created through an act of willing, and if we think that (as I claim above) these situations are ubiquitous in clinical practice, we should embrace shared decision making as an appropriate solution to non-determinacy problems in clinical decision making. In the following section, I further discuss what this might entail for our understanding of what this shared decision making ought to look like.

SHARED DECISION MAKING

In the first section of this article, I argued that comparative, value-theoretical non-determinacy is

ubiquitous in clinical practice. I described comparative non-determinacy by an argument that health promotion entails non-determinacy, but I hope that readers will agree with me that similar arguments can be made almost regardless of which ideals one embraces. In the second section of this article, I suggested that the appropriate way to deal with comparative, value-theoretical non-determinacy in this area is through shared decision making. I based this on Chang's suggestion that there are essentially two different kinds of reasons. There are reasons that are given; these take priority, but sometimes lead to non-determinacy since they fail to, in every situation, fully determine what we ought to do. And there are reasons that are created through acts of willing; these reasons only apply to situations in which one faces comparative non-determinacy. In the case of clinical decision making, I suggested that we should accept that created reasons that are valid must be preceded by shared decision making, in which both caregivers and patients play a role. In this section, I discuss what this means in terms of the actual nature of the shared decision-making process.

Lars Sandman and Christian Munthe have developed a conceptual analysis of shared decision making and outlined no less than nine different versions of it, all of which appear somewhat reasonable.²⁵ Without going into too much detail of Sandman and Munthe's conclusions, their research can be summarized as illustrating that one can understand the different components of shared decision making in different ways. Is consensus desirable? If so, who has the final say when consensus cannot be reached? Is it the caregiver, the patient, or should the parties accept some kind of compromise? What is the nature of the deliberative process? Is the role of the patient merely to provide the caregiver personal information, or is the role of the caregiver merely to provide the patient medical information, or should they engage in some form of collaborative deliberation process? Different views can be defended on various grounds, and it is not entirely clear what the nature of shared decision making is supposed to be like when proponents of person-centered care advocate it.

Accepting that a fundamental reason for engaging in shared decision making is to solve non-determinacy problems gives us a clue on how to understand what shared decision making should look like. First of all, it is clear that, in so far as valid created reasons must be created through an act of willing by the patient rather than the caregiver, the will and commitments of the patient (and not only the desires) must be at the core of the shared decision-

making process. This means that as long as patients are conscious and have a sound mind, they should have the final say about the created reasons in light of which a final decision is made in face of non-determinacy. It is the patient's will and the patient's commitments that constitute the ground for created reasons that apply to situations in which non-determinacy occurs. This does not necessarily mean that patients should always have the final say about which treatment to choose, but, in face of comparative non-determinacy, it is the patient's will and the patient's commitments that provide valid grounds for which decision to make. In the case above, the following questions thus become relevant: Is the patient committed to a physically active life, or is she or he committed to living as long a life as possible? What sort of person does the patient want to be, who is she or he? Physicians can help patients think about these issues in different ways, and also to assist in ranking alternative treatments in light of what the patient is committed to, but it is the patient's will that solves the non-determinacy.

Although the theoretical risk that patients fail to see what follows from the commitments they make certainly exists, for practical purposes, this provides us with good reason to give patients final say when patients and caregivers disagree. In the vast majority of cases, we must assume that the individuals who make commitments are better at inferring what they entail than bystanders who learn about the commitments secondhand. Caregivers can, of course, still aid in this process by providing guidance concerning how different treatments match up with the commitments patients make, but patients should have the final say. This does not mean that caregivers should let patients make *any* decisions concerning treatments, but, in the face of comparative non-determinacy, patients have the final say concerning the grounds for selecting among the better alternatives (the alternatives that are not determinately worse than other alternatives). Granting patients this role is a minimum criterion for the created reasons to be valid.

Complications arise when patients are prevented from engaging in sound reasoning in different ways, but also, in such situations, it is more warranted, in light of the argument above, to search for answers to what patients *would have willed*, as expressed in recorded narratives or the patients' life history, than to leave it to caregivers to decide what matters. Past decisions and expressed commitments are not perfect sources for inferring commitments and reasons that can settle cases of comparative non-determinacy, but they still seem to be better sources than com-

mitments made by individuals who are merely providing treatment.

It is less obvious what the nature of the deliberation process ought to look like in light of the argument above. Yet, some things seem clear enough. It is, first of all, essential that caregivers provide patients with relevant medical information about their situation. Patients can make commitments to various values without understanding the medical complications they face. In so far as patients are given the final say in the decision process, they must have a good understanding of the situation at hand. This translates into two different obligations for caregivers. First, caregivers must share their knowledge, be honest about the complications, and provide information that can be relevant. Second, caregivers have an obligation to do what they can to make sure that patients actually understand the information they are provided. It is not, for example, sufficient to hand over a brochure with information about an illness, assume that patients read it, and then act in accordance with the patients' expressed will. Caregivers should do their best to assure that patients are well informed.

Shared decision making that aims at reaching a decision based on valid created reasons, in the light of which one can establish a unique course of action that is best, will consist of at least these parts:

- The patient will provide the grounds for the created reason through acts of willing, or commitments. Ideally, the patient makes a commitment in the face of the situation that requires a choice. If this is not possible, these grounds should be looked for in the patient's personal history.
- In so far as the patient is of sound mind, the patient should have the final say concerning how to apply the created reasons to the situation and concerning which treatment to select. If the patient is not of sound mind, a decision should be formed in light of the reasons the patient would have embraced.
- The caregiver has an obligation to provide information to the patient. Caregivers must be honest, and are obliged not to withhold any potentially relevant information.
- The caregiver has an obligation to ensure that the patient fully understands the information that has been conveyed.

Although these conclusions seem robust in light of the specific view of the role of shared decision making presented above, there is still room for controversy regarding the details of the shared decision making that caregivers and patients should engage

in. Cases in which patients are not of sound mind or unconscious are perhaps the most problematic. First, what counts as “of sound mind”? Second, what sources should be used to discern commitments in these situations, and how should they be selected? Two general issues that are worth exploring here are: (1) to what extent should the patient’s personal history and the often-mentioned recorded narrative that is part of the general framework of person-centered care be invoked? (2) What is the role of a spouse, children, and other family members in these kinds of situations? A different issue that becomes of utmost importance from the perspective of this argument is: What are the conditions under which comparative non-determinacy arise? One can point to non-determinacy and argue that no alternative is better than or equally good as every other alternative when one deals with radically different alternatives that both are good in very different ways. Yet, the argument above tells us that the difference between facing comparative non-determinacy and a situation in which a best option exists is massive. The existence of non-determinacy justifies shared decision making. If one treatment is determinately better than every other treatment, this particular justification for shared decision making is not there any longer; rather, it is in such situations rational to pursue the best treatment.

CONCLUSION

In this article I presented an argument in favor of person-centered care, and in particular in favor of shared decision making. I started by arguing that we must accept widespread comparative non-determinacy in clinical practice. In a large number of cases, it will, in light of the given reasons at hand, not be true that any alternative is either better than or equal to every other alternative with respect to the objectives of clinical practice, for example health promotion. In the second section, I presented Ruth Chang’s suggestion of how to deal with comparative non-determinacy, and I suggested that we should accept this suggestion, but re-interpret it so that in clinical settings it is not merely an act of willing that is required, but rather shared decision making, the purpose of which is the creation of a reason through an act of willing.

This view of the grounds for person-centered care and shared decision making enables us to pose a range of more precise questions that have been largely overlooked in the literature. In particular, although there is a widespread acceptance of person-centered care and shared decision making, little

research has been devoted to the *limits* of shared decision making. If comparative non-determinacy is the grounds for shared decision making, we can frame this question in a new and promising way: when is it, in light of given reasons, determinately true that some treatment is a best treatment? The grounds to use shared decision making track non-determinacy in this view, and this particular reason to engage in shared decision making disappears when one treatment is determinately better than all others. Furthermore, this framework allows us to develop more precise notions of what the role of patients’ narratives is in person-centered care. Much of the research mentions the importance of these narratives, but it has not been studied as systematically as shared decision making. If we accept that acts of willing and commitments provide the grounds for solving comparative non-determinacy, we can start asking important questions concerning the extent to which we can discern such commitments in recorded patients’ narratives, for example when dealing with comatose patients.

Doubtlessly, more research is needed before we have a full picture of how to apply person-centered care in clinical practice, and what the appropriate practices of shared decision making require further study. I hope that the argument presented in this article contributes to this effort, by illustrating how these practices can be grounded, and by providing a framework within which new interesting and important questions can be posed.

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NOTES

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Incapacitated Surrogates: A New and Increasing Dilemma in Hospital Care

Karen Smith, Patrice Fedel, and Jay Heitman

ABSTRACT

A power of attorney for healthcare (POAHC) form gives designated individuals legal status to make healthcare decisions when patients are unable to convey their decisions to medical staff. Completion of a POAHC form is crucial in the provision of comprehensive healthcare, since it helps to ensure that patients' interests, values, and preferences are represented in decisions about their medical treatment. Because increasing numbers of people suffer from debilitating illness and cognitive deficits, healthcare systems may be called upon to navigate the complexities of patients' care without clear directives from the patients themselves. Hence, the healthcare industry encourages all individuals to complete a POAHC form to ensure that persons who have the patients' trust are able to act as their surrogate decision makers. However, sometimes POAHC agents, even when they are patients' trusted agents, lack the capacity to make fully informed decisions that are in the patients' best interests. We describe designated surrogate decision makers who have impaired or diminished judgment capacity as *incapacitated surrogates*. Decision making that

is obviously flawed or questionable is a significant impediment to providing timely and appropriate care to patients. Moreover, failure to redress these issues in a timely and efficient manner can result in significant costs to an institution and a diminished quality of patient care. The authors offer a legal, ethical, and interdisciplinary framework to help navigate cases of incapacitated surrogates.

INTRODUCTION

Despite two decades of concerted effort by the healthcare industry, a majority of hospitalized patients with serious illness have no documented advance directive. An advance directive can voice patients' decisions on important healthcare decisions and designate and empower surrogate decision makers (also called agents) by completing a power of attorney for healthcare (POAHC) form. Agents named in patients' POAHC forms make decisions and carry out patients' healthcare choices when patients become incapacitated. Studies report, however, that POAHC agents often fail to make the decisions that are indicated by patients' previously stated preferences.¹ Some healthcare professionals question the adequacy of specifying only one POAHC agent, although it is common practice to designate only one primary surrogate decision maker.² Our aim is not to address process standards with regard to POAHC agents. We offer a framework that members of ethics committees and other medi-

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cal staff may utilize when they question the decision-making capacity of a POAHC agent.

Given the growing number of persons living into very old age and the increasing numbers of persons suffering from Alzheimer's disease and other cognitive deficits, designated POAHC agents are more likely to have medical conditions that impede their decision-making capacity. Furthermore, healthcare teams may struggle with the impairment of POAHC agents due to the agents' psychological issues, substance abuse, mental illness, conflicts of interest, or replacement of their own personal values and judgments for those of patients.³ A number of ethical and legal issues are involved when an agent's capacity is faulty or questionable. Central issues are whether surrogates' decisions represents the patients' best interests, and not the interests of surrogates, and whether decisions that are made by surrogates are fully informed, reasonable choices.

When issues of incapacitated surrogates arise, the healthcare system has limited options to remove surrogates. Failure to effectively manage these situations can result in poor outcomes for patient care and excessive burdens for the healthcare system. Instead, care teams must look for ways that are systematic, fair, and justifiable to evaluate those whose decision making we question while teams continue to provide optimum patient care. This article details two cases in which the capacity of surrogates was in doubt because they made questionable decisions or went against the stated preferences of the patients. The focus is on the reliability of the surrogates' decisions and on the hospital's responses. The authors offer a framework to identify and clarify issues to facilitate healthcare providers' navigation of potentially complex ethical and legal situations involving incapacitated surrogates. Specifically we aim to identify a threshold for when it is appropriate to pursue legal channels to remove POAHC agents.

CASE PRESENTATIONS

The Case of Mr. M

Mr. M was a 66-year-old man diagnosed with Alzheimer's disease and chronic dysphagia (difficulty swallowing) who exhibited an altered mental status when his brother brought him to the emergency department from a subacute rehabilitation facility (SAR). Evaluation at admission noted that Mr. M suffered from dementia with superimposed mixed-type delirium. He was treated with intravenous (IV) antibiotics for aspiration pneumonia. Mr. M was severely malnourished and his mental status

fluctuated from unresponsive to severely confused, with agitation and nonsensical speech. Mr. M failed a video swallow evaluation and multiple bedside swallow evaluations. Meetings with Mr. M's only involved family member and POAHC agent, his brother, Mr. D, included the palliative care consultation team, a registered nurse (RN), case management, and rehabilitation services, and discussed artificial nutrition and placement of a PEG (percutaneous endoscopic gastrostomy) tube. After these discussions, Mr. D consented to placement of a PEG tube and initiation of artificial nutrition.

Mr. D attended all family meetings with the care team. His beliefs about his brother's condition, however, were inconsistent with the medical diagnosis. That is, Mr. D believed that Mr. M's acute mental status change, overall decline in cognition and functional status, and dysphagia were due to the patient's being out of his home environment. Mr. D insisted that Mr. M would "snap out of it" and return to baseline if he was allowed to return home. Mr. D did not change his point of view, even after attempts to educate him about the patient's medical condition, the nonreversible decline of dementia, the cause of cognitive and functional decline, and the patient's dysphagia.

During the course of family meetings, the care team became concerned that Mr. D's denial of Mr. M's condition was not due to ineffective coping with the potential loss of his brother, but an inability to understand, remember, and process information. Questions about Mr. D's decisional capacity prompted further concerns that the patient would not be properly cared for at home. For example, Mr. D talked about placing the patient, who was quite emaciated, on a hardwood floor to sleep because Mr. M had preferred sleeping on the floor, rather than on a mattress, in his younger, healthier days. Furthermore, Mr. D described wanting to give the patient his favorite foods as a way to help him recover. The team became increasingly concerned about Mr. D's attempts to feed the patient solid food when the patient clearly demonstrated aspiration on all consistencies of a modified diet. Attempts to discuss these concerns with Mr. D led to his insistence that sleeping on the floor and eating his favorite foods was what his brother needed.

Given these concerns and the patient's overall functional impairment, the medical team felt that a skilled nursing facility would be the most appropriate option for Mr. M, but Mr. D felt very strongly that he was responsible for the patient and needed to care for him at home. He stated that several generations of his family had cared for elderly loved

ones with complex needs within the home. Mr. D felt that it was his duty to care for his brother and this was the only way that he would recover.

The in-patient team expressed concerns about discharging Mr. M to the care of his brother when it was clear that the brother did not fully understand Mr. M's condition. The team believed that the patient would be at risk of harm.

Legal counsel and risk management were consulted for advice on discharging the patient to a potentially unsafe environment. Despite Mr. D's unwillingness or inability to understand his brother's medical condition, he was open to learning new skills to care for his brother at home and appeared to have his brother's best interests at heart. Furthermore, the hospital could not require Mr. D to submit to a formal capacity evaluation to determine whether he was capable of making appropriate medical decisions for the patient. Taking action to prevent the patient's discharge to his brother would have obligated the hospital to pursue costly measures for alternative guardianship, further delaying his discharge and putting him at risk for hospital-acquired complications.

The care team was advised that, in the absence of overwhelming evidence that Mr. D could not adequately care for his brother, the organization's obligation was to teach Mr. D the necessary skills to care for his brother, set up home services for him, and document their concerns and the education that had been provided to Mr. D. The patient was eventually discharged to his home with his brother and home care services.

The Case of Mrs. P

This case involved an 82-year-old woman, Mrs. P, who was admitted to the intensive care unit (ICU) with acute chronic congestive heart failure, acute renal failure, and respiratory failure. This admission came three days following her previous discharge from a 36-day hospital stay. Prior to intubation, in a documented conversation with an RN, Mrs. P stated that she would agree to intubation but did not want it to continue to the point of requiring a tracheostomy. No other family was present. Mrs. P had her POAHC activated⁴ when intubation was approaching two weeks and important decisions needed to be made. It was apparent that a tracheostomy was needed to continue treatment, or a decision was needed to follow Mrs. P's wishes and remove her from life support. Further, if Mrs. P's aggressive treatment continued, it would require her transfer to a long-term acute care facility (LTACH) or a nursing home where she could be on a ventilator for long-

term care. Mrs. P's POAHC form was closely looked at by the care team. Her husband was listed as the first agent, but he voluntarily deferred to his son, Tom, the second agent. A third agent was listed, Mrs. S, the patient's sister-in-law. It was later learned that the husband had had a dementia diagnosis for more than two years. Tom was Mrs. P's only child, and lived in California. Tom sent his wife to assist in his father's care and to oversee his mother's hospital stay while he was working in California. Tom was often unavailable for arranged phone conferences with medical staff and seemed to focus on irrelevant issues. Early in his mother's treatment, he demanded that the hospital administration provide documentation that seemed to have little to do with his mother's well-being. For example, he requested the names of the people at her insurance company who had been contacted regarding his mother's care, and *exactly* what information had been shared. The son issued veiled threats of litigation and informed staff that he worked in a law office. When Tom did come to see his mother, he had poor social interaction skills and poor personal hygiene and demonstrated paranoid thinking. He exhibited the signs and symptoms of someone with mental illness and a personality disorder.

The son did not believe that removing his mother from the ventilator was an option and was unwilling to accept that his mother's comments concerning refusal of tracheostomy were true. He believed he was acting in his mother's best interest by pursuing a tracheostomy, yet further concerns about his capacity were raised based on other exhibited behaviors. He consented to a tracheostomy but denied consent for a PEG tube for feeding without giving a reason. Members of the family expressed inconsistent statements about what the patient would have wanted. An ethics consult was requested to assist with decision making. The son reported that his mother would want "every chance at life" and his wife reported, "She told me she would never want to live in a [nursing] home." Over the next several weeks, Mrs. P continued to be confused, semi-sedated, and restrained, and made little progress on weaning from the vent. During multiple conversations between Tom and the medical staff, he was unable to maintain the "track" of conversation and would become hostile, focus on small unrelated details, and make unreasonable demands (such as knowing the name of all persons who might come in contact with his mother in the next 24 hours, and their role in her care). He demanded to "only speak to hospital administrators" for two weeks, even when the staff explained that the ICU physicians

had more direct and more pertinent information. He visited with his mother twice, for a few days each visit, but would not address her caregivers and spent his time on his phone or laptop. He appeared to most of the staff to be paranoid and hostile.

The ethics committee was notified, three weeks after its initial consult, that the sister-in-law of the patient, Mrs. S, the third agent listed on the POAHC form, and Mrs. S's daughter, the patient's niece, had come to visit from several hours away. The patient's niece was an RN. Both women reported that shortly after the death of Mrs. P's brother, Mrs. P clearly stated that she would not want to be maintained on long-term life support such as a ventilator. Ms S was very upset that Tom was not following the known and expressed wishes of Mrs. P or the wishes that were listed in her POAHC form. Ethics advised Mrs. S and her daughter that they could independently pursue legal action to become the patient's guardian or to remove the current acting POAHC agent via court order, if they believed that the son's actions were not in keeping with the stated wishes of the patient.

Seven weeks into her hospitalization, Mrs. P was not alert and remained restrained on the ventilator, not showing much improvement other than occasionally opening her eyes and crying. After two months, Mrs. P became more alert, but was still confused. She was able to progress to a speaking trach during the day, but required a ventilator at night. During this time, multiple attempts were made to reach Tom for permission to transfer his mother to a LTACH to facilitate greater rehabilitation and final weaning from the ventilator. Tom did not answer or return phone calls. His wife stated that he was "ignoring" her as well. Legal counsel was contacted for an opinion regarding how long to wait for the son's response before the staff could justifiably go to the third POAHC agent for consent. After 72 hours, the son had not replied, and the patient was transferred to LTACH using the consent of the patient's third POAHC agent.

Mrs. P was hospitalized in the ICU for four to six weeks longer than her medical condition warranted. Her extended hospitalization was due to the inability of hospital staff to work in an effective manner with her POAHC agent. Although the team was unable to have the agent's capacity tested, the staff suspected that he suffered from some form of mental illness. This suspicion was also supported by his aunt, the third POAHC agent. In this case, the team would have pursued emergency guardianship had we not been able to utilize the third listed POAHC agent.

COST TO THE HEALTHCARE SYSTEM

Cases such as these present financial risk to an organization, overrun costs for treatments that are neither medically necessary nor advisable, and impede the effective delivery of patient care. Healthcare providers' competence in navigating issues of incapacitated surrogates can potentially minimize costs to an institution. When a patient has a POAHC agent who makes inappropriate decisions regarding the patient's care, oftentimes the hospital staff is unable to expedite a safe discharge plan, and the patient's length of stay (LOS) increases, resulting in complications and hospital-acquired conditions (HACs) for the debilitated patient.⁵ HACs and complications to patients' medical conditions can significantly and unnecessarily increase the cost of medical treatment.⁶ Additionally, financial costs may be significant in pursuit of legal action and guardianship for patients when surrogates' decisions pose a risk of harm to the patients. Legal action, however, is not only costly but takes time, putting patients at risk of HACs and increasing the likelihood that they will require otherwise unnecessary treatment.

If at all possible, an institution would be better served by working with the resources at hand to reach a reasonable solution in the plan of care for such patients. For example in the case of Mr. M, the healthcare team had no medical or legal authority to determine if the POAHC agent *understood* Mr. M's needs, but the agent was consistently willing to work with the hospital towards his brother's benefit. He was willing to learn and take on a caregiving role for his brother at home, and while his comments and viewpoint were at times troubling, his overall concern for his brother appeared to be intact. Rather than incurring large financial costs to remove the agent, the team utilized an interdisciplinary approach to work with the patient's brother to create a compromise on a plan of care.

Psychological impact can also be a significant cost that is carried by the staff. The moral distress caused by the controversial and complex nature of such situations cannot go unmentioned. It is an added concern for maintaining the resiliency of the staff and high-quality services. Moral distress occurs when a person's actions are in direct conflict with what she or he feels should be done for a patient. Staff's feelings that their actions are not in line with the patient's best interests or wishes can lead to moral distress and burnout. The case of Mrs. P, in which her POAHC agent went against her wishes as stated in her advanced directive and what she had told nursing staff, is an example of the moral dis-

stress that can be experienced by ICU nursing staff. The staff expressed feelings of helplessness, anxiety, and anger in managing the care of Mrs. P and in interacting with her challenging surrogate decision maker. Although it may appear, given the patient's statements prior to intubation, that the hospital had no reason to interact with Mrs. P's son as an agent when he appeared to be going against the patient's wishes, that is only correct in theory. In actual hospital practice, staff are often forced to attempt to work with family members who dispute the staff's record of the patient's expressed wishes, deny a patient's prior expressed desires, or claim absolute decision-making authority for the patient, given the POAHC endorsement. The staff, in the case of Mr. M, expressed feelings of moral distress due to a plan of care that might have caused great harm to him.

While the long-term consequences to staff in either case aren't yet known, it can be reasoned that such distress had a negative impact on the quality of patient care. Qualitative research by Gutierrez found that end-of-life care decisions and issues of futility were the biggest sources of moral distress for nurses in a critical care environment.⁷ Gutierrez reported that the psychological effects of moral distress on nurses included feelings of sadness, anger, frustration, guilt, fear, and disgust. Nurses also reported physical symptoms from moral distress such as nausea, vomiting, and insomnia, which in turn could lead to calling in sick and lost work days. Many staff reported the social impact that moral distress had on their family life, expressed as withdrawal from family members or friends. Professional consequences included a reluctance to come to work, a desire to avoid patients and avoid providing primary care, and questioning of their ability to remain in their job. Similarly, Elpern and colleagues reported that moral distress had a direct impact on staff's job satisfaction, psychological and physical well-being, self-image, and spirituality.⁸ These effects, in turn, resulted in a greater incidence of nurse turnover. Without a standard framework for working through complicated situations caused by incapacitated surrogates, healthcare teams are likely to waste valuable time, energy, and resources grappling with such issues.

THE LEGAL ISSUES

When the decision-making capacity of a POAHC agent is in question, legal options for the healthcare system are limited. Statutory safeguards are provided to protect patients with substitution or removal of agents, but virtually all states in the United States

lack a mechanism to specifically address an agent who exhibits questionable decision-making capacity. In the state in which these patients presented, the circumstances of an agent with questionable decision-making capacity are not specifically addressed in the statutory chapter that addresses POAHC.⁹ Even the federal U.S. Uniform Health-Care Decision Act does not include a provision to evaluate surrogates for their lack of decision-making capacity.¹⁰

Patients can elect to designate an alternate agent in their POAHC. If a POAHC provides for an alternate in the event that the primary agent is unable or unwilling, a healthcare provider can turn to the secondary agent as the legal decision maker.¹¹ But this substitution requires that the first agent to *voluntarily* express an inability or unwillingness to serve. Secondary agents also become available when reasonable attempts by healthcare providers to contact the primary agent are unsuccessful. Yet it is often difficult to obtain a voluntary expression of inability or unwillingness to serve from primary agents because they may lack the recognition that they are unable to properly continue to serve as an agent. Without such self-recognition, which may be caused by a variety of reasons, most primary agents do not voluntarily resign. In instances when agents voluntarily resign, documentation is easily performed. But when agents must be involuntary removed, that process can delay necessary decision making, compromise patient care, and increase the length of stay as well as healthcare costs. This is demonstrated in the case of Mrs. P, in which her hospital stay was four to six weeks longer than her condition indicated.

Another statutory safeguard allows patients to revoke their POAHC and invalidate it at any time. This is achieved through several methods.¹² Each requires action by patients and a willingness to remove an agent. None of the presently available safeguards protect patients from an incapacitated surrogate. An alternate safeguard, provided by statute, requires court involvement. This safeguard allows any interested party to petition the court to review whether healthcare agents are performing their duties in accordance with the terms of the POAHC.¹³ In the case of Mrs. P, the third agent was informed of the option to petition the court to remove the first agent, but declined to do so. The third agent stated concerns about the potential costs and length of the process in petitioning the court.

Petitioning the court is a safeguard provided under state statute, but statutes do not allow a healthcare provider to compel POAHC agents to accept an evaluation of their decision-making capacity. This

inability presents a difficulty in presenting the court with evidence that a POAHC agent is unfit or unable to serve as a surrogate decision maker. If a healthcare provider is able to provide direct testimony of a formal evaluation of a POAHC agent's lack of decision-making capacity, the court would be well grounded in the removal of the agent. But a healthcare provider has no authority to subject a POAHC agent to formal evaluation.

An interested party must demonstrate to the court that the POAHC agent is failing to perform his or her duties in accordance with the POAHC instrument, or, alternatively, that the decisions made by the POAHC agent are not in the best interests of the patient. It is a high burden for a healthcare provider to demonstrate to a court that an agent that the patient chose as a surrogate should be removed. Courts are averse to negating patients' decisions regarding their choice of surrogate, and courts are often unwilling to do so unless presented with overwhelming evidence that agents have not acted in patients' best interests. In addition, by the time the matter is presented to a court, decisions concerning the patients often have since long passed and have become moot. In the case of Mr. M, the surrogate had not yet had an opportunity to demonstrate his inability to care for Mr. M properly. The staff's concern was that, when given the opportunity, the agent would not care for the patient properly. There was not yet adequate evidence that the POAHC agent should be removed.¹⁴

THE ETHICAL ISSUES

When valid POAHC forms exist, there is an expectation that the surrogates will follow the explicit directions given by the patients, if any were listed or verbalized, and that the surrogates will have knowledge of the patients' values that can direct care when no explicit directions were given. This way of making decisions is called *substituted judgment*, and it is generally considered the ideal when making decisions for others. The next best approach is to utilize knowledge of the patients' values to determine what is in their best interests, called the *best interest standard*. A third approach used to make decisions for others is called the *reasonable person standard*, and, as the name implies, it relies upon a determination of what reasonable persons would want in similar situations when the particular values or goals of the person are not known. Each of these standards uses the evidence available to make choices for patients when they are unable to express their judgments for themselves. However, none of

these methods directly addresses how staff should respond when there are genuine questions as to the decision-making ability of the POAHC agents to *carry out their duties* under the POAHC forms.

There are very few ways to challenge the decision-making capacities of surrogates. The options seem to be reduced to simple persuasion or costly, slow, legal action. When the capacities of POAHC agents to make appropriate decisions is in question, hospitals may do well to use a two-pronged method to evaluate their capacity, developed by Rhodes and Holzman, the "Not Unreasonable Standard for Assessment of Surrogates and Surrogate Decisions."¹⁵ The not unreasonable standard looks closely at the reasons given for decisions and the outcomes that are expected from those decisions. It also unapologetically requires that a higher bar be used to judge these reasons when surrogates are making decisions for patients. This method of analyzing decision making, first described in 2004, has received little acknowledgment in the literature, and so has been little examined, tested, or verified in practice—or shared with the ethics community for discussion. We seek to reopen this conversation and demonstrate how this two-pronged framework has been helpful in determining when a hospital system is justified in pursuing legal action to remove a POAHC agent.

Generally it is the physician directing a case who first evaluates that a patient has questionable ability or clearly is lacking the ability to make independent healthcare decisions. Society has entrusted physicians to make these decisions and also at times to override a patient's refusal of treatment, if the physician believes the patient is lacking in capacity and the need for treatment is emergent and lifesaving. If the treatment is not emergent or lifesaving, then a psychiatric consult is routinely requested to evaluate a patient's capacity, and if capacity is determined to be lacking, the patient's POAHC form is activated. Once a POAHC form is activated, the POAHC agent has the legal authority that the patient would have had to consent to or deny treatment, transfer, or procedures. However, when the POAHC agent's capacity is questionable or the agent is clearly unable to make informed decisions, physicians and the healthcare system have no power (other than attempts to persuade the agent to voluntarily step down) to mandate a similar evaluation of capacity. Hospital ethics committees are often consulted in an attempt to work with an agent who demonstrates questionable capacity, but committee members are also limited to using their persuasive powers or directing others (if others exist) to begin a legal battle to change to an alternative POAHC agent

or to recommend obtaining guardianship to allow a competent decision maker to prevail. Only in situations when clear danger or maleficence is apparent from the decisions of a POAHC agent do hospital systems resort to legal channels. As seen in our two cases, such clear-cut maleficence is rarely apparent, even when there is ample concern about a POAHC agent's decision making. We believe that the not unreasonable standard is helpful as a marker for the threshold of when to advance to court. The not unreasonable standard utilizes a two-pronged approach: the first prong looks at the *reasons* given for a decision; the second prong looks at what the *likely outcome* a decision may have on the patient. Both prongs help in deciding when a poor decision by a POAHC agent might meet the threshold that marks when to seek court intervention.

When physicians doubt the decision-making ability of a patient, it is either because the patient cannot make decisions due to severe mental or medical conditions (such as being psychotic, on a ventilator, comatose, or demented) or, although the patient is able to state a decision, the patient is unable to meet the requirements for informed consent in making the decision. It has long been accepted that informed consent requires the following components:

1. The ability to receive information.
2. The ability to understand information, including risks and benefits.
3. The ability to evaluate information using the patient's own values.
4. The ability to make a decision that is in the patient's best interests and to give *reasons* that others can understand regarding the decision.

It is the fourth component, the requirement for reasons that others can understand, that is often most

difficult to evaluate in a patient. The requirement that a patient give reasons does not say we must *agree* with the patient's reasons; the requirement is merely that we can understand those reasons in light of that specific patient's values. When a surrogate decision maker is involved, it is often difficult to evaluate the third component as well; that is, evaluating a situation using the patient's values may not be possible when we may have no knowledge of the patient's values nor whether the surrogate is aware of the patient's values or is utilizing them in making decisions for the patient. It is very difficult, if not impossible, to determine what is in another's "best interests" if we have no knowledge of that person's values. Yet we may be able to evaluate what would be "reasonable" or at least "not unreasonable," using an approach described in the next section.¹⁶ This is the first prong of the two prongs used in the not unreasonable standard to evaluate a surrogate's decision making.

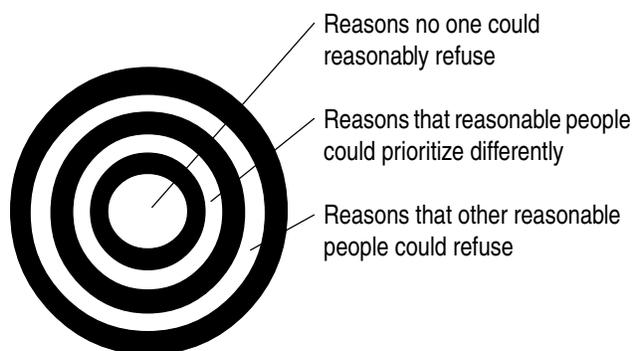
THE FIRST PRONG: THERE ARE REASONABLE REASONS

A broad evaluation of the kinds of reasons used by surrogates is consistent with the levels of reasoning that have long been promoted by James Drane.¹⁷ Drane used three levels, based on how dangerous a refusal of treatment might be to a patient. In developing the not unreasonable standard to evaluate reasons, Rhodes and Holzman also used the work of T.M. Scanlon.¹⁸ Figure 1 depicts a model of the three levels. At the center or core level, there are reasons that everyone would accept (or could not reasonably reject). Such examples might be cleaning out a wound and stitching it up to stop severe bleeding following an accident, or accepting surgery for a ruptured appendix to preserve life. In the same way, refusing stitches to repair a lacerated artery or refusing antibiotics to treat a severe infection would call reasonable persons to question a person's ability to accurately make decisions that are in her or his own best interests.

In the second or middle level are those treatments that may be assessed differently based on individuals' values or risk aversion that lead to refusing a treatment. This could include treatment like chemotherapy when the costs or burdens associated are high and the outcome is uncertain. Reasonable people could understandably prioritize differently when looking at the benefits and burdens of treatment.

The outside rings represent the kinds of reasons that seem very idiosyncratic, but the reasons are

FIGURE 1. Kinds of reasons.



accompanied by logical explanation, and others will be able understand the values that support the reasons. These may include personal commitments, values, or religious views. An example of such a reason that is held by many would be Jehovah's Witnesses who refuse blood transfusion, even when refusal will lead to certain death. Or a reason may be one that is strongly held by only one person; for example, a person who, as a child, lost a parent following surgery and has stated over the course of a lifetime, to all who will listen, that she or he would rather die than go under the knife. A strong value may inform a patient's decision to refuse a treatment or procedure; if that value can be reasonably understood, it is not necessary to agree with it. One patient's strong value may be rejected by other reasonable people, perhaps easily; for example, those who are not Jehovah's Witnesses probably would not refuse blood in a life-threatening situation.

How would the not unreasonable standard work in practice? In the case of Mr. M, his brother, Mr. D, would seem to fail as a surrogate using the best interest standard, because Mr. D did not meet all the requirements of informed consent, namely:

1. The ability to receive information: Mr. D would pass this requirement, as he was involved and concerned.
2. The ability to understand information, including risks and benefits: Mr. D appears to fail this requirement, in that he does not accept that allowing Mr. M to eat a cheeseburger after failing a swallow study could cause aspiration or choking. This lack of understanding is of concern because it could easily endanger the patient.
3. The ability to evaluate information using the patient's own values: Mr. D and Mr. M probably share similar values, as they have lived together for years.

4. The ability to make a decision that is in the patient's best interests and to give reasons that others can understand regarding the decision: Mr. D's failure of the second step of this list may indicate that he cannot pass this requirement.

Utilizing the not unreasonable standard, Mr. D's reasons—"he will do better at home" and "he likes to sleep on the floor," coupled with the staff's belief that Mr. D does know his brother's values—can be evaluated differently than they would be using the best interest standard. Using the not unreasonable standard, Mr. D's reasons are ones that *reasonable people could understand, even if they prioritized differently*. Thus, Mr. D would pass the first prong of the not unreasonable standard.

THE SECOND PRONG: THE LIKELY OUTCOME OF A SURROGATE'S DECISION

The not unreasonable standard does not allow stopping evaluation of a surrogate at the point of understanding the surrogate's reasoning. The second prong requires evaluating how the treatment decisions, based on the surrogate's reasons, will likely affect the *outcomes* for the patient. Outcomes may be seen broadly as fitting into one of three boxes, as depicted in figure 2.

Beneficial outcomes go in Box 1: outcomes that are expected to be good with treatment, and, when treatment is refused, there is an expectation of significant harm. Usually, no reasonable person would refuse the treatment, but an autonomous patient has the right to do so. An example is accepting a blood transfusion for a hemorrhaging injury; a Jehovah's Witness patient may knowingly accept death rather than accept a simple medical procedure, based upon his or her personal values.

FIGURE 2. Outcomes of the second prong of the not unreasonable standard.



- Box 1: Treatment is beneficial
- Required
 - Unreasonable to refuse



- Box 2: Treatment is optional
- More than one reasonable choice
 - Not unreasonable to refuse



- Box 3: Treatment has no significant benefit
- Palliation is preferable

In the middle box, Box 2, the treatments offered and their benefits are less certain, or there are significant burdens attached to the “hoped for” benefits, such as a new line chemotherapy for a lung cancer with metastasis that has not responded to two previous treatments. A surrogate’s choices in these situations may not be characterized as completely unreasonable or irrational because the outcomes are uncertain or highly variable. If we don’t know that the surrogate’s choice will produce a poor outcome, pursuing the court removal of a POAHC agent or pursuing guardianship cannot be justified.

The last box on the right, Box 3, is for outcomes that we expect to be poor regardless of treatment, for example when a patient has a diagnosis of brain death or an invasive, nonresectable tumor that is resistant to chemotherapy. In these cases, treatment may merely prolong dying, and palliative or hospice care would usually be encouraged by a physician. In these cases, even if a surrogate appears to be making a poor decision, it will not affect the outcome *significantly enough* to justify a lengthy and expensive court intervention.

The not unreasonable standard requires a higher standard when a surrogate is making decisions for another person. This is appropriate, given the vulnerability of incapacitated patients and the importance of treatment decisions. A surrogate’s choices can harm the patient, and this is the threshold for legal intervention.

One distinction to be made between deciding for oneself and deciding for an incapacitated other is the difference in reasons. In figure 2, Box 1 collects required, beneficial treatments that would typically be seen as unreasonable to refuse. At the far right of figure 2, Box 3 is for treatments that offer no significant benefit. A decision to refuse a beneficial treatment, at one extreme, and to insist on treatment with no significant benefit, at the other extreme, would be paradigmatically unreasonable, absent some very personal and unusual considerations. Such decisions can only be justified by reasons from the outer domain of the idiosyncratic, or group reasons that other reasonable people can refuse to endorse. Although personal reasons are sufficient to guide one’s own life, because physicians have a fiduciary responsibility to their patients, physicians cannot accept a surrogate’s personal reasons for refusing significantly beneficial treatment when that choice would violate universal values. Unless physicians have strong evidence for believing that the surrogate’s unusual reasons were shared by the patient, they must refuse to honor a surrogate’s refusal of treatment in these situations.¹⁹

The first prong of the not unreasonable standard is a tool to help those working on ethics committees and in healthcare to begin deeper discussions with POAHC agents regarding the agents’ core reasoning as they make decisions for patients. The second prong of the standard helps members of ethics committees and healthcare providers to directly tie agents’ decisions to the outcomes for patients. If POAHC agents are unable to give a reasonable justification when they make a decision to refuse a treatment with a likely good outcome, a case can be made to pursue legal channels. The not unreasonable standard is a solid and reasoned process to evaluate surrogates when the hospital questions their capacity to make decisions for their patients. When POAHC agents are not able to meet the not unreasonable standard, it may be necessary to pursue legal channels to protect vulnerable patients.

It is not easy to remove patient-appointed POAHC agents, and it is unlikely to become easier in the future. Thus it is important to evaluate those agents whose decision making we question, to determine which cases should be pushed to legal limits. But it is important to balance concerns for patients’ well-being or beneficence against the harms of overriding their prior autonomy in selecting a POAHC agent. All hospitals suffer limited resources, and we do not want to overburden the legal system, but we must protect the best interests of patients who may not be served by their surrogates. Although the not unreasonable standard requires us to prod surrogates’ reasoning more deeply, it may sometimes allow us to prevent costly court battles when it appears that surrogates may not be capable. The efforts required to question surrogates’ reasonings and have them made explicit are justified by concerns for the well-being of patients.

Going back to the case of Mr. M: while his surrogate’s judgments may have seemed questionable, the patient’s outcome may not have been dramatically different whether he returned home or went to a skilled nursing center. This, and the likelihood that the brothers shared numerous values because they had lived together for many years, makes it easier to accept the decisions of the surrogate, even though they were not what had been recommended by the medical professionals. Concepts of “the good” are individually constructed and include both health and nonhealth issues, such as wanting to support Mr. M’s values related to being at home and eating his favorite foods. There was a possibility that Mr. M’s brother was benevolently maleficent, by engaging in a harmful action while having a disposition to do good for patient. But he did not refuse a feed-

ing tube for the patient, and did agree to learn what was needed to allow him to take his brother home, showing that he was not unreasonable and was willing to compromise. Although the surrogate's plan was perhaps not what the hospital staff thought was optimal, it was a plan that was ultimately consistent with the patient's values, and not completely unreasonable.

In the case of Mrs. P, it was clear that her son was not using substituted judgement because he did not follow what was written in Mrs. P's advance directive regarding her wishes for not being maintained on life support. The son also denied having had any specific conversations with his mother on the topic of being on a ventilator, and refused to believe a documented conversation in which Mrs. P stated that she would not want a tracheostomy. Using the not unreasonable standard, here is an examination of the capacity of the son/agent to discern the patient's best interest:

1. The ability to receive information: The patient's son was not always willing to participate in information sharing and would not accept recommendations or prognoses as valid.
2. The ability to understand information, including risks and benefits: It was often difficult or impossible to evaluate the son's understanding due to his not being readily available or willing to communicate, and his tendency to force conversation to irrelevant subjects such as who the insurance reviewers were and how to contact them.
3. The ability to evaluate information using the patient's own values: The son failed to acknowledge the patient's values as recorded in her advance directive. The son held that the patient "would want everything done."
4. The ability to make a decision that is in the patient's best interests and to give *reasons* that others can understand regarding the decision: Although it was unexpected, Mrs. P did end up improving, at least upon hospital discharge, to the point of sitting in a chair, being alert, and being able to communicate (even if the communication was confused). Mrs. P still required a ventilator at night, and it is possible to question whether her values and interests supported a greater quality of life versus the quantity of days in her life, as her son maintained.

Using the not unreasonable standard to evaluate the capacity of the son's decision making as a surrogate, it is possible to determine that his decision to proceed with tracheostomy and ongoing ventilator sup-

port was a decision that reasonable people could prioritize differently, and its outcome could be variable or uncertain.²⁰ Thus, progressing in ongoing medical treatment in accordance with the decision of the POAHC agent (even though this was not what Mrs. P had stated as her wishes) can be seen as an acceptable option and in keeping with supporting life. But the son's decision to refuse to return calls requesting authorization to transfer the patient to the next level of rehabilitation care was a decision that most persons would say no one would reasonably refuse (that is, moving to the next step in healing). A decision to move the patient to a lower care level had a high likelihood of a good outcome and benefits to the patient, as it would allow weaning her off mechanical ventilation and increasing her strength and independence. Not moving the patient from the ICU posed risks of significant harms such as nosocomial infections and setbacks. At that point, removing the son as surrogate and approaching an alternative agent named in the POAHC was justified. Using the not unreasonable standard, if the patient had not named alternative agents in the POAHC, the threshold to involve legal channels would have been reached.

In this case, the staff was left greatly dissatisfied with the outcome. Using the not unreasonable standard addresses the *capacity* of a surrogate and not the pure *content* of a surrogate's decision making (that is, in this case the son did not follow the patient's wishes). Still, use of the not unreasonable standard in this case would lead to removing the surrogate via legal channels, due to the real harms to the patient posed by the surrogate's treatment decisions. Further work and greater moral courage will be needed to access legal channels when competent surrogates choose to ignore patient's wishes documented in advance directives.

CONCLUSION

As increasing numbers of people suffer from debilitating illness, substance abuse, and cognitive deficit due to dementia-type illness or mental health disorders, healthcare systems may be called upon to navigate the complexities of patient care with an increasing likelihood of potentially incapacitated POAHC surrogate decision makers. The current inability to address incapacitated agents in a timely and efficient manner can result in significant unnecessary (and often uncompensated) costs to the institution and to patient care. The not unreasonable standard offers a framework from which to navigate these complex cases. Technological advances

increase the complexity of evaluating the benefits and burdens of treatment; they also make decision making about potential treatments and procedures more complex. Holding a POAHC agent to a higher standard of decision-making capacity is acceptable, given concerns for vulnerable patients. Healthcare institutions can utilize the two-pronged method in the not unreasonable standard to evaluate the decision making of POAHC agents to assist in determining when to pursue time-consuming and expensive legal channels to ensure that patients receive proper, effective, timely, and high-quality care.

PRIVACY

Although the cases described in this article are real, the characteristics and names of all of those described have been changed to assure anonymity and continued confidentiality for those involved.

NOTES

1. D.I. Shalowitz, E. Garrett-Mayer, and D. Wendler, "The accuracy of surrogate decision makers: A systematic review," *Archives of Internal Medicine* 166 (2006): 493-97.

2. K. Baerøe, "Patient Autonomy, Assessment of Competence and Surrogate Decision-Making: A Call For Reasonableness in Deciding For Others," *Bioethics* 24, no. 2 (2010): 87-95. doi:10.1111/j.1467-8519.2008.00672.x.

3. K.A. Bramstedt, "Questioning the Decision-Making Capacity of Surrogates," *Internal Medicine Journal* 33, no. 5-6 (2003): 257-9.

4. In the state of Wisconsin, unless stated otherwise in the POAHC instrument, an advance directive that names an individual as power of attorney must be activated by either two physicians or a physician and a psychologist who have a finding of incapacity regarding a patient, in order for the agent to have authority to be a legal decision maker.

5. K.M. Gutierrez, "Critical Care Nurses' Perceptions of and Responses to Moral Distress," *Dimensions of Critical Care Nursing* 24, no. 5 (2005): 229-41.

6. E.H. Elpern, B. Covert, and R. Kleinpell, "Moral Distress of Staff Nurses in a Medical Intensive Care Unit," *American Journal of Critical Care* 14, no. 6 (November 2005): 523-30.

7. Gutierrez, "Critical Care Nurses' Perceptions," see note 5 above.

8. Elpern, Covert, and Kleinpell, "Moral Distress of Staff Nurses," see note 6 above.

9. Both patients in the cases presented resided in the state of Wisconsin. As a result, the legal issues related to their POAHC instruments are discussed in the context of Chapter 155, which is the governing chapter for POAHC instruments in the state of Wisconsin.

10. See Uniform Health Care Decisions Act §§ 1-19, 9 U.L.A. 93 (1993).

11. Wis. Stat. 155.05 (5).

12. Wis. Stat. 155.40 provides the following methods to revoke a power of attorney. The patient (1) cancels, defaces, obliterated, burns, tears, or otherwise destroys the power of attorney for healthcare instrument or directs another in the presence of the patient to so destroy the power of attorney for healthcare instrument; (2) executes a statement, in writing, that is signed and dated by the patient, expressing the patient's intent to revoke the power of attorney for healthcare; (3) verbally expresses the patient's intent to revoke the power of attorney for healthcare, in the presence of two witnesses; (4) executes a subsequent power of attorney for healthcare instrument.

Many states allow for revocation of a document and removal of an agent, irrespective of whether the document is activated.

13. Wis. Stat. 155.30 (4) (a).

14. Alternatively, in those circumstances when it would not be prudent to proceed with court involvement, but a patient's physician still does not agree with the agent's decisions or ability to serve as a proper agent, in order to preserve the immunities under the statute, the physician must make a good faith attempt to transfer the patient to another physician who will comply with the decisions of the agent. The likelihood of another physician accepting would be low, but, with sufficient documentation of the good faith attempts, the action preserves the immunity provided under the statute.

15. R. Rhodes and I. Holzman, "The Not Unreasonable Standard for Assessment of Surrogates and Surrogate Decisions," *Theoretical Medicine and Bioethics* 25, no. 4 (2004): 367-86.

16. *Ibid.*, 132.

17. J.F. Drane, "Competency to Give an Informed Consent," *Journal of the American Medical Association* 252, no. 7 (1984): 925. doi:10.1001/jama.1984.03350070043021.

18. T.M. Scanlon, *What We Owe Each Other* (Cambridge, Mass.: Belknap, 1998).

19. Rhodes and Holzman, "The Not Unreasonable Standard for Assessment of Surrogates," see note 15 above.

20. It is important to note that we do not address in this article the important, yet separate, issue that Mrs. P's son did not follow her advance directive on issues regarding ventilator care. He was adamant that he was the legal agent authorized to make all decisions. This is a situation that is all too common in many hospitals.

Alida Naudé and Juan Bornman, "Measuring Instrument for Ethical Sensitivity in the Therapeutic Sciences," *The Journal of Clinical Ethics* 28, no. 4 (Winter 2017): 290-302.

Measuring Instrument for Ethical Sensitivity in the Therapeutic Sciences

Alida Naudé and Juan Bornman

ABSTRACT

There are currently no instruments available to measure ethical sensitivity in the therapeutic sciences. This study therefore aimed to develop and implement a measure of ethical sensitivity that would be applicable to four therapeutic professions, namely audiology, occupational therapy, physiotherapy, and speech-language pathology. The study followed a two-phase, sequential exploratory mixed-methods design. Phase One, the qualitative development phase, employed six stages and focused on developing an instrument based on a systematic review: an analysis of professional ethical codes, focus group discussions, in-depth interviews, a review of public complaints websites, and an expert panel review. The development phase culminated in the Measuring Instrument for Ethical Sensitivity in the Therapeutic Sciences (MIEST), a pen-and-paper measure for studying ethical sensitivity in the therapeutic sciences.

Phase Two, the quantitative stage, focused on implementing the MIEST in two different stages. A total of 100 participants completed the instrument. MIEST scores were found to be comparable for all four professions, which confirmed the multidisciplinary usability of the instrument. Participants tended to base decisions

on the ethical principle of beneficence. The MIEST is effective to assess and describe the ethical sensitivity of professionals in the four specified therapeutic sciences. The constructed vignettes also make the MIEST appropriate for use in problem-based learning programs.

INTRODUCTION

Ethical decision making has been one of the main foci in the field of healthcare ethics in the past decade. Concomitantly, there has been a growing call for future ethics studies to be directed at designing methods to measure ethical decision making that include the components of ethical sensitivity, ethical judgement, ethical motivation, and ethical action.¹ Healthcare professionals, including those in the therapeutic sciences, need to know whether they can reliably interpret ethical issues; articulate the norms, values, laws, and codes that govern professional practice; and be able to implement defensible action plans effectively and efficiently.

Ethical sensitivity is an independent component within the ethical decision-making process. Most frameworks and models of ethical decision making explicitly include ethical sensitivity as the critical first step in the process of ethical decision making.² Unless the ethical aspects of a situation are recognized, it is nearly impossible to address any ethical dilemma, for without initial recognition that something is amiss, no ethical problem can be identified.

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Despite a general consensus in the literature that ethical sensitivity is a critical factor in ethical decision making, and that it can be operationalized because of an established and agreed-upon ethical code of a profession, research studies focused on ethical sensitivity in the therapeutic sciences are glaringly absent. An extensive, systematic literature search of five databases—Cambridge, EbscoHost, JSTOR, Sage, and SpringerLink—found a paucity of research that examines the level of ethical sensitivity in the therapeutic sciences including audiology, occupational therapy, physiotherapy and speech-language pathology.³ The 14 empirical studies on measuring ethical sensitivity encountered in the search included the fields of dentistry, business management, nursing, and science. The first ethical sensitivity measurement appeared in 1984.⁴ The measuring instruments used in these studies ranged from interviews with judging panels to various types of surveys. One of the most likely contributing factors for the lack of research in this field relates to the complexity of measuring ethical sensitivity. Bebeau relates the lack of progress in measuring ethical sensitivity to the fact that the process is relatively expensive—as it requires not only the transcription of semistructured interviews, but also the scoring of these transcriptions by trained raters—due to the lack of easy-to-administer and objective measuring instruments.⁵

In view of the above, objective measuring instruments that can be used in the clinical context are needed in healthcare practice.⁶ There are several advantages to using standardized measures of ethical sensitivity. First, they make it easy for individuals who are not specifically trained in ethics to evaluate the ethical sensitivity of a particular group of professionals; for example, an administrator in the healthcare context could measure the ethical sensitivity of therapists as part of their continuing professional development. Second, the work of several individuals can be compared using the same set of standards; for example, the ethical sensitivity of a group of final-year students in the therapeutic sciences can be measured before graduation to determine whether they meet the required minimum exit criteria that would allow adequate service delivery when they start practicing. Without a formalized measure, the evaluator may grade each individual differently, which could lead to biased results. Third, standardized objective measures also maximize efficiency in grading and thereby help to ensure professional accountability.⁷

Measuring ethical sensitivity may (as part of professional reality) reveal some vulnerability that

should be addressed rather than denied. Healthcare professionals would benefit from the information that can be provided by a standardized measuring instrument to promote competence in the ethical decision-making process, since it allows professionals the opportunity to identify their strengths and shortcomings and to compare themselves to their peers as well as to seasoned and exemplary colleagues.⁸ Researchers recognize that vulnerability is necessary for professional growth and for a more holistic consideration of the complexities of professional life and work. Ethical sensitivity relates to being interested in the transformation of “the ways things are” into more just and healthy relations, structures, and ways of thinking, which can lead to increased levels of professionalism and responsible conduct.

Although the available literature provides valuable input regarding ethical sensitivity, it highlights a number of important issues that justify the development of a measuring instrument for ethical sensitivity specifically for the therapeutic sciences.

First, the available studies conclude that ethical sensitivity is case dependent, which implies that the measuring instrument should consider ethical dilemmas relevant and current to the specific discipline.⁹ Second, research indicates a need for multidisciplinary perspectives on ethical sensitivity because multidisciplinary perspectives would make the instrument useful to a wider population and allow for comparison between different professional disciplines. This could lead to insights into ethical behavior and how they are applied within a group.¹⁰ The development of a measure for ethical sensitivity based on a consolidated definition that incorporates agreement from the different therapeutic science professions (regarding the characteristics, boundaries, and consequences of ethical sensitivity) will facilitate optimal knowledge development related to the care and services provided to clients.¹¹

The purpose of this study is twofold: first, it aims to develop a new instrument to measure ethical sensitivity in the therapeutic sciences; second, it aims to pilot the use of this instrument to measure the ethical sensitivity of final-year students in four different therapeutic disciplines: audiology, occupational therapy, physiotherapy, and speech-language pathology.

METHOD

Study Design

A two-phase, sequential, mixed-methods research design was used. This framework is usually

applied in new areas of inquiry¹² and was therefore considered relevant for the current study. It is also effective when developing components of a pluralistic concept such as ethical sensitivity. Hence it was used to explore participants' views with the intent to use the information to develop an instrument and then implement it with a sample from a representative population. The methodology used for the project is summarized in figure 1. The design for this study was reviewed and approved by the University of Pretoria research ethics committee.

Phase 1: Development

The development of a new Measuring Instrument for Ethical Sensitivity in the Therapeutic Sciences (MIEST) was conducted in five stages. The authors first conducted a systematic review to analyze the published literature (Stage 1a). One specific therapeutic science was selected, namely audiology, as audiologists are particularly vulnerable to the changing requirements of the profession that compel them to balance professional obligations and business principles.¹³ The systematic review allowed for a comparison between research-related ethics in audiology and ethics in physiotherapy, as a systematic review on ethics knowledge in physiotherapy had been done with literature published between 1970 and 2000.¹⁴ The systematic review confirmed the need for research in the area of ethical sensitivity, as well as for knowledge on the specific ethical issues that each profession in the therapeutic sciences routinely encounters.

Stage 1b followed, which aimed to develop a summary of ethical codes from all four therapeutic sciences. Ethical codes reflect the ideals that various professional boards hold as necessary for ethical professional practice. The researchers developed a grid of the ethical principles articulated by the professions of audiology, occupational therapy, physiotherapy, and speech-language pathology. They

attempted to build a measure that would embed ethical principles in depictions of acts of unprofessional behavior. This resulted in the identification of four principles common to all professional codes of conduct, namely autonomy, beneficence, justice, and nonmaleficence.

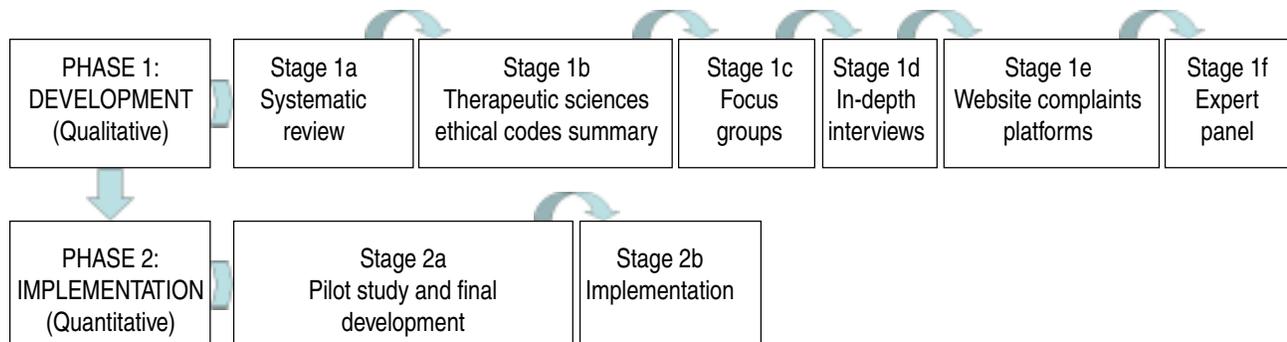
In Stage 1c, five focus group discussions were conducted to determine which ethical dilemmas were viewed as most relevant and likely to result in ethically insensitive behavior in practice. These five separate focus groups consisted of five to eight professionals, with at least one professional from each of the therapeutic sciences. Ethics approval was obtained from the relevant institutions. After being provided with a definition of ethical sensitivity, each focus group discussed the following five aspects:

1. Specific situations in which ethical sensitivity is needed.
2. The ethical challenges currently experienced in their respective professions.
3. Areas or issues that might lead to future ethical problems.
4. The skills that professionals need to deal with these ethical challenges.
5. The kind of vignettes that should be included in a measure for ethical sensitivity.

Each of the five focus group discussions lasted for approximately one hour and all were audio-recorded and transcribed verbatim. The results indicated the importance and relevance of specific ethical principles and skills from the perspective of professionals in the therapeutic sciences.

In addition to the focus group discussions, eight individual in-depth interviews were conducted with two ethics experts in each of the four different therapeutic sciences (Stage 1d). These therapists were not part of any of the five focus groups. However, the same five questions were used as during the focus group sessions. The data added to constructing the

FIGURE 1. Two-phase sequential mixed-method design.



final vignettes by confirming the importance and relevance of specific ethical principles and skills in the therapeutic sciences.

To align the measuring instrument with both the professional and the client dimensions of ethics, Stage 1e aimed to gain insight into the public's perspective of ethical issues in the delivery of therapeutic services. Two online platforms that offer members of the public anonymity were used to identify themes related to clients' complaints. The data obtained represent 165 members of the public.

The collected data (Stage 1a through Stage 1e) were used to construct the first 25 vignettes by following the process of content analysis.¹⁵ A total of 20 vignettes with five ethically neutral ones that served as control vignettes—each vignette targeted one of four ethical principles (autonomy, beneficence, justice, and nonmaleficence) and one of seven ethical skills (controlling social bias, relating to others, taking the perspective of others, effective verbal communication, interpreting ethics in a situation, perceiving and responding to diversity, and understanding emotional expression)—were presented to therapists with expert knowledge of and special interest in the realm of ethics (Stage 1f). The expert panel of eight professionals consisted of two professionals per profession (that is, audiology, speech-language pathology, occupational therapy, and physiotherapy).

During the expert panel review, it became evident that 20 vignettes with five controls were too extensive for a 60-minute measuring instrument. After discussion with the experts, it was estimated that 12 vignettes with three controls would be more reasonable for a 60-minute measuring instrument. To eliminate eight vignettes and two controls, the vignettes in which agreement between the target principle/skill and the experts was less than 75 percent (6 of 8) were excluded from the measuring instrument. An example of two vignettes are shown in table 1: Vignette 5, which was excluded due to

low expert agreement scores (3/8 and 4/8), and Vignette 14, which was included due to high agreement scores (7/8).

In addition to clarity (which was determined by using the expert panel as discussed above), distribution was also considered. All of the vignettes that passed the 75 percent agreement mark were then scrutinized for distribution in terms of ethical principles and ethical sensitivity skills. The four target ethical principles were each presented three times in the 12 vignettes (4 x 3), while each of the seven ethical sensitivity skills were represented twice (7 x 2). Thus, two of the vignettes contained two skills each. Phase 1 resulted in the construction of the MIEST,¹⁶ which consists of 12 vignettes, each stated in a single paragraph. The vignettes are intended to reflect a situation that a therapist might reasonably expect to confront in professional practice, and include at least one ethical principle and one ethical sensitivity skill. The target principles and skills for all vignettes are provided in table 2.

Figure 2 contains an example of a complete vignette, namely Vignette 4.

Development of the Scoring Rules

The final step in constructing the MIEST involved the development of scoring rules. A score sheet was prepared for each of the 12 vignettes. A seven-point Likert scale score sheet (1 = Strongly disagree and 7 = Strongly agree) was used for each of the 11 statements (four related to an ethical principle, and seven related to an ethical sensitivity skill). If the participants correctly identified the target ethical principle, a score of +2 was awarded. If they failed to identify the target principle, they were awarded a score of -2. Negative marking was needed, as identifying an alternative incorrect ethical principle could result in unethical action and would imply the lower ethical sensitivity of the participant. However, the score sheet also included "alternative options," in other words, a nontarget principle that

TABLE 1. Comparison of expert panel opinion regarding principles and skill represented in the vignettes

Vignette	Target principle/skill	AUD1	AUD2	OT1	OT2	PT1	PT2	SLT1	SLT2	Total score
5	Target principle: Justice	x					x		x	3/8
5	Target skill: Controlling social bias			x			x	x	x	4/8
14	Target principle: Autonomy	x	x	x	x		x	x	x	7/8
14	Target skill: Effective communication	x	x	x	x	x	x		x	7/8

Key: AUD = audiologist; OT = occupational therapist; PT = physiotherapist, SLT = speech-language pathologist

could be debated in terms of its relevance, in which case a score of 0 was awarded.

Since the identification of nontarget ethical sensitivity skills in the vignette would not result in an

unethical course of action, negative marking was not implemented as was done with the identification of ethical principles. If the participants correctly identified the target ethical sensitivity skill, they were

TABLE 2. The final 12 vignettes with target ethical principles and skills that make up the MIEST

Vig.	Principles and skills	Reasoning
1	Principle: Justice	The therapist responded in line with society's expectations of what was fair and right in the eye of the law.
	Skills: Perspective taking	The therapist considered possible challenges related to this scenario, as well as implications for the future.
	Interpreting ethics in a situation	The therapist chose an appropriate way of dealing with clients' concerns.
2	Principle: Autonomy	The therapist showed that she respected clients' rights to make their own decisions, as well as the principles of privacy and confidentiality where applicable.
	Skills: Relating to others	The therapist indicated that she was able to competently and skillfully support her clients and show concern, while also understanding what was important to them.
	Emotional expression	The therapist identified and responded appropriately to emotional cues from the client.
3	Principle: Beneficence	The therapist actively brought about positive change, while keeping clients' best interests in mind.
	Skills: Effective communication	The therapist communicated effectively with clients.
	Emotional expression	The therapist identified and responded appropriately to emotional cues from clients.
4	Principle: Nonmaleficence	The therapist acted in a way that actively protected clients from harm.
	Skill: Perspective taking	The therapist indicated that she was able to take the perspective of clients.
5	Principle: Justice	The therapist responded in line with society's expectations of what was fair and right in the eye of the law.
	Skill: Relating to others	The therapist indicated that she was able to competently and skillfully support clients and show concern, while also understanding what was important to them.
6	Principle: Autonomy	The therapist showed that she respected clients' rights to make their own decisions, as well as the principles of privacy and confidentiality where applicable.
	Skill: Effective communication	The therapist communicated effectively with the client.
7	Principle: Beneficence	The therapist actively brought about positive change, while keeping clients' best interests in mind.
	Skill: Emotional expression	The therapist identified and responded appropriately to the emotional cues from clients.
8	Principle: Nonmaleficence	The therapist acted in a way that actively protected clients from harm.
	Skill: Controlling social bias	The therapist recognized her own preconceived judgements and adjusted her actions to be neutral.
9	Principle: Justice	The therapist responded in line with society's expectations of what was fair and right in the eye of the law.
	Skill: Responding to diversity	The therapist took into account the possible cultural differences and perceptions of interpreting a situation when making decisions regarding client assessment and/or management.
10	Principle: Autonomy	The therapist showed that she respected the clients' rights to make their own decisions, as well as the principles of privacy and confidentiality where applicable.
	Skill: Responding to diversity	The therapist took into account the possible cultural differences and perceptions of interpreting a situation when making decisions regarding client assessment and/or management.
11	Principle: Beneficence	The therapist actively brought about positive change while keeping clients' best interests in mind.
	Skill: Controlling social bias	The therapist recognized her own preconceived judgements and adjusted her actions to be neutral.
12	Principle: Nonmaleficence	The therapist acted in a way that actively protected clients from harm.
	Skill: Interpreting ethics in a situation	After considering possible challenges related to this scenario, as well as possible future implications, the therapist chose an appropriate way of dealing with her concerns.

awarded a score of +2. If they identified an alternative possible skill, they were awarded a score of +1. If the skill was not relevant to the vignette, a score of 0 was allocated. The scores were used to determine the participants' level of ethical sensitivity. A

value of 22 reflected the highest possible score (maximum) on the Miest, while a value of -8 reflected the lowest possible score (minimum) on the Miest.

The scoring criteria were developed by determining an acceptable level of performance in con-

FIGURE 2: Vignette 4 of Miest.

Mr. H is a 34-year-old client who makes an appointment for an assessment at a therapy practice. During the case history, he tells the therapist that he has been diagnosed with tuberculosis (TB) but did not go to the hospital for admission. He says that his wife will leave him if she finds out and that he will also lose his job. They recently had a baby and his family is relying on him for financial support. The therapist explains the impact of his diagnosis on others, and that he will have to be admitted to the hospital and this family will have to be notified so that they can also be tested. During the assessment, the therapist ensures adequate ventilation in the room, and both the therapist and Mr. H wear face masks. The therapist uses disinfectant sprays in the consultation rooms as standard practice. The therapist examines the client and refers him to the hospital where he should be admitted. Mr. H tells the therapist that he is going home and that nobody can force him to go to the hospital. The therapist feels sorry for him, but also realizes that it is his decision to make. The therapist ends the session by asking him to contact the practice should his symptoms get worse.

Below you will find 11 statements related to the scenario. Indicate your level of agreement with each sentence on the right by choosing a number ranging from 1-7.

	1	2	3	4	5	6	7
	Strongly disagree	Disagree	Disagree some-what	Neither agree nor disagree	Agree some-what	Agree	Strongly agree
Mr. H							
The therapist recognized her own preconceived judgments and adjusted her actions in a way to be neutral.							
The therapist communicated effectively with the client.							
The therapist acted in a way that actively protected the client from harm.							
The therapist indicated that she is able to take the perspective of her client.							
The therapist indicated that she can competently and skillfully support the client by showing concern while understanding what is important to him.							
The therapist responded in a way that is in line with societal expectation of what is fair and right in the eye of the law.							
The therapist took the possible cultural differences and perceptions of interpreting a situation into account while making decisions regarding client assessment and/or management.							
After considering possible challenges related to this scenario, as well as the implications in terms of the future, the therapist chose an appropriate way of dealing with her concerns.							
The therapist actively brought about positive change with the client's best interest in mind.							
The therapist identified and responded appropriately to the emotional cues from the client.							
The therapist showed that she respected the rights of the client to make his own decisions, respecting the principles of privacy and confidentiality where applicable.							

junction with input from our expert panel. In accordance with the guidelines of the Health Professions Council of South Africa regarding ethics performance, the researcher selected a score of >70 percent as an indicator of established ethical sensitivity skill. Higher education requires a score of >50 percent to pass any assessment, and therefore <50 percent was labelled as unacceptable performance. Since it is recommended in the literature that the distance between points should be equal, performance in the 61 percent to 70 percent range was described as emerging. This level would be acceptable for undergraduate students with limited clinical experience, but with presumably adequate theoretical knowledge. The performance level just below the acceptable performance range was consequently labelled as inadequate. These five performance levels can be used to measure ethical sensitivity, to describe strengths and weaknesses in the professions, and to monitor professional growth.

The five performance levels based on the scoring results of the Miest, as well as the acceptable level of performance, can be grouped as follows:

- Unacceptable (a score of between -8 and 2): This level is unfavorable and, without intervention, serving the community could lead to detrimental outcomes.
- Inadequate (a score of between 3 and 5): Does not yet meet the acceptable standard for insight into the ethical components represented in the 12 vignettes.
- Emerging (a score of between 6 and 11): Meets the acceptable standards for final-year students in the therapeutic sciences. Understanding of the ethical components represented in the 12 vignettes is still developing. Although on the right track, mastery is not thorough.
- Established (a score of between 12 and 17): Demonstrates a sound understanding of many of the ethical components represented in the 12 vignettes and approaches the excellence level.
- Excellent (a score of between 18 and the maximum total of 22): Exceptional insight into the four principles and seven skills represented in the 12 vignettes.

Reliability of Scoring

An independent observer—a dually qualified speech-language pathologist and an audiologist enrolled in postgraduate studies, with 14 years of experience—scored 20 percent of the randomly selected responses obtained from participants who had completed the Miest. These scores from the determined Miest responses were compared with those

scored by the researcher, and agreement was 100 percent.

Phase 2: Implementation

The pilot study was the final step in preparing the Miest for implementation and was used as a small-scale feasibility trial to pretest the measuring instrument in practice. It also served to improve the methodological quality of the procedures and material related to the implementation of the Miest. Eighteen final-year students in the therapeutic sciences were included in the pilot study, after which small changes were made to the Miest, specifically related to the layout and the length.

Once the measuring instrument was refined, the final Miest was administered to 100 final-year audiology, occupational therapy, physiotherapy, and speech-language pathology students at one South African university that offers all four of these professional degree programs. Participants were not limited with regard to the time allowed to complete the Miest, but, as was expected, all of them completed the Miest within the allocated 60 minutes.

Participants

The 100 participants who participated in the main study included 20 audiologists, 30 occupational therapists, 27 physiotherapists, and 23 speech-language pathologists. In terms of gender of representation, 90 percent of the participants were female—there were only one male in the audiology group and nine males in the physiotherapy group. The average age of the participants across the four groups was 22 years (range: 21 to 27 years); 70 percent of the participants reflected that, in their opinion, their ethics training was adequate to equip them for the delivery of professional services. Only 4 percent of the participants stated that they had received additional training over and above the standard graduate training program.

Reliability of Participants' Responses

The likelihood that participants had randomly selected responses was determined with the use of the Excel NORMSDIST function. This standard normal cumulative distribution function was used to test the following hypotheses:

- π_0 Population proportion appropriate of ethical principle from the vignettes = 0.5
- π_0 Population proportion appropriate of ethical principle from the vignettes = >0.5.

The results (0.98 > 0.5) indicated that the likelihood of participant's guessing the correct answers

was low, which increased the reliability of the responses.

RESULTS

The key results of this study are presented in terms of the total scores obtained by participants of the four different therapeutic disciplines. Results are shown for the group as a whole, as well as per therapeutic discipline. The scores were also categorized according to performance levels and ranged from unacceptable to excellent. Specific attention was awarded to results that yielded statistical differences between these four therapeutic disciplines.

PERFORMANCE: OVERALL SCORES AND SCORES PER THERAPEUTIC DISCIPLINE

The total scores obtained by participants in the four different therapeutic disciplines were calculated for each vignette by awarding a value to each answer provided on the measuring instrument. The overall performance of the participants is summarized in table 3. Each vignette was numbered and the target ethical principle and ethical sensitivity skill(s) were specified. The total score was also categorized according to the five performance levels, ranging from unacceptable to excellent. In the case of a significant difference between total scores of the four therapeutic disciplines, the analysis of variance (ANOVA) was used to test H_0 at a 5 percent level of significance (H is the hypothesis; H_0 is the null hypothesis; H_1 is the alternative hypothesis):

H_0 The population mean score is the same across the four therapeutic disciplines.

H_1 The population mean score differs across the four therapeutic disciplines.

Overall, the four therapeutic disciplines performed similarly in relation to the Miest with statistically significant differences in only five of the vignettes (1, 4, 6, 9, and 11) on the 5 percent level of confidence ($p < 0.05$). Total scores on the Miest were lowest on Vignette 4 and highest on Vignette 2 for all four professions. The overall scores on the Miest in relation to all 12 vignettes showed comparable total average scores for audiology participants (7.8), occupational therapy participants (8.9), physiotherapy participants (7.1), and speech-language therapy participants (8.5), which indicated emerging levels of ethical sensitivity for all four therapeutic disciplines.

In the five vignettes for which the H_0 was rejected, multiple pairwise comparisons were con-

ducted to determine which therapeutic disciplines' mean scores were statistically significant. *Post hoc* analyses using the Scheffé *post hoc* criterion for significance ($\alpha = 0.05$) were used for this purpose. The results are presented in the form of a box plot in table 4.

Occupational therapy participants performed significantly better than physiotherapy participants in two of the vignettes (1 and 4). Both of these vignettes incorporate the target ethical skill of perspective taking. Speech-language pathology participants also performed significantly better than physiotherapy participants in three vignettes (6, 9, and 11). Vignette 6 targets the ethical skill of effective communication, while Vignettes 9 and 11 target diversity and social bias. Each of the four ethical principles appeared at least once in terms of the five vignettes, which revealed statistically significant data.

DISCUSSION

The primary objective of this study was to develop the Measuring Instrument for Ethical Sensitivity in the Therapeutic Sciences (MIEST), and then administer this instrument to four different therapeutic disciplines to assess its utility and validity as a multidisciplinary measure of ethical sensitivity. The discussion section focuses on the results that emerged from Phase 2—the implementation phase. Participants' overall scores on the Miest were comparable for audiologists, occupational therapists, physiotherapists, and speech-language pathologists, which confirmed the multidisciplinary usability of this instrument.

On average, participants showed the lowest ethical sensitivity in relation to the principle of nonmaleficence, which held both ethical and legal implications. In two of the three vignettes dealing with the target ethical principle of nonmaleficence, namely Vignettes 4 and 12, the therapist was depicted as someone trying to do good and assuming the perspective of the client. This is essential information for developing ethical sensitivity in the therapeutic sciences, as it emphasizes the importance of realizing that even though beneficence is a central principle in the therapeutic sciences (and often the principle overemphasized in ethics training), it must always be balanced by considering the principle of nonmaleficence. Blindly following the principle of beneficence could result in unethical (or unlawful) practice, even if unintentional.¹⁷

In contrast, participants showed, on average, the highest ethical sensitivity for the target principle

autonomy. Autonomy is a Western presupposition based on the idea that individuality and free will are to be encouraged. Given the dominance of West-

ern thought in philosophy and ethical inquiry, it makes sense that discussions of ethics in the therapeutic sciences would also consider autonomy as a

TABLE 3. Summary of 12 vignettes with target principles and skills with final scores

Vig.	Principle	Skill	Total score N = 100	AUD n = 20	OT n = 30	PT n = 27	SLT n = 23	ANOVA p-value	Ho
1	Justice	Perspective taking Interpreting ethics in a situation	8/22 Emerging Range: -3 - 22	8/22 Emerging	10/22 Emerging	5/22 Inadequate	8/22 Emerging	0.01	Reject
2	Autonomy	Relating to others Emotional expression	11/22 Emerging Range: 1 - 20	11/22 Emerging	11/22 Emerging	10/22 Emerging	10/22 Emerging	0.90	Accept
3	Beneficence	Effective communication Emotional expression	10/22 Emerging Range: -6 - 22	8/22 Emerging	11/22 Emerging	9/22 Emerging	10/22 Emerging	0.15	Accept
4	Nonmaleficence	Perspective taking	3/22 Inadequate Range: -5 - 22	11/22 Emerging	5/22 Inadequate	2/22 Unacceptable	2/22 Unacceptable	0.02	Reject
5	Justice	Relating to others	8/22 Emerging Range: -1 - 22	7/22 Emerging	9/22 Emerging	7/22 Emerging	9/22 Emerging	0.17	Accept
6	Autonomy	Effective communication	7/22 Emerging Range: 14 - 22	7/22 Emerging	7/22 Emerging	5/22 Emerging	9/22 Emerging	0.03	Reject
7	Beneficence	Emotional expression	10/22 Emerging Range: -6 - 19	11/22 Emerging	9/22 Emerging	10/22 Emerging	11/22 Emerging	0.15	Accept
8	Nonmaleficence	Controlling social bias	9/22 Emerging Range: -8 - 22	8/22 Emerging	11/22 Emerging	9/22 Emerging	10/22 Emerging	0.30	Accept
9	Justice	Responding to diversity	9/22 Emerging Range: -8 - 15	9/22 Emerging	10/22 Emerging	8/22 Emerging	11/22 Emerging	0.02	Reject
10	Autonomy	Responding to diversity	11/22 Emerging Range: -8 - 18	11/22 Emerging	11/22 Emerging	11/22 Emerging	10/22 Emerging	0.28	Accept
11	Beneficence	Controlling social bias	5/22 Emerging Range: -6 - 18	6/22 Emerging	6/22 Emerging	3/22 Inadequate	7/22 Emerging	0.01	Reject
12	Nonmaleficence	Interpreting ethics in a situation	6/22 Emerging Range: -4 - 18	7/22 Emerging	7/22 Emerging	7/22 Emerging	5/22 Inadequate	0.47	Reject

Key: AUD = audiologist; OT = occupational therapist; PT = physiotherapist, SLT = speech-language pathologist

fundamental principle of ethics.¹⁸ This focus in the therapeutic science professions on autonomy would also make participants more sensitive to violations of autonomy.

With respect to their performance on the MIEST, speech-language pathology participants displayed exceptional insight into the ethical sensitivity skill known as controlling social bias. Due to extensive

and increasing global linguistic and cultural diversity, there is a specific need for culturally valid and reliable developmental assessment instruments that can accommodate the diversity of the population. Speech-language pathologists are specifically trained to view clients holistically and consider the impact of their cultural (a way of life of a specific group of people) and linguistic background. Devel-

TABLE 4. Statistically significant differences between the four groups of participants

Vignette number with target principle and skill(s)	Participants' performance related to the identification of the target ethical principle and skills
<p>Vignette: 1 Principle: Justice Skills: Perspective taking Interpreting ethics in a situation The multiple pairwise comparisons indicated that there was a statistically significant difference between the total population mean score for occupational therapists and physiotherapists ($F = 5.3, p < 0.05$).</p>	<p>Audiologists Occupational therapists Physiotherapists Speech-language pathologists</p>
<p>Vignette: 4 Principle: Nonmaleficence Skill: Perspective taking Similar to Vignette 1, the multiple pairwise comparisons indicated that there was a statistically significant difference between the total population mean score for occupational therapists and physiotherapists ($F = 3.44, p < 0.05$).</p>	<p>Audiologists Occupational therapists Physiotherapists Speech-language pathologists</p>
<p>Vignette: 6 Principle: Autonomy Skill: Effective communication The results revealed a statistically significant difference between the total population mean score for speech-language pathologists and physiotherapists ($F = 4.2, p < 0.05$). (Table 4 is continued on the next page.)</p>	<p>Audiologists Occupational therapists Physiotherapists Speech-language pathologists</p>

opmental assessments should never be tests of cultural knowledge.¹⁹

Cultural awareness will influence a therapist's ability to control social bias and respect diversity, and it explains the difference between speech-language pathology and physiotherapy participants with regard to these two ethical skills. The level of awareness is considered a developmental process that evolves over time through the process of attaining cultural knowledge. Cultural awareness involves internal changes associated with the qualities of openness and flexibility in relation to others. All individuals are at various levels of awareness, knowledge, and skills along the cultural competence continuum. Bennett constructed a developmental model of intercultural sensitivity in which he examined attitudes towards intercultural sensitivity and how these related to intercultural competence.²⁰ Intercultural sensitivity is viewed as occurring along

a continuum consisting of six different levels: Level 1: denial/cultural destructiveness; Level 2: defense/cultural incapacity; Level 3 : minimization/cultural blindness; Level 4: acceptance/cultural precompetence; Level 5: adaptation/cultural competence; and Level 6: integration/cultural proficiency. Speech-language pathologists, as a group, are considered to function in the adaptation stage of this model. Ethical sensitivity towards factors related to cultural competence will greatly benefit this therapeutic discipline in the diverse cultural setting where most therapists find themselves.

CONCLUSION

The MIEST presents an original approach to examining ethical sensitivity in therapists across four different disciplines. Theoretically grounded in the first step of Rest's four-component model (ethi-

TABLE 4, Continued

Vignette number with target principle and skill(s)	Participants' performance related to the identification of the target ethical principle and skills
<p>Vignette: 9 Principle: Justice Skill: Responding to diversity Similar to Vignette 6, the ANOVA test showed a statistically significant difference between the total population mean score for speech-language pathologists and physiotherapists ($F = 3.45, p = <0.05$), hence rejecting H0.</p>	
<p>Vignette: 11 Principle: Beneficence Skill: Controlling social bias In line with Vignettes 6 and 9, the ANOVA showed a statistically significant difference between the total population mean score for speech-language pathologists and physiotherapists ($F = 3.95, p = <0.05$), hence rejecting H0.</p>	

cal sensitivity) and based on principles identified in codes of professional ethics, the Miest can be used to investigate the relative impact of training courses in ethics on the development of ethical sensitivity.²¹ The custom-developed vignettes provide a stable platform for training workshops based on the principles of problem-based learning, which are considered effective for the development of deeper competency in adult learners.²²

This study demonstrates that a measuring instrument that asks therapists to identify ethical issues by using vignettes has the potential to discriminate between participants within each therapy group, as well as between therapy groups. The authors sought to describe the extent to which young therapists (final-year students in the therapeutic sciences) are aware of the ethical dimensions of dilemmas and the principle(s) on which they mostly base their decisions. The research study demonstrated that participants in the therapeutic sciences reflect a range of sensitivity to ethical issues embedded in the vignettes that were developed for the Miest. This suggests that although they are not sensitive to all ethical concerns, they have a solid foundation to build on as they gain experience in their profession.

LIMITATIONS

Sequential exploratory research designs emphasize internal validity and not external validity, which implies that the results have to be interpreted with care in terms of their universal application. Not all of the ethical principle/sensitivity skill combinations were included in the Miest. The use of a paper-based measuring instrument implied that therapists' sensitivity in terms of effective communication could only be assessed in terms of verbal communication. The assessment of measurement validity in the Miest focused on content and construct validity. Criterion-related validity was not part of the aim of this study, but is considered as a next step in validating the Miest. Although objectivity is central to ethical decision making, there is a psychological side to decision making as well.²³ These factors were not measured.

FUTURE RESEARCH

The ultimate goal of research on ethical sensitivity would be to relate it to ethical/unethical decision making. It would therefore be valuable to administer the Miest in conjunction with a decision-making assessment instrument to investigate the relationship between the findings. The Miest re-

quires further work in testing and refining both the vignettes and items to meet higher standards of reliability and validity. Ethical sensitivity can be investigated in relation to a cognitive empathy scale and/or levels of emotional intelligence. By piloting the Miest with other professions registered in the healthcare sciences (for example optometry, dietetics, and nutrition), the methodology that was applied in the current research may be used to construct new and relevant vignettes.

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Make It Plain: Strengthening the Ethical Foundation of First-Person Authorization for Organ Donation

James L. Benedict

ABSTRACT

One response to the chronic shortage of organs for transplant in the United States has been the passage of laws establishing first-person authorization for donation of organs, providing legal grounds for the retrieval of organs and tissues from registered donors, even over the objections of their next of kin. The ethical justification for first-person authorization is that it is a matter of respecting the donor's wishes. The objection of some next of kin may be that the donor would not have wished for his or her loved ones to have their preferences overridden, had they considered that possibility. This article examines the basis of the conflict and suggests a remedy grounded in the provision of donor-intent options that have the ability to clarify the donor's wishes.

TRAGEDY

Two related tragedies unfolded in the summer of 2013. The first tragedy was of an all too common kind—a 21-year-old male riding home from work on his bicycle was struck by a car. He suffered major head trauma and was declared brain dead the following day. The second tragedy was of a far less common kind. When the family of the cyclist was informed that he had registered as an organ donor

while applying for his driver's license several months before, they were caught off guard. He hadn't mentioned it to them, and they did not wish for his organs to be removed. Representatives of Lifeline of Ohio, the regional organ procurement organization (OPO), explained that the objections of the family carried no legal force and made clear that they intended to proceed with organ retrieval.

Eventually the case wound up in court, where a judge sided with Lifeline of Ohio, which had argued that the law prevented anyone other than the donor from amending or revoking a person's status as an organ donor. In response, the young man's family argued that he must not have fully understood the choice that he had made. In the end, the family was left feeling anger and frustration, while those involved in organ procurement were left with the emotional burden of knowing that they had forced an outcome on a family who were already experiencing a deep sense of loss and powerlessness.¹

FIRST-PERSON AUTHORIZATION

The staff of the OPO was correct about the law. Ohio, like all other states in the U.S., has adopted a law that establishes first-person authorization (FPA) for organ donation.² This law is based on the revised 2006 Uniform Anatomical Gift Act (UAGA). A greater emphasis on first-person authorization was a major focus of the 2006 UAGA.³ In brief, the pur-

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pose of FPA is to provide legal grounds for OPOs to follow through on organ retrieval from registered donors over the objections of the donor's next of kin; something that occurs in less than 10 percent of cases.⁴

The term "authorization" was intentionally chosen by advocates of FPA to distinguish and distance it from the notion of informed consent.⁵ FPA is understood as a form of simple consent, which does not include an expectation that those who seek consent bear an obligation to provide information or assess the donor's understanding.⁶ Advocates for FPA argue that authorization for postmortem organ donation is more akin to gift giving than it is to agreeing to medical treatment. While informed consent would be required for medical treatment, simple consent is sufficient for giving a gift or making a donation, since we do not ordinarily assume that there is any duty to provide information to those who wish to give us a gift.

Yet it may be argued that we do have an ethical duty to inform people who express a desire to give us a gift if we can reasonably anticipate the kind of conflict with loved ones to which FPA policies have sometimes led. At the least, most would agree that organizations actively requesting gifts (as OPOs do) behave more ethically when they provide information to avoid or mitigate these conflicts. Furthermore, given that it frequently has been argued that FPA is grounded in the ethical principle of respect for a donor's autonomy,⁷ questions may be raised about whether one could be properly described as respecting the autonomy of another while simultaneously maintaining a system in which the meaning of a person's choices are often unclear and sometimes counterintuitive.

There is plenty of evidence that the organ donation system in the U.S. is poorly understood by the general population.⁸ The information provided in printed materials and on websites of OPOs tend to emphasize that there are a number of "myths" and misconceptions that surround organ donation.⁹ Among the misconceptions noted are the belief that many religions frown upon or forbid donation, a fear that physicians will not work as hard to save patients who are registered as organ donors, and the concern that families of donors may have to pay for the cost of organ retrieval. Research indicates that many people are unaware or confused about the number and specific types of organs or tissues that may be used, and about the rights (or lack thereof) of the family.¹⁰ In addition, while OPOs may not consider postmortem organ donation a form of medical treatment that is subject to the requirement of

informed consent, the average person may assume otherwise, given that organ retrieval takes place in a healthcare facility and is performed by trained and licensed healthcare professionals.¹¹ Confusion is also engendered by the inconsistent practices of various OPOs, as some are much more likely to enforce FPA than others.¹²

Still other misunderstandings are plausible and even probable. For instance, some people might assume that if they do not register as a donor, or if they revoke their designation as a donor, it is the same as declaring their wish to not become a donor and that their organs will never be removed for transplant. But to legally establish a means to prevent the retrieval of one's organs and tissues after death, one must create one's own "I do not want to be a donor" document.¹³ The lack of a donor card or absence from a donor registry is not understood as a refusal to donate. It is understood as not making a choice one way or another, leaving it up to one's next of kin to decide whether or not one's organs or tissues will be donated.¹⁴

Likewise, those who have previously agreed to have the donor symbol on their driver's license may believe that asking for the symbol to be removed from a subsequent license is the same as revoking their authorization to donate, but it may not be.¹⁵ Their names may remain on the donor list unless or until they officially revoke their donor designation, following a process laid out under state law. Even when persons do officially revoke their status as a donor they do not become registered as someone who does not want to donate. They are regarded only as persons who have not expressed a preference, and their loved ones will be consulted about donation if there is a possibility of retrieving usable organs or tissues.¹⁶

MAKE IT PLAIN

The ethical justification for FPA for donation is grounded in the principle of respect for autonomy, which affirms the right of self-determination. In plain language, FPA is the assertion that we ought to do what the "donor" wanted. Yet if the donor did not understand the terms of the agreement,¹⁷ or was unaware of other options or how to avail himself or herself of them, then it becomes less certain that donation was what the individual wanted or would have wanted, had he or she understood better or had been more aware of the various options available. As Dale Gardiner has argued, donor registration under such conditions is more like expressing a wish than giving consent. As he notes, we often have

multiple wishes, not all of which are compatible. Unless some attempt is made to examine and weigh one's options, it may not be legitimate to consider a choice to become a donor as the act of an autonomous will.¹⁸ If it is not the act of an autonomous will, then the justification for considering donor registration as a legitimate expression of the right of self-determination is called into question.

In light of the likelihood of various misunderstandings, some have suggested that the informed consent standard be applied.¹⁹ However, implementing a system of informed consent could be problematic in at least two ways.²⁰ First, it could generate extended debate over the nature and extent of the information required for adequate consent, and debate over how, when, and by whom the information should be conveyed. Second, it could be difficult to implement use of the informed consent standard under the current system of donor recruitment without risking a substantial negative impact on the number of persons who would agree to become a registered donor. The negative impact would not necessarily result from the content of the information provided, but from the extra time involved. As it stands, most decisions about becoming an organ donor in the U.S. take place in the context of an application for or renewal of a driver's license, a process most people prefer to keep as brief as possible.²¹ Many might also be discouraged by the extra time it would take if an online registry required them to show they understood key information about donation before it allowed them to register.

There is, however, a way to address the potential for confusion in recruiting donors without requiring the adoption of full informed consent. It is, quite simply, to make the commitment to donate as first-person consent explicit by offering other options, set forth in plain language. In a system in which one may choose between registering as an organ donor, registering a refusal to be an organ donor, or registering a desire to leave the decision up to one's next of kin, FPA would rest on a much stronger ethical foundation.

Such a system is already in place in the Netherlands. In the Netherlands, persons are offered four options:

- I want my organs and tissues to be used for transplantation.
- I do not want my organs and tissues to be used for transplantation.
- I wish to leave the decision to my family and possible partner.
- I am authorizing this [specific] person to make the decision.²²

By offering the option to refuse and the opportunity for individuals to delegate the decision to others,²³ the Dutch system demonstrates a strong commitment to the ethical principle of respect for autonomy.

The implementation in the U.S. of a donor registration system that includes three or more options would require changes to state laws and the creation of registries that record choices other than a simple willingness to be a donor. Yet it would not entail a challenge to the understanding of organ donation as a gift or require more than simple amendments to the existing UAGA. The increased clarity about the meaning of one's choices might also increase trust in OPOs by providing greater transparency, which demonstrates respect for donors as decision makers.²⁴ Above all, while it would not eliminate all objections by next of kin when families are informed that a loved one is a registered organ donor, it should reduce the number and intensity of objections and provide a much more robust ethical foundation for proceeding with organ retrieval over objections by next of kin.

NOTES

1. A. Manning, "Family Loses Fight to Keep Son's Organs from Donation," *Columbus Dispatch*, 12 July 2013.

2. Some recent research has suggested that first-person authorization laws have not actually been effective in increasing the number of organs and tissues donated, perhaps because OPOs seldom take steps to enforce them. K. Callison and A. Levin, "Donor registries, first-person consent legislation, and the supply of deceased organ donors," *Journal of Health Economics* 49 (2016): 70-5.

3. Ohio Revised Code, Title 21: 2108.08, Action by Person Other than the Donor; W.J. Chon et al., "When the Living and the Deceased Cannot Agree on Organ Donation: A Survey of U.S. Organ Procurement Organizations (OPOs)," *American Journal of Transplantation* 14 (2014): 173; National Conference of Commissioners on Uniform State Laws, "Revised Uniform Anatomical Gift Act (2006): Last Revised or Amended in August 2009," http://www.uniformlaws.org/shared/docs/anatomical_gift/uaga_final_aug09.pdf.

4. A family's objection to the wishes of a registered donor should be distinguished from a family's refusal to donate the organs of a potential donor who did not register as a donor. The latter rate is significantly higher. H.M. Traino and L.A. Siminoff, "Attitudes and Acceptance of First Person Authorization: A National Comparison of Donor and Nondonor Families," *Journal of Trauma and Acute Care Surgery* 74, no. 1 (2013): 296; Chon et al., "When the Living and the Deceased," see note 3 above, p. 174; P.A. Stahler et al., "Honoring Patients' Organ Donation Decisions When Family Conflict is Present: Experience From a Single Organ Procurement Organization," *Journal of Trauma and Acute Care Surgery* 77, no. 4 (2014):

557-8. For comparable rates in the U.K., see A. Vincent and L. Logan, "Consent for Organ Donation," *British Journal of Anaesthesia* 108, supp. 1 (2012): i81. Even in those cases in which the family initially objects, the family often concedes in time. Sometimes OPOs respect the wishes of the family even though the law is on the side of the OPO. Objections that end up in court are exceedingly rare. Regardless of how the conflict is handled, however, it is undoubtedly emotionally distressing for all involved. It may also interfere with timely retrieval of organs, allowing some organs to deteriorate. Furthermore, publicity about such conflicts may discourage others from registering as organ donors or persuade those already registered to remove their names from a registry.

5. OPTN/UNOS Organ Procurement Organization Committee, "Report to the Board of Directors," 2014, Richmond, Va., http://optn.transplant.hrsa.gov/converge/committeereports/board_main_opocommittee_11_17_2014_15_3.pdf. Scotland has also chosen "authorization" over "consent" for similar reasons. Vincent and Logan, "Consent for Organ Donation," see note 4 above, p. i80.

6. For a discussion of the difference between informed and simple consent and a compelling argument in favor of requiring informed consent for organ donation, see A.S. Iltis, "Organ Donation, Brain Death and the Family: Valid Informed Consent," *Journal of Law, Medicine and Ethics* 43, no. 2 (2015): 369-82.

7. D. MacKay and A. Robinson, "The ethics of organ donor registration policies: Nudges and respect for autonomy," *American Journal of Bioethics* 16, no. 11 (2016): 3-11; M.B. Gill, "Presumed Consent, Autonomy and Organ Donation," *Journal of Medicine and Philosophy* 29, no. 1 (2004): 55.

8. J.R. Rodrigue et al., "Vascularized Composite Allograft Donation and Transplantation: A Survey of Public Attitudes in the United States," *American Journal of Transplantation* 17, no. 10 (2017): 2689-90.

9. "Busting Myths about Organ Donation," Gift of Life Donor Program, <http://www.donors1.org/learn2/myths/>.

10. Note: Some scholars of ethics argue that organ donation does in fact require informed consent rather than simple consent. Iltis, "Organ Donation," see note 6 above; D. MacKay and A. Robinson, "The Ethics of Organ Donor Registration Policies: Nudges and Respect for Autonomy," *American Journal of Bioethics* 16, no. 11 (2016): 3-12.

11. Traino and Siminoff, "Attitudes and Acceptance of First Person Authorization," see note 4 above, p. 299.

12. Chon et al., "When the Living and the Deceased Cannot Agree on Organ Donation," see note 3 above, pp. 174-5; R. Girlanda, "Deceased organ donation for transplantation: Challenges and opportunities," *World Journal of Transplantation* 6, no. 3 (2016): 457.

13. The sole example of this type of card or statement this author was able to find appears deep in the text of the revised 2006 UAGA, where an ordinary person is highly unlikely to find it: National Conference of Commissioners on Uniform State Laws, "Revised Uniform Anatomical Gift Act," see note 3 above, pp. 1-60. Govert den Hartogh argues that when it is made difficult to register

refusal, one's right to decide about what happens to one's body is "disrespected." G. den Hartogh, "The Role of Relatives in Opt-in Systems of Postmortal Procurement," *Medicine, Health Care and Philosophy* 15 (2012): 195-205, 197.

14. National Conference of Commissioners on Uniform State Laws, "Revised Uniform Anatomical Gift Act," see note 3 above, p. 29.

15. *Ibid.*, 25.

16. As den Hartogh notes, most "opt-in" systems operate in this way, delegating the right to donate to one's next of kin in the event that one does not register as a donor during one's lifetime. den Hartogh, "The Role of Relatives," see note 13 above, p. 197.

17. This was the claim of the family in the opening story, and they may well have been correct.

18. In the case of organ donation, we may wish to become organ donors, but wish even more that our grieving loved ones have their wishes respected. However, if we are not offered a clear and simple way of expressing this stronger wish, those who insist on retrieving organs may end up doing something other than what we actually wanted. D. Gardiner, "An Unethical Marriage—The Human Tissue Act and the UK NHS Donor Register," *Journal of the Intensive Care Society* 8, no. 2 (2007): 42-3. For another perspective on the issue, see MacKay and Robinson, "The Ethics for Organ Donor Registration Policies," see note 10 above, pp. 3-12.

19. Iltis, "Organ Donation," see note 6 above; R. Truog, "Consent for Organ Donation—Balancing Conflicting Ethical Obligations," *New England Journal of Medicine* 358, no. 12 (2008): 1209-11, in the U.S.; Gardiner, "An Unethical Marriage," see note 18 above; M.D.D. Bell, "Emergency Medicine, Organ Donation and the Human Tissue Act," *Emergency Medicine Journal* 23 (2006): 824-7, in the U.K.

20. Members of the Washington State SB 5386 Work Group mention a third: "Restructuring the organ donation laws outside of gift law principles . . . would be a fundamental change that could not be accomplished with a simple statutory amendment to the UAGA. Further, eliminating gift law as the basis for organ donation could have unintended consequences such as undermining the legal foundation that prohibits the buying and selling of organs." J. Reyes et al., "Report to the Washington State Legislature on Strategies for Increasing Organ Donation, Senate Bill 5386," January 2012, http://app.leg.wa.gov/ReportsToTheLegislature/Home/GetPDF?fileName=Organ%20Donation%20Report%20to%20WA%20Legislature_d497ab47-e0f8-48fb-9249-383b1c34a90f.pdf, p. 7.

21. K.P. Whyte et al., "Nudge, Nudge or Shove, Shove—The Right Way for Nudges to Increase the Supply of Donated Cadaver Organs," *American Journal of Bioethics* 12, no. 2 (2012): 32-9, 35.

22. "Options," Donorregister Duidelijkheid en zekerheid door registratie, <https://www.donorregister.nl/english/aboutdonorregistration/options/>. Under the third option, "family and possible partner" refers to relatives listed and prioritized by the law. First priority goes to a spouse or "registered partner." Dutch law allows for those who do not wish to marry to register a formal partnership agreement that conveys certain rights and privileges.

Changes in the Dutch organ procurement system are currently being considered, including a shift from “opt-in” to “opt-out.” “Dutch MPs vote for ‘yes unless’ organ donor register,” *Dutch News.nl*, 27 December 2016, <http://www.dutchnews.nl/news/archives/2016/09/dutch-mps-vote-for-yes-unless-organ-donation-register>.

23. It is ethically permissible and reasonable for individuals to delegate decision making. The decision to delegate is itself an act of autonomy that should not be denied to persons. In the case of organ donation after death, people may feel it is more appropriate for their next of kin to decide because the next of kin will be affected emotionally and have a responsibility to assist those engaged in organ retrieval by providing a health history and other information. It is well established that not all persons wish to make their own decisions, even in the course of regular healthcare. See R.B. Deber et al., “Do people want to be autonomous patients? Preferred roles in treatment decision making in several patient populations,” *Health Expectations* 10 (2007): 248-58.

24. Distrust is a recognized problem. See M.J. Irving et al., “Factors that influence the decision to be an organ donor: A systematic review of the qualitative literature,” *Nephrology Dialysis Transplantation* 27 (2012): 2530-2; “Organ Donation Depends on Trust,” *Lancet* 387 (2016): 2575.

Lisa Fuller and Margot M. Eves, "Incarcerated Patients and Equitability: The Ethical Obligation to Treat Them Differently," *The Journal of Clinical Ethics* 28, no. 4 (Winter 2017): 308-13.

Cases from the Cleveland Clinic

Incarcerated Patients and Equitability: The Ethical Obligation to Treat Them Differently

Lisa Fuller and Margot M. Eves

ABSTRACT

Prisoners are legally categorized as a vulnerable group for the purposes of medical research, but their vulnerability is not limited to the research context. Prisoner-patients may experience lower standards of care, fewer options for treatment, violations of privacy, and the use of inappropriate surrogates as a result of their status. This case study highlights some of the ways in which a prisoner-patient's vulnerable status impacted the care he received. The article argues the following: (1) Prisoner-patients are entitled to the same quality of care as all other patients, and healthcare providers should be vigilant to ensure that the stigma of incarceration does not influence care decisions. (2) Options for treatment should reflect what is most medically appropriate in the hospital or other healthcare setting, even when not all treatments would be available in the correctional setting. (3) The presence of guards at the bedside requires that additional measures be taken to protect the privacy and confidentiality of prisoner-patients. (4) When end-of-life decisions must be made for an incapacitated patient, prison physicians are not well placed to act as surrogate decision makers, which heightens the obligations of the healthcare profession-

als in the hospital to ensure an ethically supportable process and outcome. Therefore, healthcare professionals should provide extra protection for those prisoner-patients who do not have decision-making capacity, by utilizing a robust process for decision making such as those used for incapacitated patients without surrogates, rather than relying solely on prison physicians as surrogates.

INTRODUCTION

Prisoners are legally categorized as a vulnerable group for the purposes of medical research. However, their vulnerability is not limited to the research context. The current literature reflects a recognition that prisoners are also more vulnerable than non-incarcerated patients when they are undergoing treatment.¹ This article will begin with a preliminary discussion of vulnerability before proceeding with an analysis of a recent case involving a prisoner-patient. The case study highlights some of the ways in which a prisoner's vulnerability may manifest in the hospital setting.

A person is vulnerable when she or he has "a greater likelihood of . . . being denied adequate satisfaction of certain legitimate [moral or legal] claims."² While in one sense all human beings are fragile and therefore "vulnerable," certain circumstances or situations expose people to an increased chance that their rights may be violated or their interests disregarded. This notion is specifically po-

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litical, in that someone's circumstances are the source of her or his vulnerable state, and those circumstances are created by socially constructed norms, policies, and institutional constraints. Being located within these social circumstances is, then, what puts a person at greater risk of being wronged and/or harmed as compared with others not similarly placed.³ Generally speaking, individuals who are vulnerable in this way are more exposed to harm and threats of harm and have fewer resources with which to protect themselves from such threats. This greater exposure generates a moral claim on others to provide members of vulnerable groups with special protection.⁴ The concept of vulnerability is useful in connection with the current case because although hospitalized patients are vulnerable for many reasons, they are not ordinarily under the power of a "totalizing" institutional authority. Despite being guaranteed access to healthcare by law,⁵ prisoners nevertheless may have their interests undermined in various ways while receiving treatment, since they remain under the power of the prison authorities and may be subject to stigma, disrespect, and unfairness as a result of their status.

CASE DESCRIPTION

Mr. Maken was a 66-year-old male inmate at a federal prison. He was admitted to a nearby community hospital after experiencing chest pain and severe shortness of breath. Mr. Maken had a history of chronic obstructive pulmonary disease, hypertension, chronic kidney disease, diabetes, and coronary artery disease. He had undergone quadruple coronary artery bypass graft surgery 20 years prior. A few days after admission, he had a heart attack and his condition deteriorated. As a result, he was transferred to the cardiac intensive care unit (CICU) at a large tertiary care teaching hospital for continued treatment. Mr. Maken was successfully treated for cardiogenic shock and significant retroperitoneal bleeding. His heart failure was treated with dobutamine, an infusion drug intended only for short-term support. Unfortunately, Mr. Maken was not a candidate for cardiac surgery or heart transplantation.

During his CICU stay, he rarely responded to commands and was typically either confused or non-responsive. Therefore, he was unable to demonstrate the capacity to make his own medical decisions. Prison personnel informed the CICU team that the prison physician would be responsible for providing consent, or acting as a surrogate decision maker, until or unless the patient regained decision-making capacity. Even though Mr. Maken was not able

to get out of bed on his own, he was supervised by two guards at all times. They sat in his room at bedside. They did not know him before they were assigned to guard him at the hospital.

After Mr. Maken had been in the CICU for 12 days, Dr. Holt requested an ethics consultation due to concerns arising from a suggestion made by the prison physician about treatment options. Dr. Holt explained that attempts to wean Mr. Maken from dobutamine were unsuccessful, effectively making it a life-sustaining intervention. Dr. Holt reported that during his conversation to update the prison physician about Mr. Maken's condition and discuss implementation of a do-not-resuscitate (DNR) order, the prison physician said the hospital could stop the dobutamine, that is, withdraw life-sustaining treatment. Dr. Holt expressed concern that this decision might be premature, and sought guidance regarding the ethical permissibility of proceeding.

The ethics consultants conducted some independent research. The bioethics literature regarding prisoners primarily focuses on human subject research in prison populations; there is a dearth of literature pertaining to clinical decision making for prisoners. The United States Department of Justice Federal Bureau of Prisons (DOJ/FBP) published a Program Statement on Patient Care, which was informative.⁶ The prison cited this document as the source of its authority to make medical decisions if there were no family members available. It also provided documentation in which Mr. Maken declined, on two separate occasions, to have family notified in the event of emergency or death. However, a careful reading of the DOJ/FBP Program Statement raised questions as to whether the prison's interpretation was accurate, or if the statement authorized nonprison hospitals to use their usual institutional protocols for decision making when an incarcerated patient is hospitalized. Additionally, a colleague with more experience in caring for incarcerated patients reminded the ethics consultants that Mr. Maken retained his privacy rights as a patient under applicable state and federal law.⁷

DISCUSSION

Over the course of the consultation, it became clear that Mr. Maken was vulnerable in three ways: (1) to unjustified limitations on treatment resulting from his status as a prisoner, (2) to inappropriate deference to the prison authorities as decision makers, and (3) to unjustified invasions of his privacy. It was also clear that most clinical caregivers had not interacted with someone in Mr. Maken's particular

situation before, and did not realize that his status as a prisoner had the potential to ethically complicate his care in distinct ways. Principles of fairness, respect, and protection of the vulnerable require healthcare professionals to *actively* ensure that prisoner-patients receive the same care—in both the processes and outcomes of medical treatment—that non-incarcerated patients would typically receive.

Fairness and Nondiscrimination

Basic fairness requires healthcare professionals to treat incarcerated patients as they would any other patient. Incarcerated patients risk facing suboptimal medical care as a result of the (often unconscious) bias associated with their status as prisoners. For example, they may be seen as lacking social worth, or as less valuable members of society because of their transgressions. A significant social stigma attaches to involvement with the correctional system, and this may negatively impact healthcare professionals' interactions with incarcerated patients. Lack of equal treatment on the basis of such stigma is, nevertheless, a form of invidious discrimination, and, as such, requires that healthcare professionals make a conscious effort to avoid it.

One way that such unequal treatment can occur is when healthcare professionals unconsciously “import” constraints and permissions from the correctional setting into the hospital. For instance, in this case, prison guards were often present for Mr. Maken's physical examinations and likely overheard information regarding his condition and treatment plan. Although prisoners' rights to and expectations of privacy are reduced (or non-existent) in correctional facilities, and even though some prison officials are entitled to access to prisoners' healthcare information, the manner in which prisoners are treated in the correctional setting is inappropriate in the hospital setting. One reason is that the fundamental goals of the institutions differ. The purpose of correctional facilities is to punish inmates by depriving them of their liberty, which is a goal that inmates presumably do not share, and so its pursuit requires constant surveillance and coercion.⁸ By contrast, the purpose of hospitals is to promote the health of patients, which requires treating each patient as a unique individual with whom healthcare professionals must develop a relationship of trust, and whose interests are at least equal to, and often supersede, other stakeholders' interests. Additionally, patients typically want to feel better. Unlike prisoners, patients share this broad purpose with those responsible for providing medical care, or those in the position of power or authority.

Another ethically challenging issue to consider is the allocation of resources. Prisoners have a constitutional right to healthcare, based in the Eighth Amendment to the U.S. Constitution, which prohibits cruel and unusual punishment.⁹ Correctional facilities are responsible to provide medical care or to transfer prisoners to a hospital with the capacity to provide it, as well as to provide payment for the care. Prison resources might constrain what can be offered upon a patient's discharge due to capacity issues or possible budget considerations; however, this is true of most patients, as insurance coverage often determines what type and level of continuing care patients are eligible to receive. Nevertheless, while being treated in the hospital, choice regarding interventions should reflect the usual standard of care for patients with the same medical profile as the prisoner-patient. An issue may arise when a prison physician acts as the patient's surrogate and recommends a course of treatment that would be normal in the correctional setting, when that setting does not offer the same level of care as the hospital. In Mr. Maken's case, Dr. Holt was not comfortable discontinuing the dobutamine without further exploring whether it would be available after discharge. There was also the question of whether Mr. Maken might be eligible for hospice, which needed to be explored, given his status. The ethics consultants recommended that all options be explored for Mr. Maken that would be appropriate to his medical condition, even if ultimately those options after discharge were determined by what the prison system could provide.

Decision Making for Prisoners without Capacity

At first it was unclear whether the hospital should make efforts to locate Mr. Maken's family, or if this had already been done by the prison health officials. Once the prison health administration forwarded documentation of the patient's wish that no family be contacted, the ethics consultants began exploring the prison's assertion that their physicians were the authorized surrogate decision makers. The prison referenced the DOJ/FBP Program Statement on Patient Care to substantiate its position. The document specified that “the authority, parameters and procedures for creating such proxies are governed by the laws of the state in which the institution operates,” but also that “all DNR orders . . . must be approved by the Clinical Director.”¹⁰ In a separate passage concerning DNR orders, which specified that such an order may be written when it is “the attending physician's decision that the inmate is in a terminal condition,” no clear distinction was

made between patients located in community hospitals and those in correctional medical facilities.

In this case, the attending physician was not the prison doctor, and because state law did not identify correctional staff as potential surrogates for incapacitated patients, the ethics consultants were not convinced that the prison doctor was authorized to serve as a surrogate decision maker. Although the corrections system has custody of inmates and is responsible for their welfare, there did not seem to be adequate legal or ethical grounds to support giving the prison doctor sole responsibility for decision making regarding the end of an inmate's life.

Ideally, end-of-life decisions are made by patients themselves, in person or through an advance directive, or more often, by an appropriately identified surrogate decision maker using a substituted judgment standard. By contrast, if a surrogate decision maker does not know the patient very well, or does not know what the patient would have wanted in an end-of-life situation, then the surrogate must fall back on the "best interest standard" in order to make decisions. Since Mr. Maken did not have capacity for decision making throughout his hospitalization and did not wish for family members to be contacted, no one who knew him personally was available to apply substituted judgment. Therefore, the best interest standard was the applicable framework for making decisions about his care. This meant that the prison doctors were no better positioned to make decisions regarding Mr. Maken's care than his healthcare team at the hospital.

Utilizing a prison physician as a surrogate decision maker raised several ethical challenges beyond those that faced hospital personnel. One challenge was that the correctional facility (and its employees) had a financial conflict of interest: prison healthcare is administered through the correctional budget, not through a separate payer source (for example, Medicare or other third-party insurance). As such, there was an intrinsic conflict among three competing interests: the government's interest in preserving life, its interest in meting out punishment for criminal activity, and the potentially high cost of complex healthcare. Nancy Dubler highlighted another challenge: "the options offered [in the correctional setting] are generally not all those that medicine could and should provide given the condition of the inmate," and the recommendations of a correctional setting are likely to be formed by its everyday practice.¹¹ Further, it has been argued that prison physicians may become acculturated to their institutions, which may cause them to see patients as lacking agency and individual worth.¹² Prison phy-

sicians may begin to adopt "custodial values and norms in place of health care values and norms," which prioritize cost reduction, security, and order.¹³ As such, the ethics consultants recommended that Mr. Maken's care team take a *hybrid* approach to surrogate decision making.

The essence of this approach is as follows: the care team could utilize a prison physician as a surrogate decision maker on the condition that the team's own professional medical judgments acted as a safeguard to ensure that Mr. Maken's care reflected the same high standard of care that other patients received. In furtherance of this responsibility, less deference would be afforded to the prison physician as a surrogate than would normally be afforded to a surrogate decision maker, since the prison physician had no additional knowledge of the patient's wishes. Since respect for autonomy was not grounding the decisions, and the prison physician might have been influenced by institutional (prison) culture and constraints, professional integrity required that Mr. Maken's care team should oversee his care as they would if he were an incapacitated patient without a surrogate. This hybrid approach operationalized moral concern for Mr. Maken's vulnerability, since it offered him an extra layer of protection against the incentives and culture of the penal system.

Privacy and Confidentiality

A prisoner-patient has the same legal rights to privacy and confidentiality in the treatment setting as other patients, provided this can be accomplished without putting anyone at risk of harm or creating a risk of the prisoner's escape.¹⁴ Although the terms *privacy* and *confidentiality* are frequently used interchangeably in healthcare (both in common use and in the literature), it is helpful to conceptualize them as separate but interrelated ideas. *Privacy* is primarily considered in terms of visual and physical space, while *confidentiality* refers to the disclosure, or lack thereof, of information.

The limited literature available concerning treating a prisoner outside prison indicated that the situation we found was very common. Findings of a study by Helen Tuite and colleagues indicate that "Breaches of confidentiality were considered to occur commonly in the management of prisoners who were patients," and "hospital doctors have a low awareness of guidelines for due preservation of confidentiality and also report patterns of professional conduct that militate against confidentiality."¹⁵ The study reports that only 3 percent of doctors "always" asked guards to leave the room during examinations

or physical care, and 31 percent “never” did this. Other studies report that guards “listen attentively to conversations,” watch women in labor, and gossip with colleagues about events that should have been kept confidential.¹⁶

While this should prompt healthcare professionals to take special care to ensure that these rights are respected, one might question the ethical significance of doing so in a case such as Mr. Maken’s. After all, given his unresponsive or inconsistently responsive condition, it was unclear whether Mr. Maken was able to appreciate that his privacy had been invaded and confidentiality might have been breached. Additionally, while the guards who attended him were not entitled to information about his medical condition, the federal prison system was entitled to it. Ultimately, although Mr. Maken did not enjoy the same degree of protection of his confidentiality, this diminished protection did not waive the healthcare professionals’ obligation to protect it to the fullest possible degree. The ethical importance of confidentiality has been defended on a variety of grounds. That Mr. Maken’s personal autonomy and his overall well-being might not be compromised if his privacy rights were breached does not mean that there was no ethical obligation to honor them. In cases such as this, the values of respect and dignity required that Mr. Maken be treated as any other patient would.

Anita Allen has argued that “standard accounts of the value of health privacy . . . rely upon privacy to help control or limit health disclosures that could result in tangible, material losses” such as the loss of insurance or employment.¹⁷ Typically, medical confidentiality is understood to be valuable because it fosters a relationship of trust between the patient and the medical team. But privacy does not merely involve the disclosure of information. Privacy in the healthcare setting also applies to when bodies and behavior may be observed, and by whom. Nudity, the administration of personal care services, and invasive physical procedures are private. Even when patients are unconscious or severely mentally incapacitated, and so will not be embarrassed should strangers witness the patients undergoing this type of care, moral respect demands that we prevent patients’ intimate moments and experiences of suffering from becoming objects of curiosity or spectacles to be viewed by strangers.

Especially relevant to this case was the particular respect for privacy owed to those who are approaching the end of their lives. Allen observes that “there are occasions when nothing less than respect for human dignity and welfare demand that the un-

wanted stranger, and even the unwanted friend, stay away. Illnesses, including hopeless ones that spell the end of life, are such occasions.”¹⁸ Certainly if anyone is an “unwanted stranger” at the bedside of someone close to death, the agent of the state responsible for the punishment of the dying patient is one. During his last days, Mr. Maken was entitled to be treated as a distinctive, irreplaceable individual, rather than as a fungible, dehumanized “prisoner.” Maintaining his privacy was one way his care team could demonstrate respect for his human dignity and affirm his value as an equal member of the moral community.

Given this analysis of the patient’s rights to privacy and confidentiality, the ethics consultants reminded his clinical caregivers that his guards were not his family nor his designated powers of attorney, and so they were not entitled to his private medical information. The ethics consultants strongly recommended that Mr. Maken’s healthcare professionals consistently pull the curtain around his bed or ask his guards to step out during physical care, and to hold discussions about Mr. Maken’s condition and treatment plan in a more private location. One team member articulated her appreciation for this specific guidance and noted, “I don’t think we have been doing that so far.” As reflected in the literature discussed above, the need to heighten caregivers’ awareness regarding the need for additional vigilance is not unusual and supports the argument that positive steps need to be taken to protect prisoner-patients from violations of their privacy rights.

CONCLUSION

Several days following the original consultation request, a DNR order was put in place, on the basis that it was reasonable for any patient in Mr. Maken’s condition. The care plan was to discharge him to the hospital where he was originally admitted, while maintained on dobutamine, but he died before the transfer was accomplished.

It is easy for the vulnerabilities of prisoner-patients such as Mr. Maken to remain invisible. The authority of prison physicians and officials can be difficult to question, and the stigma attached to being incarcerated may cause prisoner-patients to be treated differently than other patients. Nevertheless, healthcare professionals are ethically obligated to provide prisoner-patients with the same quality of care provided to all patients. To do this, healthcare professionals need to be aware of the greater likelihood of violations of privacy and unjustified limitations on care for this patient population. This

awareness should be coupled with the acknowledgment that increased vigilance is necessary to prevent accidental violations. Healthcare professionals should provide extra protection for patients who do not have decision-making capacity by adopting a hybrid approach to decision making—particularly with respect to end-of-life decisions—rather than relying solely on prison physicians as surrogates. These special protections will ensure that healthcare professions will provide prisoner-patients with the care they deserve.

Although there has been much discussion in the literature of prisoners' participation in research involving human subjects, there has been little attention given to their clinical care needs. Importantly, further inquiry and consideration of relevant issues in clinical medicine, such as organ transplantation (both as recipients and donors), treatment of death row inmates, and other treatment limitations or access issues for this population is warranted.

PRIVACY

All names in the case have been changed to protect the stakeholders' confidentiality. Other personal characteristics about the patient have also been changed for the same purpose. Participants in the Cleveland Clinic Clinical Ethics Immersion Program (CLEIP) are integrated into the Ethics Consultation Service team and are held the same high expectations of confidentiality.

NOTES

1. H. ten Have, "Respect for Human Vulnerability: The Emergence of a New Principle in Bioethics," *Bioethical Inquiry* 12 (2015): 395-408.

2. N. Tavaglione et al., "Fleshing Out Vulnerability," *Bioethics* 29, no. 2 (2015): 98-107.

3. There are other ways to elaborate the concept of vulnerability that do not (only) emphasize external circumstances. However, this more limited notion is all that is needed for the purposes of the current analysis.

4. For a thorough review of the literature on the concept of vulnerability, see ten Have, "Respect for Human Vulnerability," see note 1 above.

5. In 1976, the U.S. Supreme Court recognized a right to healthcare for prisoners on the basis of Eighth Amendment protections against cruel and unusual punishment. Given that prisoners must rely on prison authorities to meet their medical needs, prison authorities who display a "deliberate indifference" to these needs are regarded as responsible for the unnecessary pain and suffering that results. Deliberate indifference can take several forms, for instance, "a refusal to investigate further when there is evidence that prisoner may need medical care or the choice to treat in a manner which is 'easier and less efficacious.'" See M.S. Smith, L.A. Taylor, and A. Wake, "Healthcare Decision-Making for Mentally Incapacitated Incarcerated

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17. A. Allen, "Face to Face with 'It': And Other Neglected Contexts of Health Privacy," *Proceedings of the American Philosophical Society* 151, no. 3 (September 2007): 300-8.

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Rebecca L. Volpe, "Ongoing Evaluation of Clinical Ethics Consultations as a Form of Continuous Quality Improvement," *The Journal of Clinical Ethics* 28, no. 4 (Winter 2017): 314-7.

Clinical Ethics Consultation

Ongoing Evaluation of Clinical Ethics Consultations as a Form of Continuous Quality Improvement

Rebecca L. Volpe

ABSTRACT

Ongoing evaluation of a clinical ethics consultation service (ECS) allows for continuous quality improvement, a process-based, data-driven approach for improving the quality of a service. Evaluations by stakeholders involved in a consultation can provide real-time feedback about what is working well and what might need to be improved. Although numerous authors have previously presented data from research studies on the effectiveness of clinical ethics consultation, few ECSs routinely send evaluations as an ongoing component of their everyday clinical activities. The primary purpose of this article is to equip and encourage others to engage in ongoing evaluation of their own ECS. Toward that end, the following resources are shared: (1) the survey tool used to gather the evaluation data, (2) the procedure used to elicit and collate responses, and (3) how the resulting data are used to support continuous quality improvement and justify the continued financial support of the ECS to hospital administration.

INTRODUCTION

Numerous authors have conducted research examining participants' satisfaction with clinical eth-

ics consultation. For example, Robert Orr found that attending physicians at one institution thought clinical ethics consultations were important in clarifying ethical issues, educating the team, increasing confidence in decisions, and managing patients in more than 90 percent of cases. Orr found, however, that clinical ethics consultation resulted in significant changes to patient care in only 36 percent of cases.¹ Likewise, Gordon DuVal conducted a national survey of intensivists in the United States, and found that most physicians (72 percent) thought clinical ethics consultation was useful. Some reported hesitating to seek clinical ethics consultation because of a belief that it would be too time consuming (29 percent), might make the situation worse (15 percent), or that the ethics consultants were unqualified (11 percent).² These prior research studies, and numerous others like them, present data on the effectiveness of clinical ethics consultation.³ Few ethics consultation services (ECSs) routinely send out requests for evaluation as an ongoing component of their everyday clinical activities. One question that may arise is, "Why would an ECS want to send evaluations in an ongoing way if it is not interested in conducting research?"

The answer to this question is that ongoing evaluation of an ECS allows for continuous quality improvement. Continuous quality improvement (CQI) is a process-based, data-driven approach to improving the quality of a service. CQI rests on a

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philosophy that encourages everyone on a team to continuously ask, “How are we doing?” and “Can we do it better?” The core of CQI is curiosity.⁴

PROCEDURE

After an ethics consultation at the Milton S. Hershey Medical Center is complete, the key stakeholders who were most involved in the case receive a form email from the ECS, inviting them to complete a survey. The text of the email follows.

Hello,

Recently you had contact with a member of the Ethics Consultation Service (ECS). The role of the ECS is to assist patients, family members, and healthcare providers who are facing ethical dilemmas. The goals of the ECS are to help identify ethical issues, clarify conflicts, analyze possible options, and move the process toward resolution. Please take a few minutes to rate the helpfulness of the ECS by completing a survey at the link below.

Thank you,
Ethics Consultation Service

You may open the survey in your web browser by clicking the link below: [Link to form; see table 1 for the survey text and results]

TABLE 1. Survey text and results (N = 114)

Questions	
The primary ethics consultant:	%
Was knowledgeable about the relevant ethical issues	4.65
Respected the opinions of all involved parties	4.71
Listened to me	4.76
Helped clarify and analyze options	4.57
Helped clarify the ethical issue	4.59
Clarified who the appropriate decision maker should be	4.55
The ethics consultation:	
Was completed in a timely fashion	4.75
Involved the necessary parties	4.88
Was easy to initiate	4.68
Was helpful to me	4.58
Was responsive to my needs	4.57
Addressed the problem that prompted the consult	4.62
Was overall satisfying to me	4.61
As a result of the ethics consultation (check all that apply):	n
The presenting ethics problem was addressed/resolved	76
A significant problem was prevented or avoided	76
A conflict between the patient and medical staff was prevented, avoided, or resolved	37
A conflict between members of the medical staff was prevented, avoided, or resolved	18
The ethical issues were clarified	89
Patient care was improved	39
Patient length of stay was reduced	2
The medical staff received relevant information	44
It was easier for the medical staff to do their job	35
There were no results of the ethics consultation (please elaborate)	3

In general, one to three individuals are invited to complete an evaluation following every ethics consultation. The ethics consultants focus on those individuals who had the most contact with the ECS, on the principle that those with less contact would be less qualified to evaluate the ECS.

A limitation of our process is that we rarely email families and patients. This is true in large part because while we have ready access to the email addresses of hospital employees, we do not have ready access to the email addresses of patients and families. Some institutions do regularly include patients and families in their evaluations, and report that these data are essential for inclusion and lead to valuable feedback.⁵

After receiving the email, a respondent can click on the embedded link and be taken to the online survey. The survey is hosted on Redcap, a secure, web-based survey platform. We also use Redcap to document our ethics consultations. An advantage of using the same platform for documenting consultations and seeking evaluations is that Redcap can then link individual evaluations with particular consultants and consultations.

THE SURVEY

To complete the survey, the respondent clicks through four pages. The first page contains the text of the email above, the date of the ethics consultation, and the primary consultants' name. There is nothing for respondents to do other than read the information. The second page asks questions about the primary ethics consultant, and respondents are

asked to rate the consultant on a five-point Likert scale ranging from “Strongly Disagree” (1) to “Strongly Agree” (5). The third page asks questions about the process of the ethics consultation, and respondents are asked to rate the process on a five-point Likert scale ranging from “Strongly Disagree” (1) to “Strongly Agree” (5). The fourth and final page is a list of possible outcomes of the ethics consultation, and respondents are asked to check all that apply. A free-text box is provided, and respondents are asked to comment on how the ECS can improve its service. Last, respondents are asked to indicate their role (for example, trainee, attending, nurse), and respondents are invited (but not required) to give their name and email address. The last item asks, “Would you like someone from the Ethics Committee to contact you about your feedback?”

When respondents are finished, they press “Submit” and the data are saved in Redcap.

RESULTS

Our ECS started sending evaluations in 2008 and we have received 114 evaluations since that time (see figure 1). To provide some context for the evaluation data, we provide the number of consultation requests our service receives each year in figure 2.

Unfortunately there is no way to track a response rate; although Redcap *will* calculate a response rate; we only began using Redcap in 2015. Prior to that time we used a program developed by our institution that does not calculate response rates.

Most of our respondents (60 percent) are physicians, which makes sense, in that most of our consultations are initiated by physicians. We also have responses from nurses (17 percent), social workers (6 percent), and mid-level careproviders, such as advance practice nurses (4 percent) and physician assistants (2 percent) (see figure 3).

Evaluations of the ECS show a consistently high regard for the service, with the mean overall satisfaction of the service at 4.6 on a five-point scale. This is especially noteworthy given that ethics consultations often are called after other attempts to resolve conflicts have been unsuccessful.

DISCUSSION

We use the data from the ongoing evaluation in numerous ways. The most immediate use is following an ethics consultation, when we receive the evaluations. Individual ethics consultants get real-time feedback about how key stakeholders felt the consultation went, which is essential for the ethics consultants’ ongoing refinement of their skills. We use the cumulative data for the continuous quality improvement of the ECS. We examine change over time (for example: Is there a dip in the overall rate of satisfaction for one year? If so, what might explain it?) and use the data to reflect on the successes of the ECS as well as opportunities for improvement. Finally, we create an annual report of the evaluation data for the medical executive committee (the hospital committee to which the ECS reports). This quantitative evidence of our productivity and our users’ satisfaction helps us to justify the .5 full-time equivalent salary support the ECS receives from the hospital.

Our process of collecting evaluations has several limitations, which other institutions may seek to avoid. First, although it is impossible to calculate a response rate, it seems evident that ours is low. A low response rate can lead to a biased sample and skewed results, making interpretation of those results difficult. Second, our respondents are mostly physicians. Finally—and most importantly—it is imperative to note that stakeholders’ satisfaction is not necessarily the same as a measure of quality.

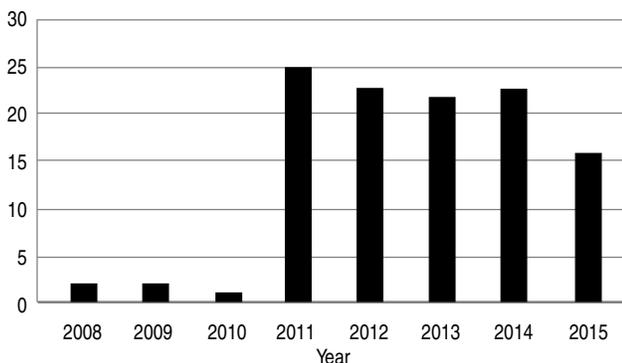


FIGURE 1. Number of ECS evaluations ($n = 114$).

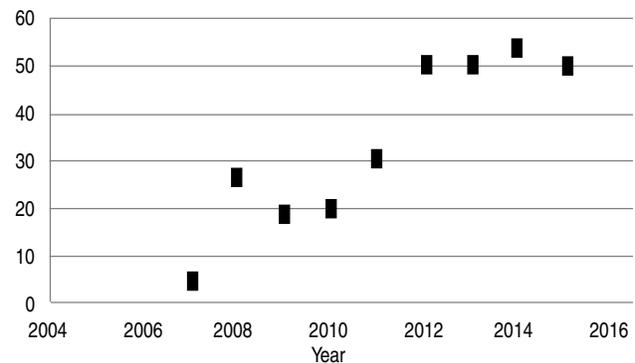


FIGURE 2. Number of consult requests by year ($n = 360$).

For example, a participant might be perfectly satisfied with an ethics consultation that results in an ethically unjustifiable outcome.

One additional issue for institutions to consider as they develop their own process for collecting ongoing evaluations of an ECS is the view of patients and families. As noted above, we do not collect data from this group of stakeholders. Initially this decision was informed mostly by logistical barriers; however, there may also be philosophical reasons to exclude this group. The fundamental question an ECS must consider is: Whom does the ECS serve? Whatever the answer to this question, seeking evaluations from a “customer” is essential. In our institution, the primary “customer” of the ECS is the clinical team. We view our role as inhouse ethics experts, who mostly stand behind the scenes and equip and empower healthcare professionals to engage in ethically appropriate treatment. That said, institutions that gather data from patients and families report that these data are invaluable, and that the perspective of patients and families is more helpful to the institution as a CQI tool than the perspectives of healthcare providers.

In conclusion, ongoing evaluation of an ECS can be burdensome to set up, but once in place may be easy to use. The results can be used in numerous beneficial ways, and at numerous levels including, but not limited to, individual consultant improvement, ECS improvement, and justification of the ECS to the institution’s administration.

NOTES

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4. National Learning Consortium, “Continuous Quality Improvement (CQI) Strategies to Optimize Your Practice,” in *Center HITR*, ed. HealthIT.gov2013:20.

5. R.L. Volpe, “Ongoing Evaluation of Clinical Ethics Consultations as a Form of Continuous Quality Improvement,” paper presented on 21 May 2016 at the 13th Annual International Conference on Clinical Ethics Consultation (ICCEC) in Washington, D.C.

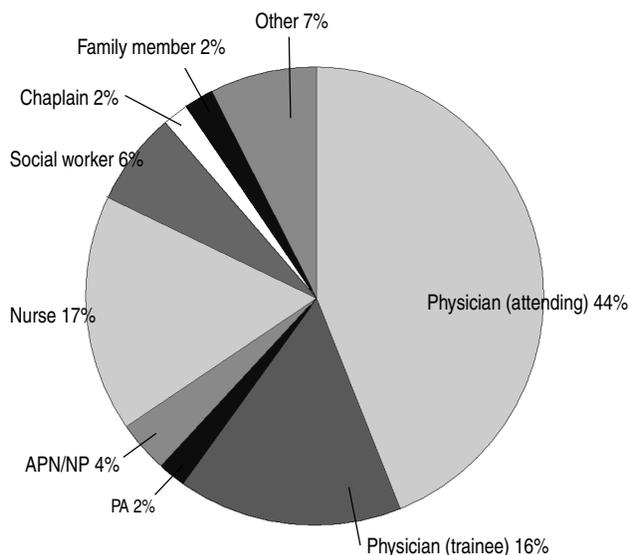


FIGURE 3. Respondents’ role in case ($n = 107$).

Donna Messutta, "Moral Distress, Ethical Environment, and the Embedded Ethicist," *The Journal of Clinical Ethics* 28, no. 4 (Winter 2017): 318-24.

Moral Distress, Ethical Environment, and the Embedded Ethicist

Donna Messutta

ABSTRACT

Interest in understanding the experience of moral distress has steadily gained traction in the 30 years since Jameton first described the phenomenon. This curiosity should be of no surprise, since we now have data documenting the incidence across most caregiver roles and healthcare settings, both in the United States and internationally. The data have also amplified healthcare providers' voices who report that the quality of the ethical environment is pivotal to preventing and containing the adverse effects caused by moral distress. Healthcare providers are asking for a moral space where ethics occurs at the bedside, in real time, applied to real cases. They are asking for ethics expertise to be available as part of the care team during their daily work, when treatment goals must be determined and decisions must be made. They are asking for an embedded ethicist who can help cultivate an ethical environment where formal ethics policy is properly applied to practice. This discussion advocates for an embedded ethics resource model that responds to contemporaneous ethics needs as a strategy to mitigate the effects of moral distress.

INTRODUCTION

In 1984, Andrew Jameton proposed that moral distress (MD) occurs "when one knows the right

thing to do, but institutional constraints make it nearly impossible to pursue the right course of action."¹ MD research is a relatively recent endeavor, but there is already a plethora of published data and commentary, including multiple systematic reviews. Although the concept of MD was initially applied to nurses, it has now been identified across many healthcare provider (HCP) roles, both domestically and internationally. MD research includes data about its incidence, intensity, contributing factors, as well as its negative effects on individuals, members of the HCP team, and the quality of patient/family care. Interventions to ameliorate MD are gaining momentum, but are not as well analyzed. Research data strongly suggest an inverse relationship between MD and morally habitable environments.² Formally structured, "explicit" ethics resources, while valuable, may alone be insufficient to cultivate a robust ethical environment. Feedback from HCPs suggests a need to integrate informal or "implicit" ethics resources at the bedside. The current bioethics literature supports having an ethics consultant embedded in daily clinical operations to decrease MD by contributing implicitly and explicitly to a more morally habitable environment.

RESEARCH

Tools and Measurement

Several tools have been developed and validated to measure MD and institutional ethical climate, in-

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cluding the Moral Distress Scale (MDS),³ the Moral Distress Thermometer (MDT),⁴ and the Hospital Ethical Climate Scale (HECS).⁵ Amended versions, the Moral Distress Scale-Revised (MDS-R),⁶ and the Hospital Ethical Climate Scale-Shortened (HECS-S),⁷ have been developed to adapt to non-nursing HCPs and other study variables.

In 2001, Mary Corley developed the Moral Distress Scale, an instrument to measure MD as a way to better understand the factors that influence nurses' job satisfaction and turnover. Corley's research is motivated by the hypothesis that nurses' practice includes their own value systems, and nurses competently identify ethical issues and rate how these issues cause MD. Corley discovered that an institution's ethical environment is a major factor in nursing attrition.⁸

The MDS is based on Jameton's concept of moral distress, role conflict theory by Robert J. House and John R. Rizzo,⁹ and Milton Rokeach's work on values.¹⁰ In 1993, Jameton expanded the concept of MD to include initial and reactive distress. *Initial distress* describes the feelings experienced when actions are constrained by institutional barriers or differences in values with others. *Reactive distress* describes when nurses are unable to act upon initial distress. House and Rizzo's role conflict theory explains how competing authorities can create conflicting professional expectations. Rokeach's value theory describes the way that personal values affect and motivate behavior. Incorporating the understanding that nurses frequently have greater amounts of responsibility than authority, these theories can be applied to nurses' autonomy and their ability to balance their professional responsibility to the patient with institutional authorities.¹¹

Ethical Environment

Corley found moderately high MD scores, and also that demographic variables and prior resignations were not predictive factors; 15 percent of the nurse subjects reported that they had left a previous position due to MD caused by poor communication, a factor influencing the quality of an ethical environment. Corley recommended further research regarding how relationships with others (peers, management, physicians) and the "ethical work environment" could help to clarify the relationship between MD and job attrition.¹²

In 2005, Sara Hart researched the influence of an ethical environment on nurses' intent to leave their position or their profession. She reported that 25.4 percent of the nurse subjects considered changing positions and 15.8 percent contemplated leav-

ing their profession due to a poor ethical environment.¹³

In 2007, Ann B. Hamric and Leslie J. Blackhall surveyed nurses and physicians in intensive care units (ICUs) to investigate relationships between MD, ethical environment, collaboration, and the quality of care. They found similar results: 28 percent had considered quitting and 17 percent had previously resigned. Nurses rated their ethical environment lower than physicians.¹⁴

In 2011, Phyllis B. Whitehead and colleagues furthered understanding of the link between MD and the ethical environment, as well as the prevalence of MD found in nonnursing- and nonphysician-only studies. They used the MDS-R and added two questions about the subjects' intention (currently or in the past) to leave a position, and Olson's HECS-S to study MD among all HCPs in all practice settings of a Virginia hospital system.¹⁵ MD was found to be prevalent in all HCPs across all practice settings in HCPs serving both pediatric and adult patients. MD was higher for those who had previously considered leaving a position (36.9 percent), who had actually left a job (16.7 percent), or were considering leaving when surveyed (18.7 percent).¹⁶ MD was found to be inversely related to a positive ethical climate for all HCPs. Continuity of care and inadequate team communication, factors directly related to the quality of an ethical environment, were ranked by all HCPs as the most common causes of MD.¹⁷

ETHICS RESOURCES

Requirements

Since 1992, the Joint Commission (formerly the Joint Commission on Accreditation of Healthcare Organizations—JCAHO) has required that institutions have in place a mechanism by which HCPs, patients, and families can address health-related ethical issues. Most institutions utilize an ethics committee, ethics consultation service, individual ethicists, or a combination of all three. The goals of these ethics resources are to provide ethics case consultation, develop ethics-related policies, and disseminate ethics education.¹⁸

To achieve the effective use of these ethics resources, stakeholders must have a "moral space" where ethical values and obligations can be negotiated. Ann B. Hamric and Lucia D. Wocial describe four characteristics that are essential to promoting an effective moral space: knowledgeable ethics representatives, resource visibility/awareness, 24/7 availability, and institutional support.¹⁹ In other words, HCPs need to know how to ascertain the

“who, what, where, and how” of integrating the science and the ethics while practicing in the live theatre of healthcare. They need a bridge between formal ethics resources and the immediate care needs at the bedside. They need an embedded ethicist.

Inter-Ethics

Historically, the traditional model of bioethics was directed at doctors and focused on codes of conduct. It was a bioethical point of view that was “normative and prescriptive,” derived from moral theory and principles.²⁰ But Tineke A. Abma and colleagues suggest that it is not enough for today’s bioethicists to coach HCPs from the sidelines. Instead, since learning is contextual and accomplished by doing, ethicists must facilitate learning by combining theory with practice. Abma and colleagues call this expanded approach “inter-ethics,” and contend that ethicists need to be “embedded and interactive” with those they serve.²¹ Inter-ethics is relational, multidisciplinary, and based on moral knowledge derived from experience. Theory becomes more meaningful when applied to practice. The embedded ethicist’s role is strengthened as it becomes more integrated.²²

Implicit Versus Explicit

A Dutch study investigated the types of clinical ethics support (CES) found in healthcare facilities. The authors categorized types of CES as either implicit or explicit. Explicit CES includes an organization’s structured processes, roles, and tools codified by policy, such as ethics committees, ethics consultation services, ethicists, codes of conduct, and ethics education. Explicit CES is a systematic approach to creating an ethical environment dedicated to serving all HCPs’ roles.²³

Implicit CES is not formally structured, but instead is spontaneous and narrative. Sometimes implicit CES is provided by pastoral care, team exchanges, or curbside conversations.²⁴ Implicit CES avoids the delay and formality sometimes associated with explicit CES. Implicit CES integrates ethics into the daily work of HCPs and may identify ethical issues missed by formal mechanisms. Implicit CES helps HCPs to address ethics spontaneously by responding to the immediacy of their cases. Implicit CES is necessary to “anchor values and norms” initiated by the structured goals of explicit CES. Explicit policies alone cannot change a culture or create an ethical environment. Instead, combining implicit and explicit CES “embeds” ethics into a system’s culture, heightens moral awareness, encourages ethical reflection, and promotes an ethical environment that is helpful in ameliorating MD.²⁵

The ethical environment establishes the context in which ethical decision making occurs in a facility. A Canadian health system implemented a Clinical Ethics Needs Assessment Survey (CENAS) to assess staff’s perceptions of everyday ethics in their own units and how well values shaped ethical practice.²⁶ The authors found that less than 50 percent of staff were “aware” or “very aware” of the system’s ethicist, hospital ethics committee, ethics consultation service, the hospital ethics website, and ethics grand rounds. Ironically, and while lacking awareness, more than 80 percent of staff indicated that ethics education was “important” to patient care. The participants identified the greatest barrier to making an ethics referral was “access,” citing confusion regarding whom to call, who can call, and availability.²⁷ Staff favored interactive ethics education such as interdisciplinary rounds, informal discussions, and workshops rather than self-study or web-based learning. They requested information on topics including communication skills, decision making, end-of-life issues, and the integration of personal and professional ethics with clinical practice.²⁸ A poignant finding was the variability in units, suggesting that local leadership, team dynamics, history, and context are influential variables to consider when developing education that is responsive to each unit’s microculture.²⁹

EMBEDDING STRATEGIES

Rounding

One way that an embedded ethicist can implicitly increase the quality of an ethical environment is to participate in clinical rounds. Rounding occurs when an ethicist joins the medical team’s daily patient presentations to integrate ethics at the bedside, in real time, with real cases.³⁰ This opportunity allows any HCP to raise ethical concerns before a situation escalates and actions occur that contribute to MD.

Medstar Washington Hospital Center in Washington, D.C., incorporates the practice of ethics rounding, and reports that the patient mix on individual units influences the types of ethical challenges. For example, surrogacy issues occur more frequently on surgical units compared with medical or mixed units. This helps ethicists to stratify relevancy and tailor education to each unit’s need.³¹ Evan G. DeRenzo and colleagues report that rounding at Medstar refutes reports that physicians can be averse to consulting ethics committees because of time delays and context-less advice. Ethics rounding is “practical and concrete” because it tackles the

complexity of daily care while reinforcing medicine while it is simultaneously scientific and ethical.³² Rounding also helps to build skills that clinicians can use in future cases. Rounding models the use of ethical terminology, concepts, and dialogue with the interdisciplinary team. The authors report, "Rounding brings ethics training to where the training occurs."³³ Rounding increases the ethicist's visibility, establishes trust, and builds collaborative relationships.³⁴

An ethicist's presence during rounding can flatten some of the hierarchy and power imbalance that contributes to MD. By creating a safe environment where ethical concerns can be raised early, moral courage is promoted across different HCP disciplines.³⁵ Carol L. Pavlish and colleagues developed and tested an Ethics Screening and Early Intervention Tool, and found that nurses could accurately identify ethical cases early, but often avoided speaking up because they feared affecting professional relationships or blatant retribution. "Feeling considerable dissonance between moral obligation and fear of repercussions, nurses experienced uncertainty about initiating action."³⁶ An embedded ethicist can be instrumental in normalizing the interprofessional ethical collaboration that is essential to a supportive ethical environment.

The Medstar Washington Hospital Center reports that rounding increased moral confidence in decision making, which subsequently enhanced moral safety. The staff (especially nurses) showed "signs of relief" when an ethicist rounded, appreciating being able to meet patients' ethical needs. Patient advocacy about moral concerns improved.³⁷ Rounding prevents cases from escalating, utilizes teachable moments, increases moral language/dialogue, and increases the sophistication of ethical analysis. Familiarity with the ethicists increased the number of informal, "curbside consults" that promote early intervention, and subsequently decreases the repetitiveness of cases known to contribute to MD.³⁸

Curbside Consults

As Medstar Washington Hospital Center reports, increasing familiarity with an ethicist may lead to curbside consults, which occur when an ethicist responds to an HCP's request for ethical direction without including other stakeholders, completing a chart review, or entering documentation into a patient's chart. Lauren Edelstein and colleagues describe curbside consults as an opportunity for "conflict coaching" that create new "spaces" for contemporaneous ethical collaboration.³⁹

A Canadian quality improvement survey found that 62 percent of respondents would confer with a colleague before requesting a formal ethics consultation. Physicians frequently use this form of collegial consult in the course of their practice. Embedded ethicists are accessible for curbside consults to promote communication, normalize ethical concepts, and prevent case escalation. The long-term effects of such capacity building decreases risk factors for MD.⁴⁰

The American Society for Bioethics and Humanities (ASBH) Clinical Ethics Consultation Affairs (CECA) standing committee cautions about providing recommendations for specific patients during curbside consults. Curbside consults on individual patients lack comprehensiveness because they do not involve other stakeholders and do not obtain information from the patient's chart or document the consult in the patient's chart. This committee advises ethicists to be "sensitive" to staff who are averse to formal consults, and endorses coaching on routine tasks and providing generic education.⁴¹ The embedded ethicist does have an opportunity to slowly build relationships and trust with those staff who are uncomfortable with formal consults.

Pro-Active Ethics

In 2015, Carol L. Pavlish and colleagues hypothesized that identifying common ethical risk factors could be a catalyst for a "proactive system-wide approach" to ethical conflict that improves patient/family care while mitigating MD. They surveyed physicians to generate lists of ethical risk factors and effective actions by which to address the issues. The physicians requested open/frequent communication, improved teamwork, and applicable ethics education, such as incorporating ethics topics into daily rounds. "Several respondents emphasized not only the need for professional ethics consultation services but also an ethics presence, such as specific team members who have ethics training or who sit on an ethics committee."⁴² The authors suggest cultivating an environment of "ethical mindfulness," including accountability for communication that addresses difficult ethical topics.⁴³

Houston Methodist Hospital did this, and proved just that, when it created a pro-active program with the transplant population in two critical care units. The hospital developed an embedded ethics consultation model in which an ethicist attends rounds, transplant selection meetings, and pretransplant consultations. Not only did HCPs appreciate the ethics presence, the number of requests for formal consultations increased four times on the general units

and five times in ICUs. This suggests that the increased presence of ethicists heightened the staff's awareness of ethics resources.⁴⁴

BARRIERS

Opposing Views

Some may object to the embedded ethicist model because it lacks the plurality and diversity of a formal ethics committee. But ethics committees are retrospective, away from the bedside, and begin with conflict. Even when formal consultations conclude with resolution, moral residue may remain when a problem has become chronic. Many cases that make it to formal consultation are missed opportunities for an earlier intervention on festering issues. Mediation has been suggested as a way to provide the due process missing in the formal consultation model, but it too is retrospective, begins with conflict, and suffers from layers of oversight. The embedded ethicist, especially one who participates in rounding, can provide staff with immediate access to tackling the root cause of repetitive ethical issues. Rounding imparts ethical knowledge and models ethical analysis. Moral courage and assertiveness may increase in staff who feel comfortable with ethical dialogue. As their moral expertise increases, so does the moral safety of their environment, decreasing the likelihood of MD.⁴⁵

Cost and Value

Cost and satisfaction are common metrics used to measure the quality and necessity of healthcare services. The value of ethics consultation has been measured by calculating length of stay (LOS) in the hospital and ICU and the number of days requiring life-sustaining interventions. A study of the efficacy of a pro-active ethics consult model found no decrease in LOS, however, nor a reduction in nonbeneficial care nor an increase in patient/staff satisfaction.⁴⁶ Using these outcomes to evaluate the effectiveness of an ethics service is problematic. It assumes that early palliation uses fewer resources, subsequently reducing costs, and so justifies the worth of ethics consultation. It does not account for the individual reasons that patients and surrogates make decisions, or when and why they make these decisions. Some patients opt to continue aggressive treatment or lifesaving interventions to survive until a particular milestone, such as a birth or wedding. A decision to prolong life does not suggest that an ethics consult was less successful or was ineffective.⁴⁷

Similarly, dissatisfaction with ethics services by patients, family members, or staff does not always

mean ethics services have been ineffective. Moral deliberation involves challenging and emotional choices that are value laden and context dependent. Patients and family members may be dissatisfied that their choices were restricted by the patients' clinical status or technological limitations, but that does not imply that the ethical resolution was not morally sound. Dissatisfaction with a clinical outcome is different than being displeased with an ethics service.⁴⁸

Even though they are mandated by the Joint Commission, ethics services do not directly generate revenue. Ethicists do contribute to the responsible management of resources, but measuring the value of ethics resources based on the dollars saved risks prioritizing cost reduction over patients' ethical needs. A focus on cost savings might give the appearance that ethics interventions are coercive, with a fear that they may promote end-of-life decisions to save money. This association can impact the public's trust in an institution's commitment to ethical integrity.⁴⁹

Instead, the value that ethics resources add should be considered "intangible assets" or "intangible benefits." Intangible assets are created by innovation, institutional design, or human/intellectual capital. An ethicist's expertise is considered to be an example of human capital. Direct benefit is difficult to measure, but indirect benefit can be assessed by factors such as data regarding the retention of staff and feedback about ethics training. Embedded ethicists add value in terms of future benefits that advance the mission and goals of an institution and promote a healthy ethical environment.⁵⁰

FINAL ARGUMENT

Anita Ho and colleagues state, "The key to preventive ethics is access to ethical expertise, ongoing exposure to ethical wisdom, a culture of ethical reflection, and a mechanism for regular team communication."⁵¹ The present discussion has advocated improving the moral environment of health facilities by embedding ethicists in the daily activities of patient care as a strategy to decrease MD.

HCPs contend that formal ethics consults are not their first choice during their daily work, but instead that they need and want ethics support at the bedside.⁵² An embedded ethicist is uniquely situated as a bridge between explicit ethics structures and the implicit resources that are suited and essential to daily clinical activity. An embedded ethicist promotes an awareness of resources and collaborative relationships with staff, so as to better stratify the

needs that are specific to the microculture of each unit. Embedded ethicists are available in real time, debunking objections that ethics consult responses are delayed, difficult to access, or time consuming. Ethicists can mitigate power imbalances and dispel fears of retribution that may impede some HCPs from raising ethical issues.⁵³ When HCPs act against their moral intuition, their moral identity is eroded, further fragmenting their ability to practice ethically, and increasing the risks of MD. Creating a moral community depends on the support of healthcare institutions in cultivating staff's courage to voice their ethical concerns. An embedded ethicist promotes open communication and transparency, both of which are key to enhancing our moral spaces by transitioning moral reasoning into moral practice. As Wing May Kong notes, "A thriving community will provide the critical mass to enable the language of ethics to flourish and to move out of the classroom into everyday clinical discourse."⁵⁴

CONCLUSION

When I was a young ICU nurse in the early 1980s, my colleagues and I used to joke about quitting our nursing jobs and going to work at the grocery store across from the hospital. It wasn't because we didn't like being nurses, or were opposed to working hard. It wasn't because the cases we encountered were often tragic and sad—that was a part of our job. Instead, we were looking for relief from the cases fraught with ethical issues that went unaddressed. And, to make matters worse, there was the perpetual recurrence of the same ethical conflicts: another day, different case, same issue. There was no expertise available to incorporate ethical principles with new lifesaving technology that indefinitely sustained patients like never before. Paternalism was still actively contributing to decisions that caused patients to linger, suffer, and endure nonbeneficial treatment. Some of those cases still haunt me, and always will. We needed someone at the bedside with us then, a moral voice to help integrate ethics with the emerging science, so as to better care for our patients and alleviate our own MD. And we still need that guidance today. It may be unlikely that we can eradicate MD. But by "embedding" our expert resources—our ethicists—we can proactively build a more robust ethical environment and mitigate the effects of MD.

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Medical Education

The Rise of Hospitalists: An Opportunity for Clinical Ethics

Matthew W. McCarthy, Diego Real de Asua, and Joseph J. Fins

ABSTRACT

Translating ethical theories into clinical practice presents a perennial challenge to educators. While many suggestions have been put forth to bridge the theory-practice gap, none have sufficiently remedied the problem. We believe the ascendance of hospital medicine, as a dominant new force in medical education and patient care, presents a unique opportunity that could redefine the way clinical ethics is taught. The field of hospital medicine in the United States is comprised of more than 50,000 hospitalists—specialists in inpatient medicine—representing the fastest growing subspecialty in the history of medicine, and its members have emerged as a dominant new force around which medical education and patient care pivot. This evolution in medical education presents a unique opportunity for the clinical ethics community.

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Through their proximity to patients and trainees, hospitalists have the potential to teach medical ethics in real time on the wards, but most hospitalists have not received formal training in clinical ethics. We believe it is time to strengthen the ties between hospital medicine and medical ethics, and in this article we outline how clinical ethicists might collaborate with hospitalists to identify routine issues that do not rise to the level of an "ethics consult," but nonetheless require an intellectual grounding in normative reasoning. We use a clinical vignette to explore how this approach might enhance and broaden the scope of medical education that occurs in the inpatient setting: A patient with an intra-abdominal abscess is admitted to the academic hospitalist teaching service for drainage of the fluid, hemodynamic support, and antimicrobial therapy. During the initial encounter with the hospitalist and his team of medical students and residents, the patient reports night sweats and asks if this symptom could be due to the abscess. How should the hospitalist approach this question?

INTRODUCTION

Teaching medical ethics to medical students and residents presents a perennial challenge to educators. The difficulties of translating ethical theories into clinical practice are well documented, and while many suggestions have been put forth to bridge the theory-practice gap, none have sufficiently remedied the problem.¹ We believe the ascendance of hospital medicine as a dominant new force in medical education and patient care presents a unique opportunity for the teaching of clinical ethics in real

time that could redefine the translational movements that occur between ethical theory and practice.² While other clinical educators can and will contribute to the professional formation of students and trainees, the growing prominence of hospital medicine warrants a consideration of how and why they might bring medical ethics closer to the bedside.

First described in 1996 as the physicians dedicated to the delivery of comprehensive medical care to hospitalized patients, “hospitalists” have since become one of the fastest growing medical professional groups in the U.S.³ There are more than 50,000 hospitalists in the U.S. today, which makes this new field larger than any specialty except internal medicine and family medicine, and all highly ranked academic health centers in the U.S. now employ them.⁴ It is widely appreciated that, given their continuity and accessibility in inpatient care, the use of hospitalists has diminished the role of specialists and researchers on teaching services.⁵ Thus, in addition to playing a central role in clinical care, hospitalists increasingly serve as primary educators during the clinical years of medical school.

This evolution in clinical practice implies a change in the present educational paradigm and offers a unique opportunity for collaboration with the clinical ethics community. Since hospitalists have become role models for medical students and trainees, cross-training them in medical ethics, normative reasoning, and professionalism could help inculcate a professional ethos into an increasingly complex and fragmented healthcare system, creating an opportunity to inform professional formation in medical education.⁶

Teaching on the wards is essential to professional development. In that context, students and trainees are exposed to ethical quandaries, which many may feel unprepared to handle, given the stress of clinical work and the complexity of real cases versus those presented in the classroom in their pre-clinical work.⁷ On the wards, trainees develop a new perspective on the complexity of these issues that necessitates more sophisticated normative reasoning in the clinical context.⁸ Finally, ethics education, absent a robust clinical component, is fruitless and erodes the explicit curriculum taught during preclinical years. Without the endorsement of practicing clinicians, ethical theory, often grounded in principlism, may be damaged by the hidden curriculum, to be described later in this article.⁹

For hospitalists to address ethical issues in real time on the wards, they must be familiar with theory *and* practice. Understanding how an ethicist approaches a clinical conundrum enables hospitalists

to engage more fully with difficult issues—especially those that do not rise to the level of a formal ethics consult—to identify conflict and to reason through possible resolutions and to use this as a teaching opportunity. Properly trained hospitalists may provide an intellectual framework for discussing medical ethics in real time on the wards.

For these reasons, a unique opportunity exists for hospitalists to teach medical ethics, professionalism, communication, and normative reasoning to trainees and their colleagues on the ward.¹⁰ These competencies cannot be taught solely in a classroom; they require clinical experiences and so fit into the purview of hospital medicine. To fill this role, however, hospitalists must be properly trained.¹¹

Bringing hospitalists into the educational mix is a way to address what has been described as the hidden curriculum. The hidden curriculum is broadly defined as the processes, pressures, and constraints that fall outside the formal curriculum that are often not articulated or explored.¹² The hidden curriculum is an enduring problem in medical education and teaching professionalism, in which formal education on ethics and professionalism in the undergraduate medical years may be undone when students get to the wards.¹³ Hospitalists, by teaching ethics and modeling professionalism, can help counter this.

In this article, we examine why hospitalists must be an essential element in ethics education and how the emerging subspecialty can learn from and work with clinical ethicists. This will prove to be a fruitful synergy in the formation of trainees and, most importantly, to the patients who are entrusted to them.

WHY HOSPITALISTS?

As the field of hospital medicine has matured, its members have taken on an ever-expanding scope of educational opportunities and objectives.¹⁴ On teaching services, hospitalists often serve as the attending of record as well as evaluators and role models for the medical team.¹⁵ In many institutions they serve as residency and clerkship directors. Across the country, hospitalists are at the center of educational contact and patient care, which allows them to interact with patients and students in real time.¹⁶

Since hospitalists do the bulk of clinical teaching, they could serve as the center of medical ethics education in the clinical setting. Hospitalists confront many controversial topics on the wards, where they learn to handle ethical quandaries in clinical

practice in real time. Hospitalists must bring conflicting values into balance and prioritize them in the context of patients' and family members' preferences, established legal precedents, and the norms and beliefs of the medical team.¹⁷ Learning to do this is a challenge for any healthcare provider; it is even more difficult for the inexperienced practitioner.

Properly trained hospitalists would be able to identify and examine the ethical and professional issues frequently encountered (and often overlooked) in the inpatient setting. They may become the "conscience" of the clinical team and integrate discussions of norms, values, and preferences into routine clinical work.¹⁸ To achieve this, however, the ties between clinical ethics and hospital medicine must be strengthened. Hospitalists should be invited to participate in hospital-based ethics committees, and clinical ethicists should be invited to join daily ward rounds. Given their unique vantage points, both groups could partner in preclinical and clinical medical ethics education.

Hospitalists' concern about these issues can bring questions of clinical ethics and professionalism to the bedside, not theoretical musings. Every case can become a classroom. This connection to the needs of real patients and the biomedical science undergirding diagnosis and treatment can affect patient care and trainees' educational experiences.

Hospitalists' central role in clinical transactions, coupled with their standing as the attending physician, gives them a greater impact on the educational environment and the sociological variables that influence learners. This influence is amplified by hospitalists' power as students' and trainees' evaluators. If questions of ethics and professionalism are discussed on rounds, medical students and residents will follow their lead, if only to please their supervisor. Ethics is more than a mode of analysis for explicit conflict. It is a way to interact and do things. The formation of "ethical habits," over time, in the context of regular work experience, is critical. A good grade should not be the motivation for virtuous behavior, but the evaluative power wielded by hospitalists helps explain why they are well positioned to have a significant educational influence on clinical training.

In sum, the central role played by hospitalists in medical education and patient care places them at the center of clinical education for medical students and trainees.¹⁹ Hospitalists may help to consolidate curricular elements that have been emphasized in the preclinical years. Through case-based teaching and practice, hospitalists may be able to

counter the erosive effects of the hidden curriculum on professional development, and to model more constructive archetypes of care and comportment. The framework is for real students to talk about real issues that pertain to professionalism in real time.

We hope this educational ethos expands to other specialties and subspecialties, much as the hospitalist model has spread to pediatrics, surgery, neurology, and obstetrics. A preliminary role for hospitalists and the hidden curriculum in pediatric training has already been advanced.²⁰ To do this, hospitalists must become conversant in clinical ethics.

EVERY CASE A CLASSROOM

Because the influence of hospitalists on medical education will be felt through their impact on individualized patient care, it is useful to highlight the potential educational value of the case presented above. Even the most mundane medical case has ethical content that can be explored by hospitalists, even those cases not traditionally considered to be "ethics" cases.

Hospital medicine is laden with ethical quandaries and includes often-overlooked opportunities for discussions about professionalism. Consider a case drawn from our own experiences that illustrates how "routine" cases can be employed as vectors for professional education. The patient presents to the emergency room with an intra-abdominal infection and is admitted to the hospital for paracentesis, antibiotics, and hemodynamic support. The patient has a question about night sweats, a straightforward issue with a broad differential diagnosis. In response, the hospitalist shares his thinking with the team of students and residents. He explains that, while night sweats can be due to the abscess, they could also be explained by malignancy, tuberculosis, the human immunodeficiency virus, or hormonal disorders. The possibilities are open-ended, but the hospitalist is confident that the sweats are from the abscess.

The ethical question is, should the hospitalist discuss all of these diagnostic possibilities with the patient? Does the patient have a right to know? Is it wrong to withhold information? Is information an absolute right? If so, would nondisclosure violate the patient's right to self-determination? What about making a choice about what to disclose? Is that a physician's professional prerogative? If it is, how should a doctor make a judgment about *selective* disclosure? Is it a question of burdens and benefits and proportionality? Is this culturally determined? And, on the extreme of harm, is it ever justified to

completely withhold information because of a patient's emotional fragility? If that is reasonable in theory, how might a doctor know that a threshold has been reached in practice? A simple case, with a straightforward question, can result, if properly curated, in wide-ranging discussions with trainees regarding (1) truth-telling, (2) proportionality, (3) disclosure, (4) autonomy, and perhaps most importantly, (5) how we translate scientific information into value choices.

In our experience, medical students and residents have remarkably different approaches to these questions. Airing them needs to accommodate the learning styles of all involved. Logistically, the conversation could happen in a variety of places—outside a patient's room, on chart rounds, or even at the bedside, when appropriate. Hospitalists may or may not feel comfortable leading such discussions, but even cursory exposure to clinical ethics might allow a more informed conversation with trainees—one with specific educational objectives.

Temporally, the discussions can happen over time, during the course of a patient's hospitalization and over the duration of a trainee's rotation. In this way, conversations can be iterative and reflective, with students and trainees revisiting earlier decisions as new medical data come in. When these themes are integrated into rounds, conversations about ethics and practice can evolve over time in an organic manner linked to care.

The longitudinal nature of these discussions has an advantage over conventional ethics consultation. They are episodic and bring new teams into the mix. While formal ethics consults have great value, to limit ethics deliberations to times of conflict and crisis misses opportunities for education.²¹ Logistically, there are far more ethics issues than ethics consultants, and that is why hospitalists as ethics educators are indispensable. If the only time ethics is discussed on rounds is when there is a formal ethics consult, a lot of "case material" that is important to professional formation remains unaddressed. Hospitalists may serve as the beacon to detect novel trends in ethically challenging clinical problems that may not yet have reached the clinical ethics team, but would benefit from their insight.²²

If we return to the case of the patient with night sweats, we can see the role that may be played by hospitalists in bringing ethical dimensions of care to bedside teaching. For example, if the decision is to be more beneficent than enfranchising, a hospitalist may shield the patient from unlikely diagnoses that might cause emotional distress (an act of beneficence) rather than inform the patient of every

diagnosis under consideration (an act of enfranchisement). That decision could be revisited if new data suggest a heightened possibility of cancer. These developments point to the contingency of ethical judgments and the old adage, "good facts make for good ethics."²³

By living through these disclosure decisions, trainees will come to appreciate the complexity of ethical judgments when situations are fluid, and the importance of moving beyond theory. To achieve this educational mission, we call on clinical ethicists to help train hospitalists in normative reasoning to facilitate these conversations.

This vision poses challenges for hospital medicine, founded on a model of efficiency. Hospitalists must balance patient care with clinical education, administrative duties, and expanding requirements for documentation. The idea of turning "every case into a classroom" may seem untenable. In our experience—we are in year two of a hospitalist/ethics collaboration—teachable moments at the bedside need only last a few minutes and may actually save time (resolving conflicts before they emerge, fewer family meetings, and so on). Nonetheless, any new objective introduced to hospital medicine must be balanced against the demands of the job.

EVIDENCE-BASED MEDICINE, CLINICAL ETHICS, AND HOSPITALISTS

Beyond questions of individual case analysis, bringing medical ethics and value choices to clinical thinking is especially important, because medical reasoning is often reductionist and dominated by evidence-based medicine. This too is part of the hidden curriculum that endorses an objective reality, based on clinical outcomes research, that can be more fallible than practitioners care to acknowledge.²⁴ Despite our best efforts to remove uncertainty by standardizing medical care through the use of checklists, performance measures, electronic medical records, and consensus statements, clinical ambiguity remains, and this needs to be appreciated and recognized.²⁵ There are still gray zones, where judgment is necessary.²⁶ Clinical decisions inevitably blend evidence-based and normative reasoning, culminating in professionalism in practice. This may be a life lesson for novice practitioners.

This is an important lesson, that may seem to run counter to the tenets of evidence-based medicine, but it is wholly consistent with David Sackett's famous admonition, "Evidence-based medicine is the conscientious, explicit and judicious use of current best evidence in making decisions about the

care of individual patients. The practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research.²⁷ This can be modeled for trainees.

Skilled hospitalists can follow Sackett's counsel and stress that a plurality of methods should be employed, to allow a blended approach of objective and subjective dimensions of care. They could make the point with the quip, "having the right medicine for the wrong patient." When there is little or no good evidence to inform care decisions, clinicians should appreciate epistemic limits and respond professionally.

When there is ambiguity regarding the proper course of action, physicians are more likely to draw on personal experience, defer to an expert consultant, or defer to the will of the patient.²⁸ These choices—the ones for which there are neither evidence nor formal guidelines—are the most difficult to make and require professional judgments that cannot be made without a grounding in the art and science of medicine.²⁹ These dynamic moments, so important in the care of patients, are excellent occasions for teaching (and modeling) professionalism.

When hospitalists embrace the moral complexities of modern medical care, using evidence when it is available and deviating from guidelines and consensus statements when evidence is not available, they do more than improvise. They engage in a translational activity that marries numbers and values.³⁰ They act humanely, using medical knowledge, in the service of their patients, in the pursuit of the good.³¹ When trainees and students watch their mentors provide care under these circumstances, the lesson can be a profound and enduring one about professionalism and physicians' obligations.

THE HIDDEN CURRICULUM AND THE SOCIOLOGY OF LEARNING

Let us return to the hidden curriculum and why hospitalists may be positioned to counter its effects. The hidden curriculum influences the sociology of the learning environment.³² It implicitly influences a learner's educative goals and priorities, distorting the explicit curriculum. Hospitalists alter the sociology of the clinic and exert their influence over that learning environment by their presence. Their name, *hospitalist*, is a powerful reminder of where they are and where their influence is felt. Their actions and role modeling can be picked up as silent cues by students and trainees, and implicit forces in the professional formation process.³³ If medical students

were "let free" after their preclinical years into the uncontrolled world of the hospital, hospitalists can do more to positively influence students' development. The influence of hospitalists is amplified when they "walk the walk" and "talk the talk." In this way, explicit and implicit curricular elements may come together and reinforce each other. This synergy can help transform the modern clerkship and residency and realize William Osler's vision of the hospital as a college.³⁴

This is not unexpected. For more than a century, social scientists have understood how social structures and informal group culture can influence norms and individual behavior.³⁵ The great educational reformer and mid-century pragmatist John Dewey hinted at this concept in his work on "collateral learning"—that is, knowledge that is gained while doing other things—anticipating what would come to be understood as the "hidden curriculum" by the 1960s.³⁶

Dewey argued in *Experience and Education* that "collateral learning in the way of formation of enduring attitudes, of likes and dislikes, may be and often is much more important than the spelling lesson or lesson in geography or history that is learned. For these attitudes are fundamentally what count in the future."³⁷ But more critically, when considering the negative effects of the hidden curriculum, if the learning environment is adverse, education can be undermined. Dewey could have been writing of the hidden curriculum when he observed, "If impetus in this direction is weakened instead of being intensified, something much more than mere lack of preparation takes place. The pupil is actually robbed of native capacities which otherwise would enable him to cope with the circumstances that he meets in the course of his life."³⁸ Clearly these negative inputs could have bearing on trainees' cultivation of professionalism.

This argumentation was more fully articulated as the hidden curriculum by Benson Snyder in the early 1970s in his book of the same name. In *Hidden Curriculum*, he considered the unstated, inflexible social norms of college campuses and argued that these unwritten rules cause anxiety and impair students' ability to develop critical thinking and reasoning skills. The work was subsequently extended to graduate medical education, where the findings were even more robust, as medical students reported the dehumanizing effects of the hidden curriculum on their nascent professional identities.³⁹

This brief conceptual lineage of the hidden curriculum reminds us that we must attend to the sociology and the context of learning if we hope to over-

come the powerful pull of these forces. And that is why we believe that hospitalists, exerting educational influence in the clinic, might be highly effective in countering the hidden curriculum's negative influence on professional formation.

REMAINING CHALLENGES

Our vision for the hospitalist-educator, empowered to bring questions of ethics and professionalism to bedside teaching, is ambitious. Some might even say it is quixotic. Nonetheless, we believe that, with appropriate help, hospitalists are well positioned for this role based on their proximity to patients and their central role in modern medical education. With proper training in clinical ethics, to complement their considerable clinical experience, they will be able to fulfill this vital educational role.⁴⁰

To realize this we must broaden the possibilities of what it means to be a hospitalist as practitioner and as a medical educator. We need to engage leadership in hospital medicine, medical ethics, and undergraduate and graduate medical education to better apprehend how to train hospitalists for this expanded role. A first step is to strengthen the ties between clinical ethics and hospitalist communities and explore opportunities for collaborative efforts in medical education and research. Medical ethicists can (and should) be brought to the wards to initiate teaching collaborations with their hospitalist colleagues.

This connecting role with the wards may allow for earlier detection of ethical conflict, as well as for a sharper realization of the daily ethical challenges in inpatient care. Clinical ethicists have an opportunity to achieve a major educational impact on a wider proportion of medical trainees through their hand-in-hand work with an homogeneous, concentrated, and consistently available population of attending physicians. Similarly, hospitalists should have exposure to medical ethics activities such as service on hospital ethics committees and teaching in the preclinical ethics curriculum.

We also need current practice data. What are the primary ethical issues that inpatient clinicians confront? How often do they arise? How are they resolved? How do hospitalists frame these issues? By quantifying and describing these scenarios, a curriculum may be created to educate hospitalists—to “train the trainers”—so that ethical and professional issues can be woven into daily ward rounds with students and residents.

Given the demands of the job, hospitalists may initially need incentives to engage in additional eth-

ics training. This training can lead to an increase in the quality of care. Engaging in clinical ethics provides numerous benefits for healthcare professionals, not only because of the satisfaction of conducting themselves in a professionally ethical manner, but because they may then cope better with professional burnout.⁴¹

There is much work to be done to move this agenda forward, and many conversations to be had across disciplines that before now have had minimal engagement. It would be wrong to see this initiative as a threat to clinical ethics; rather, we envision a multiplier effect, in which an increase in ethically conversant physicians and trainees leads to greater awareness of the challenges encountered on the wards. To counter the hidden curriculum and sustain professionalism, it is time to move from these reactive encounters and pursue proactive, collaborative efforts with clinical ethicists to reaffirm the art and science of bedside teaching.

PRIVACY

The patient's details have been changed to protect the patient's anonymity.

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