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At the Bedside

Edge-of-the-Field Ethics Consulting: What Are We Missing?

Edmund G. Howe

ABSTRACT

Ethics consultants’ grasp of ethical principles is ever improving. Yet, what still remains and will remain lacking is their ability to access factors that lie outside their conscious awareness and thus still effect suboptimal outcomes. This article will explore several ways in which these poor outcomes may occur. This discussion will include clinicians’ implicit biases, well-intentioned but none-theless intrusive violations of patients’ privacy, and clinicians’ unwittingly connoting to patients and families that clinicians regard their moral values and conclusions as superior. I shall suggest several ways in which clinicians may seek to reduce these sources of bad outcomes or at least to do better when they occur.

In this issue of The Journal of Clinical Ethics (JCE), in “The Work of ASBH’s Clinical Ethics Consultation Affairs Committee: Development Processes Behind Our Educational Materials,” Courtenay R. Bruce, Jane Jankowsky, Barbara L. Chanko, Ann Cordes, Barrie J. Huberman, Liza-Marie Johnson, Deborah L. Kasman, Aviva Katz, Ellen M. Robinson, Katherine Wasson, and George E. Hardart describe why they wrote the ASBH’s latest guidelines for doing ethics consults as they did.1 This new ASBH Study Guide provides edge-of-our-field guidance on how clinicians can best do consults. It presents this material in a way that is especially designed to engage readers, and thus, to maximize their learning.

Still, huge challenges remain. Patients and families may, for example, leave consults feeling wronged and even embittered. As a result, they may not only carry these feelings with them for the rest of their lives; they may not seek the care they need in the future, even though they know this may be harmful to them.2 There are many reasons for such suboptimal outcomes. Persons’ values, for instance, may differ, and when their moral preferences are not respected, they may feel angry. We should learn to respond more effectively, over time, due to such gains as those provided by the ASBH Study Guide. The guide urges us, for example, to always indicate explicitly to patients and families what we understand to be their views whether or not their views differ from our own.3 This task is fundamental.

Yet, regardless of the knowledge we have and the gains we make, there are some ways that we may be less likely to progress. These are the ways in which we don’t know, for one reason or another, that we have caused another harm. Not knowing we have done this, we may not be able to correct the harm. I will consider such blind spots in this introduction to the summer 2018 issue of JCE. I will discuss three of the ways in which we may harm patients and families without fully knowing it, and I will also discuss ways in which we may try to do better.

I will do this in three sections. In the first, I will discuss how we may convey harmful, implicit biases without knowing it. We may not only not know
that this harm has occurred; we may defend ourselves if a patient confronts us with what we have done and how the patient has been affected. Defending ourselves only makes matters worse. Mutual hostility may escalate and soon dissolve our patient’s trust in us and our relationship. Such a negative downward cycle can take place in response to all of the ways that we may harm patients that I will consider here. I begin with this example so that readers can use it as a paradigm for considering aspects of later examples I will provide. These aspects primarily include other ways that we may alienate patients without knowing it, and then react defensively when they confront us with how they feel.

In the second section, I will discuss two additional ways that we may harm patients profoundly, also without knowing the extent to which they have been harmed. The two examples I will discuss are built on concerns raised in other articles in this issue of JCE. One involves clinicians who violate patients’ privacy. The other involves clinicians who share painful information that, while possibly true, may be unnecessarily hurtful, especially when the hurtful information is shared without softening it by placing it in context. Without placing the information in context, it may alter how patients see themselves, perhaps for the rest of their lives.

In the third section, the harm I will discuss particularly applies to clinicians who do ethics consultations, and applies whether the consults are formal or informal, as consults often are on the wards. The risk of harm occurs because we may, merely by taking on the role of ethics consultant, even informally, imply to a patient or family member without being aware of it that we view our moral insights as superior. The negative effect of evoking fear or resentment in a patient or family member may be much greater when we actually do believe that our insights are superior.

If patients or family members feel this fear or resentment, they may tend to respond in either of two ways. They may protest. This may be counterproductive. Their protesting may not succeed in getting them what they want, and the hostility they evoke may be painful for them and may cause those whom they confront to become even less flexible. Or, perhaps even worse, they may remain silent, but lose their trust in us, and, as a result, make suboptimal decisions. Either way, their outcomes, although hidden, may be poor, even catastrophic. I will suggest that, overall, we may do best to assign highest priority to maintaining our patients’ trust and maximizing our relationship with them. If we do this, we may enable our patients and their family members, and also ourselves, to respond more insightfully to ethical conflicts. In addition, everyone involved in making treatment decisions may be able to work more closely together, which may enhance the ultimate results.

**Implicit Bias: What It Is; How It Works**

“Implicit bias” refers to the many ways we may demean others without knowing that we have done so. Implicit bias is broad and includes prejudices and stereotypes that can affect our judgments and actions subconsciously. Prejudice and stereotyping involve different parts of the brain, and thus different approaches may reduce each. For example, prejudice may be brought about by fear, may occur only once, and may be difficult to erase. Stereotyping is more cognitive and more alterable by new learning and experiences.8 Persons who have less status in society are more likely to be the subjects of bias. Derald Wing Sue, an authority on implicit bias, states that while microaggression often involves race, it can go beyond race to the socially constructed identities that embody privilege such as income, social capital, religion, ableness, gender, and sexual orientation.7 Since, as medical professionals, we are much less likely to experience lesser status, it is particularly important for us to be aware of such slights so that we can avoid them. Unlike many more-privileged persons, we are at greater risk of inflicting harm because we may see ourselves—accurately—as not having conscious biases, or at least doing all we can to avoid them.8 With this commitment and source of professional and personal self-respect, we may be paradoxically less likely to be able to see that we may still have implicit biases that we can’t detect, and that our biases may harm others, including patients and families. We may, in other words, feel exceptionally committed to regarding all of our patients as equal. This heightened commitment may, however, make us more blind to recognizing our limits in being able to do this. Thus, we may become defensive should we be criticized for having an implicit bias.9 When this occurs, our defensiveness may trigger reciprocal responses, overt or covert, in patients and families, and this cycle may continue and grow. As a result, patients and families may respond in either of the two self-injurious ways I described above. They may feel fear and resentment, and damaged trust. Having elucidated how implicit bias may occur in general, I will give some specific examples.

**Examples That Illustrate Implicit Bias**

I will begin with an example in which the person who was offended was an MD/PhD. This doctor, a person of color, was going with his wife to a
restaurant when a patron at the same restaurant assumed that he must be a parking attendant. She dropped her car key into his hand and didn’t say a word. He reports that he felt flooded with feelings of inferiority and helplessness. Another example illustrating of such bias with people of color is the following. In an attempt to show they are not bi-ased, some clinicians say they treat everyone the same; they may say that they are “color blind.” Readers may wonder, how could this possibly be perceived as offensive? The answer is that some people experience this approach as negating the importance of their different race, ethnicity, and/or culture. As with all behaviors that some people find offensive (assuming there are valid grounds for the offense), we should all regard the behavior as offensive. The example of “treating everyone the same” is particularly useful at this point, because it illustrates how implicit bias may lie outside our common knowledge and even lie beyond what we are able to imagine. Thus, it is important to scour the literature on this topic, when we can, to become better aware of what others may find demeaning, even though we would never intend to demean another person. Fortunately, there are many writings that may help us.

Let me now add to the above example a bias that I have expressed in the past repeatedly. When I have met a person who seems clearly to be from another country, I have asked, “Where are you from?” I believed at those times that I was only expressing my genuine interest in the other person. This was not, however, what some perceived. Some feel demeaned by this, because, to them, it implies that I (and others) may see them as not fully American, but as “other.” I ask readers to note what they feel as they read this. If you experience a strong feeling of disbelief, or even irritation, you can use this to better understand how we may be at risk of responding defensively when we are confronted by another person who is offended by a bias we have expressed. That is, if a patient or family member confronts us regarding an implicit bias we unknowingly expressed, we may be vulnerable to responding, at least nonverbally, in a way that is dismissive. As David Wing Sue notes, we may express our disbelief and that we feel wronged, not only verbally but with dismissive looks, gestures, and even tone of voice.

We may make matters worse by telling ourselves, and telling the other person, that he or she is being overly sensitive. In such a situation, we may continue in our previously wrong inferences and conclude that the other person’s reaction is not only unwarranted, but unfair to us. Such denial and an attempt to rationalize away the other person’s response are common among people who are con-fronted. My purpose is not to discuss when, or whether or not, in a specific situation or in situations in general, another person’s taking offence is or is not justified. My purpose is to suggest that all of us should strive to see these responses, when they occur among our patients (and ourselves), as warranted and justified. It is necessary because only this will enable us to maximize the care we give to our patients and to grow as clinicians. Otherwise we can only sow seeds of distrust that will most likely under-mine whatever we do that is beneficial.

It may be that, in some cases, others’ “sensitivity” goes way too far. For instance, a colleague who teaches psychology described to me how she had shared an example in a class that came from the class textbook. The text said that customers may buy more cosmetics at a cosmetics counter if the salesperson, usually a woman, is attractive. She and the text pos-ited that customers might buy more cosmetics from an attractive salesperson because they might want to look good as she does. To be maximally caring to the men in her class, the teacher said, “I’m sorry, you men may not be able to relate so well to this example.” After the class, some students told her they were angry. They explained that what she said was offensive to them because there might be a transgender person in the class who had lived before as a woman. This student would have experienced as a woman what the teacher said he wouldn’t be able to understand as a man.

Regardless of how we respond to this example, if we wish to treat our patients optimally, we must respect their responses. That is, if we are as aware as we can be, it is impossible to avoid what some may experience as a slight, as in the example just given. Informing ourselves is not enough, be-cause we will miss some slights and may inadvert-ently cause harm. We must seek to avoid enacting these slights, if we can.

Another Way to Avoid Expressing Implicit Biases

If we could avoid expressing implied biases altogether, this would be ideal. Unfortunately, this is most likely impossible, because we have biases we don’t know we have and may express them, even when we have the best of intentions and do all we can to avoid it. Further, what we say may have more than one meaning or an ambiguous meaning. Thus, in spite of our best efforts, we may still be offensive. But there is a way we may avoid this: we can limit this risk by becoming aware of exceptionally strong, sudden feelings we experience in response to something a patient says or does that goes against what we expected. If we can detect these feelings before we respond, we may be able to avoid express-
ing the surprise or other unusual emotion we may feel. If we express this feeling as it occurs, we may well express an implicit bias.

To illustrate how we may do this, here is another case that is particularly instructive. A father was visiting his daughter at her college for the first time since she had entered it as a freshman. He was White, and his daughter’s roommate was Black. He took the roommates to dinner. Halfway through the meal, he said to the roommate, “I’m surprised. You speak so well. How did you come to speak so well?” She chose not to confront him. Whether or not people should confront those who offend them is, for many, a most difficult decision. It occurs more often for some people than others. Transgender persons confront this question, for example, when others speak to them using a pronoun that isn’t their gender. If transgender persons state what they feel, they know that the other person might resent them. Especially if the other person is thin-skinned, the price paid for speaking up may be exceptionally dear. To return to the anecdote about the college roommates, it is clear that the father was racially biased. He believed that all or most Black people must speak in a specific, same way. That this is the case isn’t my point. My point is that the father was surprised. That was the emotion he experienced first, as he acknowledged.

As this example illustrates, it may be possible to identify such feelings and so avoid the risk of expressing an implicit bias. It requires us to learn to identify such feelings as they occur. This goal is aspirational. It is not realizable in every instance. We can never, ever, always recognize biases that lie outside our awareness before we express them. In addition to increasing our knowledge of what our implicit biases may be, and putting ourselves more on the alert for spotting feelings like surprise that may come from these biases, and when we fail to recognize our biases and express them we must be willing and able to apologize in a way that gets through. How best to do this may be more complex than we imagine, so I will next describe how we may do this best.

**Making Amends Once We Express an Implicit Bias**

In our practices, we may not know we have expressed an implicit bias unless and until we see our patient’s reaction. If we are able to detect this, we may be able, at that time, to make amends. Doing so may enable us to restore the patient’s trust and preserve and maintain an optimal patient/clinician relationship. To notice whether a patient feels offended, we must be circumspect, able to detect even a split-second of a sudden downcast glance, for instance, that a patient may show in response to what we have said. This may be the only clue that the patient offers. How can we discern whether we have offended a patient, and how can we apologize when we have? Some ways are better than others. I will discuss some of the better ways next.

**Asking a Patient Whether the Patient Feels What We Think We May Have Seen**

Seeing what may be a patient’s negative response to what we have just said, we may ask, “I just thought I may have seen you respond to something I did or I said. Maybe you didn’t. But if you were responding to something I did or said, please tell me. This is especially important to me if I, in any way, offended you. Please tell me this, but only if you want to. But please know that if I did offend you, this is the last thing I would want to do. If I did offend you and you tell me, I can not do this again.”

Readers may note that in the words I used, I tried to ask this question in a way that leaves the patient feeling as unpressured about having to respond in any way that may be uncomfortable. I intend to make it as easy as possible for a patient to say in response, for example, “No, I wasn’t responding to anything. You didn’t offend me,” whether or not this is the truth. Allowing a patient this freedom, to the degree we can, respects the patient to the greatest extent possible. This relieves the patient of some of the burden of having to decide whether to say what the patient may not want to say in response. The patient should not need to worry unduly about how we may respond to what the patient says or what we may most want to hear.

The importance of this special effort, more generally, exists in many other clinical interactions. It may be especially important, for instance, when we want to know if a patient is dying and wants to talk about his or her feelings regarding being terminally ill. Some patients will. Some won’t. It may help to ask questions in a way that makes it easy for them to answer “yes” or “no.” This technique and others have been insightfully discussed by clinicians who are especially skilled in caring for terminally ill patients. Marco Pino and colleagues suggest that in response to a positive response to the above question, we might say something like, “Are you able to share what’s worrying you most at the moment?” I would add only to this, “Are you able to share what’s worrying you most at this moment, if anything?”

Generally, we can ask our patients if they have thoughts or feelings they would like to share with us, and, at the same time, make it clear to them that we realize they may not want to share their thoughts and feelings with us, at least not at the present time.
Saying “I’m Sorry”

If a patient shares that he or she feels offended, we should apologize. It is essential, though, that when we apologize, we do it in the right way. This is because what might appear to us to be an apology may be ambiguous and thus inadvertently may be offensive. Readers might want to test this possibility before reading further. To do this, readers could compare how they believe they would feel in response to these two different apologies: (1) “I’m sorry you feel hurt,” or (2) “I’m sorry I hurt you.” The first apology puts the “fault” more on the person who feels hurt and puts less fault on the person who did the hurting. The first apology may also imply that the person who is hurt is too or overly sensitive.

I would like to summarize this suggestion and add additional suggestions by quoting a psychologist, Harriet Lerner, who most richly instructs how to best apologize. She says that when we err, we are “apology challenged.” She relates that she was at a friend’s book signing, and she tried to be as supportive as she could be, but, to her friend, it didn’t seem that way. Her friend confronted her with how she had disappointed her. When her friend told her this, Lerner felt enraged. She had tried to be as supportive as she could be.

After reflecting, however, she saw her reaction in a wholly different light. When her friend first said that she felt offended, Lerner felt totally blind sided. She thought this was unfair and felt extremely angry. Thus she said “I’m sorry, but . . . ” She explains the error in initially responding in this way. She says, “Apologizing for the other’s feelings—as by saying, ‘I’m sorry you felt hurt’—rather than apologizing for our own behavior is often worse than no apology at all. It only deepens the original injury, but I did it anyway.” (Emphasis added.) She continues that her friend “made herself vulnerable by sharing her anger and deep hurt. Whether I saw these feelings as completely valid was irrelevant. They were her feelings.” (Emphasis added.)

“A wholehearted apology,” Lerner continues, “means valuing the relationship and accepting responsibility for our part without a hint of evasion, excuse-making or blaming. . . . It’s about ‘investing in the relationship’ and ‘accepting the person you love as they are’. . . . This means ‘to apologize for our part, even when the other person’s feelings seem exaggerated, or they can’t see their own contribution to the problem.'” She concludes, “The good apology requires that we take clear and direct responsibility for what we’ve said or done (or failed to say or do) without any ifs, ands, or buts and without bringing up the other person’s crime sheet.” This may require, she adds most insightfully, committing ourselves to not repeating what we have done, to correcting what we did, if possible, and even to listening “with an open heart” to the other’s anger, and doing it “on more than one occasion.” Lerner’s approach may fall short of achieving the authenticity we want between our friends and ourselves as we interact with them. It is open to question, however, whether authenticity and responding as Lerner suggests are mutually exclusive. This initial acknowledgment of another’s hurt may clear the air and thus be a first step to discussion and reconciliation.

Lerner’s last point about being willing to repeatedly bear another’s anger is especially counterintuitive. We might instead respond to another’s repeatedly expressing anger at us by stating we have had enough, but Lerner advises adamantly against this. Rephrasing her in terms of patients who feel offended, we should never say, “That’s enough.” To truly and effectively apologize, we must do more than just say we are sorry. We must say it in the right way to undo what we have done, if that is possible. We must not repeat the offense, and we must let a patient vent his or her anger, even if the patient feels inclined to do this many times.

A last and more general point Lerner makes in regard to apologizing applies especially to clinicians who do ethics consultation: “We’re hard-wired to seek justice and fairness. . . . Tendering an apology, however, can heal broken connections and restore trust” in relationships in which the result would otherwise be “impossibly tragic.”

Impossibly tragic: Lerner does not exaggerate. Her statement that “We’re hard-wired to seek justice and fairness” but that healing broken connections is what should count, should be taken literally by ethics consultants. She reiterates the overall priority that I urged at the beginning of this article, that clinicians who do consults should prioritize patients’ feelings ahead of a more common and tempting priority: our ethical principles. There is a risk, however, of which we should be continually aware: if we spare another our ethical objections, are we being patronizing or paternalistic?

SOWING DISTRUST IN OTHER WAYS

In this section I will discuss two additional ways that we may lose a patient’s trust. Both involve not imagining sufficiently the negative effects that our action may bring about. The first is to violate a pati-
ent’s privacy. The second is to give a patient a medical diagnosis in a way that may be accurate but may make it impossible for the patient to recover.

Searching a Patient’s Social Media Accounts

In “TTaPP: Together Take a Pause and Ponder: A Critical Thinking Tool for Exploring the Private Lives of Patients,” Leslie Kuhnel explores the ethical pros and cons of clinicians’ using the internet to learn more about their patients and of their doing this without their patients’ consent.28 This practice is paradigmatic of other violations that clinicians may make and then misjudge or underestimate how their actions may affect their patients.

That clinicians use the internet to learn about patients without first asking for permission, or even saying that they would like to do this before doing it, may be more common than we might expect. And this practice may be increasing. Kuhnel states, for example, that, according to one study, 94 to 97 percent of the psychology graduate students surveyed had engaged in patient-targeted googling (PTG) of at least one of their patients in the preceding year. Kuhnel presents a case in which members of a medical team distrusted information that a patient’s family member gave them. Concerned that “something fishy” was going on, the team members googled the patient to learn more. What they found was unsettling, and they requested advice from their ethics committee. Kuhnel reports that the American Psychiatric Association’s (APA’s) Ethics Committee holds that clinicians should engage in PTG only to promote a patient’s care and well-being, but that clinicians should consider how doing this might influence treatment and the therapeutic relationship. We might ask whether the APA committee’s view is much too broad: its requirement for “care and well-being” could be used to rationalize almost anything. In this regard, Kuhnel lists 10 contexts in which clinicians who engage in PTG activities have been seen as clinically and (presumably) also ethically justifiable. These include suspected “doctor shopping,” patients who respond evasively to clinical questions, patients who make improbable claims about their personal or family history, and even patients who make inconsistent statements regarding themselves or their family. The examples raise a common concern: they accept that clinicians might google patients under such circumstances, even though doing so might place them at odds with their patients.

Doing this always risks creating a highly suboptimal result. For this reason, I have urged clinicians to give priority to patients’ feelings, rather than to even justice and fairness. Here is a common, hypothetical example. I have a patient who greatly exaggerates. This is not at all uncommon for persons, in general. All of us may tend to do it in one way or another; for instance, we may tend to minimize our contribution to something we have done wrong, hoping that it makes us look less blameworthy in another’s eyes. Those who exaggerate may mostly want others to see them as better. This may be my patient’s predominant need. If I support my patient with the positive regard he seeks, his exaggerating over time may diminish. Given this example, we might question the APA committee’s criteria. Consistent with the APA criteria, I could google my patient who greatly exaggerates without his permission, so long as I believe that in some way, he (or someone else) would, in net, benefit.

This example suggests the importance of seeking diligently to imagine and anticipate ways in which our patients may be adversely affected by our actions, as, for example, was considered above in the discussion regarding clinicians’ recognizing their feelings of surprise. The strongest argument that can be made to justify googling our patients is that the patients made this information about themselves public when they shared it on social media; therefore, their privacy has not been violated when we google them without their consent.

While this argument is logically valid, it may be clinically shortsighted—in the same way that it is shortsighted for clinicians who have expressed an implicit bias to insist that the only thing that “counts” is their intent. In both instances the logic may be right, but how patients feel and respond may not conform to this logic. To best meet our patients’ needs, we may have to start where they are, and work with them from there. This is the case even when a patient responds in a rare and singular way.30

A second example involving privacy counter-sinks this point. It involves patients’ charts. Often there are professional guidelines to be followed, but it may be, as when making a decision whether to look at a patient’s posts on social media, we should do what most respects the patient and preserves our patient/clinician relationship. A specific example is a person who has questions about her or his gender identity. This may include what the person should or should not do, and he or she may not want any part of the discussion in the medical record.

In some cases, transgender persons may not want some of the clinicians they see to know about their gender identity. An example of such a clinician is, for instance, one they would go to for a sore throat. (I use the word “persons” rather than “patients” because some transgender persons feel strongly—as perhaps all of us should—that they do not have a
disorder. This is consistent with the reasoning presented above, that we should respect a patient's feeling that he or she has been offended by an expression of implicit bias.) What should clinicians do when they see a transgender person who wants to discuss concerns regarding gender identity, but doesn’t want anything about this in the medical record? Here, we don’t have to imagine or anticipate whether this is important. This person’s privacy is of the utmost importance to him or her, and this person will have to decide with whom to share this information for the rest of her or his life. Accordingly, with transgender persons, we may want to ask when we first meet what, if anything, they would want us to write in their chart. If they want us to say nothing, we may be faced with the question considered more than once in this article: Should we place these persons and their feelings first, or should we give greater priority to what we may see as our usual professional obligation? In this regard, I recall a clinician who faced making just this choice. The clinician decided to write nothing in the chart about what she and the transgender person she saw had regularly discussed.

Our analysis has focused to this point only on what we should anticipate and not do. It may be better to anticipate what we could do that might be additionally beneficial for our patients. I think of a clinician who tries to imagine what may be most helpful when he first sees a patient who has been raped. He takes two steps initially. One has some precedent, the other does not. First, he asks the patient whether she feels fearful being alone with him in the room—roughly similar to asking any patient with a clinician of the opposite sex whether the patient wants someone of the same sex in the room. Second, he asks the patient whether she feels fear in response to his smell, as the rapist’s smell may have been so strong that an odor even somewhat similar may trigger a terrifying, flash-back-like response. This example indicates what we should seek to imagine, anticipate, and possibly do to maximally respect and support our patients’ needs and feelings. We should seek to imagine what they might need, even if and when it has not occurred to them.

Sharing Information That May Change How Patients See Themselves

In Andrew Clark’s “Psychiatric Diagnoses and Informed Consent,” in this issue of JCE, he asks how clinicians should communicate psychiatric diagnoses to their patients. He states that the assumption that clinicians should inform patients of their diagnostic conclusions may be “reasonably valid” in traditional medical fields, but that psychiatric diagnoses often may be “different in kind.” Psychiatric diagnoses,” he states, may “pose an even greater risk to the patient than the treatment itself.”

In the last issue of JCE I discussed related ethical questions: Should we always seek to determine whether aged patients who come in for a routine exam have early dementia? And if they might: Should we always inform them of it? I suggested that, in some cases, we might consider describing the pros and cons of having testing, thus helping patients to make a fully informed decision whether they would want the testing. The concern underlying this approach is analogous to the harm that concerns Clark: learning a diagnosis of early dementia may profoundly impair patients’ capacity to enjoy their life from that moment on.

Clark uses the example of a diagnosis that he believes could pose a comparable risk, that of borderline personality disorder (BPD). Many patients may benefit from knowing that they have this diagnosis; learning this may, for example, help them better understand some difficulties in living they may continue to have, such as frequent mood shifts or becoming easily angered. These difficulties may make it harder for them to keep jobs and friends. It may be helpful to patients to hear why they have had problems and what they may do to make their lives better. For other patients, however, as Clark contends, this diagnosis may be devastating. I recall a patient who had done well in school and had many friends until, in her early adult life, she experienced a profound trauma. After this she trusted no one and often became angry. A clinician diagnosed her as having BPD. She felt extreme shame and protested mightily: “I was mentally healthy before this occurred,” she said, “and I became as I am now only after this trauma. Thus, I don’t have a borderline personality disorder.” Accordingly, to avoid or at least minimize the risk of alienating our patients to the point that they might not be willing to see us—or anyone else—there are approaches we can use to minimize the likelihood of this happening. This may be a risk only for one or a few patients in a practice, and so it is a good example of how we might alter our practice to avoid needlessly negatively affecting even only one patient.

To help reduce the risk of harming a patient with a diagnosis of BPD, for example, we could ask the patient if she or he wants to diagnose her- or himself. We can do this by reading the nine criteria that making this diagnosis involves and seeing if the patient meets at least five of them. We might state in advance that the name of the diagnosis is unfortunately most misleading, and, that, personally, we would totally change it if we could. Making this

...
statement, and perhaps more importantly, taking the time and effort to convey this information, may soften the impact of a diagnosis of BPD sufficiently that the patient will continue to see us, or someone else, for treatment.

Patients may, as Clark rightly says, make their own meaning of their diagnoses. They similarly may be most profoundly harmed by a clinician telling them that they are manipulative or attention seeking.\textsuperscript{38} This may turn them off from seeing a clinician who could help them, and they may come to see themselves as having nothing to offer others, much less themselves. Accordingly, when we suspect that we know a patient’s maladaptive psychodynamics, we should try to imagine ways in which we can share this information, if we think it will help, in a way that will not harm the patient. This may be accomplished by first placing what we will say in context, indicating to the patient our personal stance toward them, one that is highly supportive and caring. For example, if the patient expresses a concern about interacting with others, we might begin by saying something like: “It’s clear that you care greatly for other people. You may be having the same problem that many other people do, who also care exceptionally for others. They expect that others will soften the impact of a diagnosis of BPD sufficiently. They similarly may be most profoundly harmed by a clinician telling them that they are manipulative or attention seeking.\textsuperscript{38} This may turn them off from seeing a clinician who could help them, and they may come to see themselves as having nothing to offer others, much less themselves. Accordingly, when we suspect that we know a patient’s maladaptive psychodynamics, we should try to imagine ways in which we can share this information, if we think it will help, in a way that will not harm the patient. This may be accomplished by first placing what we will say in context, indicating to the patient our personal stance toward them, one that is highly supportive and caring. For example, if the patient expresses a concern about interacting with others, we might begin by saying something like: “It’s clear that you care greatly for other people. You may be having the same problem that many other people do, who also care exceptionally for others. They expect that others will treat them as they would treat others. When others don’t treat them this way, they may feel baffled, and not know how to respond.”

This kind of context-establishing statement often is true—or if it is not, the patient will surely have other strengths that we can note. With this initial expression of support we may better succeed in allying ourselves with the patient, and asking whether he or she would want to explore together why others may react as they do, in ways that the patient has said is distressing.

The critical goal is, once again, to prioritize remaining our patient’s ally above all else. This aspiration is nowhere better expressed than by the psychologist Marianne Amir, who says, “The aim of the health care team should be to create a secure environment of unconditional trust that patients can rely on to mediate between their inner world and the outside reality—an environment similar to that of maternal holding.”\textsuperscript{39}

**CONVEYING TO PATIENTS AND FAMILIES THAT THEIR MORAL BELIEFS ARE INFERIOR**

In Grattan T. Brown’s “Medical Futility in Concept, Culture, and Practice,” in this issue of *JCE*, the author discusses what might be appropriate ethical limits for dual liver-kidney transplants.\textsuperscript{40} He looks, for example, at “pretransplant illness severity,” and asks whether this intervention should be warranted if, say, due to a patient’s medical condition, even with a dual transplant, the patient would only live at most three months.

Brown also seeks to explore this question from a wider perspective by looking at what clinicians regard as futile in other contexts. He considers, for example, a baby with complex medical needs whose parents wanted to care for him at home. They knew the burdens and the benefits of doing this because they had cared for their deceased daughter who had the same genetic disease. Brown asks whether the baby’s clinicians should have allowed this. The cases that Brown presents highlight the ethical question of futility. My purpose is not to assess what should count in making this determination, but to consider how these decisions should best be made.

In answering this question, I would suggest that it may be that we can do no better than consult some guidelines offered by a leading expert on conducting mediation, Autumn Fiester. She suggests that we should loosen and widen the criteria by which we make such moral judgments as futility. First, she says, it makes sense to do so. Second, practically, if it makes sense and we are able to do it, we will be able to reach more judgments that are in agreement with our patients and their families. This possibility is particularly important, Fiester suggests, when patients’ or families’ positions initially differ from our own. She provides two steps by which we can do this. She presented these steps and a list we all can use at a workshop at the 2017 meeting of the American Society for Bioethics and Humanities (ASBH). Fiester has published these steps and the list, and they are readily available.\textsuperscript{41}

At her workshop at the ASBH meeting, Fiester challenged all of those attending to imagine positions that patients and families might hold that were the most opposite to the positions that clinicians hold dear. Fiester presented a list of ethical dilemmas that were common, yet posed the greatest ethical conflicts with patients and families that are likely to be confronted at the present time. She elicited some examples of patients’ and families’ views that the attendees said they most opposed. With this list, Fiester put forth a plausible argument for each, making these views seem not so unreasonable at all. In unearthing the sound values that might be underneath the positions that clinicians at this workshop might have adamantly opposed, she tried to convey that such views, often seen as groundless, were actually views that reasonable persons might reasonably have. Fiester’s goal was to show that, with the loosening of our more fixed ethical convictions, we...
may be more open to hearing and accepting patients’ and families’ initially seemingly wholly differing positions. Stated differently: Fiester encourages us to assess our implicit ethical biases to discern whether the values we hold, that may lie hidden, are as sound as we assume they are.

We must, she says, “dethrone” the moral commitments we may have that, even subliminally, we may take to be more “objective, absolute, and universal” than they are. Readers might want particularly to attend to the use of the word “subliminally.” These are beliefs that we may hold outside of our conscious awareness, and, as they are unknown, may be more beyond our conscious control than our other beliefs would be. If, as with implicit biases, we deliberately attempt to consider and reassess what may lie outside our awareness, we may have greater success. Fiester puts this challenge to us when we engage in ethics consultations: “Can clinicians provide a moral justification for the stance taken by each individual stakeholder in the conflict? If not,” she says, “they have more to do.”

To help us to do this, Fiester presents a list that she calls the Bioethical Positions Inventory (BPI). This list of prevalent moral views and opposing views is a tool to assess one’s own personal, normative commitments on contemporary bioethical issues and debates. With this initial self-understanding, we can work to create a values-based defense for any position that is in conflict with our own. Fiester writes, “I believe this two-step exercise—first identifying one’s own positions and reflecting on the ethical rationale that undergirds them and defending the antithetical positions held by others—protects CECs [clinical ethics consultants] from values hegemony and what I elsewhere call the ‘weaponizing’ of moral principles.”

To illustrate the kind of counterpositions Fiester takes, here is an example from the article she refers to (that actually involves “weaponizing” in its title). She considers the case of Mrs. Dee, from Nancy Dubler and Carol Liebeman’s book, Bioethics Mediation: A Guide to Shaping Shared Solutions. This case raises questions similar to the case Brown describes, of the baby whose parents wanted to care for him at home. Mrs. Dee’s clinicians see maintaining her life as futile, whereas her loved ones wholly disagree. Fiester points out that the reasons underlying the loved ones’ position may be more valid and have more moral weight than those of us who do ethical consults may customarily see and accept.

First, Fiester notes, there is the sanctity of all human life, which we all value. It is hardly a new proposition that this value exists, but, nonetheless, it should be recognized and given due respect. More significantly are two values we might not so readily see. (1) Mrs. Dee’s loved ones see her continuing to live as not being futile. This is of no small worth; we take others’ sensibilities into account in many ethical contexts. We do this, for example when we debate how much moral weight we should give to views that differ on the basis of cultural relativity. The main difference between opposing views may be different populations’ moral sensibilities.

(2) In some contexts, we have begun to consider the interests of others, besides patients, when we haven’t before (or only a few of us have). For example, medicines for children with rare, serious diseases may be scarce, and some have suggested that a last criterion to use in deciding which children should get a limited medicine is the interests of the children’s other siblings. At the 2017 ASBH meeting, two different presentations proposed giving new and greater moral weight to the competing needs of others as well as patients. The first involved mature minors. The second involved greatly medically compromised infants, like the baby Brown mentions in his article. In both cases in the two presentations, the patients’ families were not so well-off.

Fiester’s second counterproposition that supports according more validity to family members’ views on maintaining a patient’s life is intriguing. Might it not be that if Mrs. Dee were conscious and competent, and asked about her preferences, she would most likely say that she wants whatever is most important to her family members, not what is most important to her. This may mean that deferring to what Mrs. Dee would say is truly the best way to respect her autonomy. Fiester states, “Reaching beyond the limits of what an advance directive could possibly reveal about a patient’s deepest moral commitments, Pat [Mrs. Dee’s adult son] asserts that his mother would not want to forego or withdraw life-sustaining therapy if her family needed her to continue with it. This might be framed as a principle of staying alive for the sake of others, and there is a great deal of intuitive plausibility to it.”

Readers may or may not see this argument as having ethical merit. Fiester notes that she knows many people might disagree. The question we might best focus on here is not whether Fiester is right or not. It is how we might be blind sided by views we have that may not be optimally insightful because they lie outside our conscious awareness and thus outside our conscious control.

In this regard, we may trigger patients’ and family members’ automatic, oppositional reactions merely by presenting ourselves as an ethics consultant. This may occur even when we only informally offer an ethical view. An immediate loss of trust may
be triggered should we in some way hint or even unintentionally just imply that we regard our moral views as superior or more enlightened.

Fiester’s urgings may help us to see and avoid these results. Merely asking ourselves whether we are inadvertently conveying the impression that our moral views are superior may alter how we interact with others, so that we should avoid even just using verbal tones that could convey this impression. If so, the gain may be most substantial: it may enable us to make ethical decisions with our patients to a greater extent than may have been possible previously.

CONCLUSION

In this article, I noted how the authors of the ASBH’s new Study Guide have furthered our field. I addressed how we may progress still further by recognizing the ways in which we may lose the trust of patients and families without realizing it. I discussed implicit biases as a paradigm for how this can occur outside our awareness and how negative feelings can escalate if we offend patients and their family members and they confront us. I explored three other specific examples in which we may lose our patients’ trust: undervaluing their privacy, undervaluing how our sharing their diagnoses and psychodynamics may affect them, and not seeing how believing that our moral views may be superior may offend patients and family members and move them to try to effect the best end result by no longer seeking to work with us.

I offered some possible remedies for these destructive, although unintentional, behaviors. These involve looking for feelings like surprise, not seeking outside information about our patients without prior permission, not sharing potentially negative feedback with patients without discussing what it doesn’t mean first, and doing all we can to try to insure that patients don’t see us as believing that our own moral values are superior.

I suggested that clinicians may seek to imagine ways they might benefit patients, even when the patients may not know what it is that they want or need. (One example of this was asking rape victims about the male clinician’s smell.) The most controversial of these suggestions—and the one that we may most want not to accept—is loosening many of the moral views we now have. Perhaps we should not do this. It may, however, be worth considering.

I offered a number of points from the work of Autumn Fiester; the last point may involve respecting patients to the greatest degree, by asking what they would want for their loved others if they could still speak. Fiester’s ground for this is compelling. She asks, “Wouldn’t most parents at no physical cost to them want to help their children? Wouldn’t parents want to do much more?”

DEDICATION

To Rick. And to Leslie, his wife, and our managing editor, who pursued with Rick the best care possible, some of her insights from their experience often finding themselves into this journal’s pages.

ACKNOWLEDGMENT

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

NOTES


3. The ASBH has consistently urged this. In Addressing Patient-Centered Ethical Issues in Health Care, it asks readers, for example, when considering how they would respond to (what they refer to as) a “difficult” patient: “What can you imagine about his perspective or the reasons for his behaviors and interactions?” Addressing Patient-Centered Ethical Issues in Health Care (Chicago, Ill.: ASBH, 2017), 69. Previously, ASBH advised, “Reconstruct the case from the patient’s perspective,” in Improving Competencies in Clinical Ethics Consultation (Glenview, Ill.: ASBH, 2009), 39.

4. This is a biologically based, likely outcome recently presented by Daniel Kahnemann. D. Kahneman, Thinking, Fast and Slow (New York: Farrar, Straus, and Giroux, 2011). Basically, when people feel calm and supported, they may think more constructively, because their brain is less geared for a fight-or-flight response. See, also J.A. Soodalter et al., “Affective Science and Avoidant End-of-Life Communication: Can the Science of Emotion Help Physicians Talk with Their Patients About the End of Life? Patient Education and Counseling 101, no. 5 (May 2018): 960-7. A factor that may make it harder for us to accept how we might harm a patient is knowing that if we of-
fended this patient, we most likely may have harmed many others over the course of our career. Accepting this may be especially painful. One example is to learn at mid-career that giving a patient a simple reassurance in the immediate aftermath of a disaster, such as saying, “You will be okay,” may actually make the patient more tense. Uniformed Services University of the Health Sciences, “Psychological First Aid/Helping Victims in the Immediate Aftermath of Disaster,” Courage to Care, January 2005, a fact sheet for clinicians available from this author.


12. Ibid., 276-7.

13. Ibid., 277.


16. There are many such examples. All warrant respect. For example, some women who have had a bilateral mastectomy resist it when a clinician questions them if they say that they don’t want breast reconstruction. M.T. Brown and J.A. McElroy, “Sexual and Gender Minority Breast Cancer Patients Choosing Bilateral Mastectomy without Reconstruction: ‘I Now Have a Body That Fits Me,’” *Women & Health* 58, no. 4 (April 2018): 463-17.


18. Ibid., 1726.


21. The specific words used are not important, but what is important is to not inadvertently place pressure on patients to say more than they want to. We might say in response to a patient’s declining this invitation to talk, for example, “Well, that’s okay. Maybe later.” Even this, however, may place unnecessary pressure on a patient.


23. Ibid., 43-4.

24. Ibid., 46-7.

25. We may also respond to patient’s anger more effectively. Fiester states, for example, that anger is a reactive emotion, and thus a key to helping angry patients is to find its source. She says that with effective technique, anger can be abated in less than a minute by identifying and then describing patients’ concerns. A.M. Fiester, “What Mediators Can Teach Physicians about Managing ‘Difficult’ Patients,” *American Journal of Medicine* 128, no. 3 (2015): 215-6. Fiester notes that some clinicians are better able to do this than others. This presents an additional challenge, to decide when and how we should withdraw from a situation and seek the help of someone else.

26. We may find that bearing such patients’ anger is easier if we keep in mind that if the other person is speaking, he or she is, at least, not shut off. Listening may be the beginning of a future relationship that will improve.


28. Fiester asserts that we are all too prone to under-
estimate the “unwitting, involuntary role” that our deeply held beliefs play in performing ethical analysis, and that, in clinical ethics, we are therefore “quite unaware of how our unarticulated conception of the good drives our agenda.” A.M. Fiester, “Teaching Nonauthoritarian Clinical Ethics: Using an Inventory of Bioethical Positions,” Hastings Center Report 45, no. 2 (2015): 20-6, 21, https://repository.upenn.edu/cgi/viewcontent.cgi?referer=https://www.google.com&httpsredir=1&article=1077&context=bioethics_papers.


32. For an appreciation of the significance of smell, see G. Rowley and J. Hurdle, “‘Here Was America’s Dad on Top of Me,’” New York Times, 13 April 2018. The person who was sexually molested reports remembering the smell after 36 years.


34. A colleague states openly, for example, how she dreaded the possibility that she might later have early dementia. She hopes that, if she does, she can end her life before she loses her capacity to do this.


42. Fiester, “Teaching Nonauthoritarian Clinical Ethics,” see note 28 above, p. 20.

43. Fiester states that the first step is to locate one’s own positions to “dethrone” the moral commitments that one might mistakenly take to be “objective, absolute or universal.” Ibid. A plausible additional argument for us not regard our own ethical conclusions as objective and absolute is experimental findings that suggest that our moral views may be affected by substances such as serotonin. M.J. Crockett, L. Clark, M.D. Hauser, and T.W. Robbins, “Serotonin Selectively Influences Moral Judgment and Behavior through Effects on Harm Aversion,” Proceedings of the National Academy of Sciences of the United States of America 107, no. 40 (5 October 2010): 17433-8. Scientists studying the worm C. elegans, which in this regard has the same genes that we do, have found that cells in its brain may pump out serotonin to the brain’s “sprinkling system” of nerves, as opposed to this occurring only at nerve junctions, and this may alter the worms’ behavior. C. Bargmann, “Using Fixed Circuits to Generate Flexible Behaviors,” David Packard Lecture, Uniformed Services University of the Health Sciences, 3 May 2018, Bethesda, Md. If our brains work in this same way, as is likely, ethical views that we have may vary somewhat depending on when and whether our serotonin brain pumps have been active.

44. Fiester provides the Bioethical Positions Inventory, that consists of 15 common ethical positions with views that oppose them as a “useful pedagogical vehicle for teaching nonauthoritarian ethics.” Fiester, “Teaching Nonauthoritarian Clinical Ethics,” see note 28 above.


49. Ibid.
Psychiatric Diagnoses and Informed Consent

Andrew Clark

ABSTRACT

Although informed consent for treatment has become a cornerstone principle of psychiatric care, the process of diagnosis has remained largely in the hands of the physician alone. While the conferring of a psychiatric diagnosis has historically not been considered a form of medical intervention, the potential impact of a diagnosis for any particular patient may be substantial. This article explores the challenges involved in balancing respect for patients with the physician's duty of truth-telling and clinical accuracy.

INTRODUCTION

The doctrine of informed consent for clinical treatment has, over the last half century, been established as a cornerstone of medical ethics. As a result, the doctor-patient interaction has been radically transformed, with both parties now actively engaged in treatment planning and decision making and with the patient's preferences accorded privileged status.\(^1\) The process of diagnosis, however, has generally been seen as separate from medical intervention, and clinicians have largely retained their traditional authority in that arena. Typically, clinicians exercise their expertise through a process of active investigation and subsequently present the patient with a diagnosis, from which point the two begin to collaborate on treatment planning.

This article explores the idea that, given the potential personal, social, and legal impacts of a psychiatric diagnosis for individual patients, their welfare may be significantly affected by having a specific diagnosis conferred upon them. To the extent that this is the case, it raises difficult questions as to how best to balance respect for patients with clinicians' obligations for accuracy, clarity, and truth-telling as they communicate their diagnostic conclusions.

PSYCHIATRIC DIAGNOSES

Psychiatric diagnoses, as articulated through the various iterations of the *Diagnostic and Statistical Manual of Mental Disorders* (hereafter, DSM), offer phenomenologically based classifications that serve as a useful heuristic, particularly in regard to promoting interrater reliability. Introductory material to the fifth edition of the DSM (DSM-V) highlights the limits of the diagnostic framework, noting that the boundaries between diagnoses are more porous than had been originally perceived, that symptoms are fluid over the life span of patients, and that not all psychopathology can be captured by a discrete set of diagnostic categories.\(^2\) Rather than mandating a slavish adherence to symptom checklists, the DSM-V offers itself as a (hopefully) useful, flexible, and

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they come to represent not just a convenient way to
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agnoses seem to tell them something about them-
tion and treatment planning.
choose not to address the issue with their patients
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tulizes to impose a coherence on the vast multiplicity
underlying pathophysiology and a limited ability to
utilize objective data, the psychiatric diagnostician
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chiatric diagnoses are often different however; hobbled by an impoverished understanding of the
underlying disease process and cannot simply select which among many diagnoses to utilize. Psych-
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underlying pathophysiology and a limited ability to
utilize objective data, the psychiatric diagnostician
relied to a large extent on characterizing constella-
tions of symptoms as disorders, in a top-down ef-
to impose a coherence on the vast multiplicity
of symptom presentations. As a result, many or most
psychiatric disorders fail to demonstrate validity as
disease categories, despite their clinical utility, and
they lack well-defined thresholds and boundaries. The
residual, substantial role of clinical judgment in the
diagnostic process, therefore, frequently leaves the
psychiatric diagnostician with remarkable lati-
tude in selecting a preferred diagnosis from amongst
more than one reasonable candidate.
In practice, many patients may be unaware of
or indifferent to the specific diagnoses their cli-
clinician has given them, and many clinicians may
choose not to address the issue with their patients
at all, focusing rather on more global case formul-
tion and treatment planning.
However, patients make meaning of their diag-
oses in manifold ways. For many patients the diag-
oses seem to tell them something about them-
selves that they hadn’t known before, and in time
they come to represent not just a convenient way to
think about their symptoms, but a core aspect of their
identity. A person with symptoms of depression, for
example, once diagnosed as such, may come to think
of him- or herself as fundamentally a depressed per-
son. Diagnoses are regarded in this sense as more
akin to the results of a psychological biopsy than to
a simple organizational approach for an array of pre-
senting symptoms.
The trusting relationship between patient and
psychiatrist relies upon the physician’s capacity to
communicate an appreciation of the patient’s dis-
tress, a recognition of the patient’s strengths, and a
vision for the patient’s future. Psychiatric diagnoses,
by virtue of being pathologically oriented, often con-
fusing, and frequently shaming, may be experienced
by patients in ways that shake their sense of trust in
the clinicians who bestow them, and in the mental
health system more broadly. When deciding wheth-
er and how to communicate their diagnostic con-
clusions to their patients, clinicians may struggle
to balance the need for diagnostic accu-
racy and openness against their sensitivity to the
patients’ experience of being labelled in such a way.
Publicly, psychiatric diagnoses are often the
subject of intense social interest and, in our culture,
some diagnoses have become near celebrities in their
own right. In addition, psychiatric categories often
seem to touch on broader issues such as moral worth
and personal responsibility. As such, public fasci-
nation and familiarity with psychiatric diagnostic
nomenclature is remarkably high, and patients often
find that the people close to them presume an
uncomfortably high level of understanding and in-
sight based on their diagnosis alone. The contrast
with medical diagnoses is often striking—while a
hypothetical book such as Are you Married to a
Narcissist? might fly off the self-help shelves, its
company, Does Your Spouse Have Elevated Chol-
erol? would be more likely to languish.
Although protected by safeguards against indis-
criminate dissemination, psychiatric diagnoses can
often show up in arenas outside the consulting room,
where they are filtered through the ignorance and
agendas of nonclinical actors on unfamiliar stages. These
include consideration for special education services or academic supports; eligibility for gov-
ernment financial supports; military enlistment; some job applications, such as physician licensing
in many states; fitness for duty evaluations; applications for prospective adoptive parents; applica-
tions for life or health insurance; and a variety of
other civil and criminal legal matters. Certain psy-
chiatric diagnoses, if revealed in particular settings
(such as, for example, child custody determinations
or the punishment phase of capital criminal cases),
can have substantial deleterious effects for the patient. A psychiatric diagnosis often acts as a label in such circumstances, where it is mistakenly thought to accurately and comprehensively describe the important aspects of an individual’s functioning. In addition to the very real risk that a diagnostic label will do harm to patients at some point in the future, patients often harbor well-grounded fears as to the ability of our healthcare systems to truly protect their privacy.

The risks to patients of any particular psychiatric diagnosis, therefore, no matter how accurately it reflects the relevant DSM-V criteria, include that it might alter their understanding of themselves in unhelpful ways, damage their trusting relationship with their clinician and with mental health services in general, adversely influence the ways that others understand them, and prove concretely damaging in an administrative or legal forum. It can, in these various ways, do them a great deal of harm.

Psychiatric diagnoses generated in the context of forensic evaluations or research protocols serve purposes distinct from those in the clinical setting and carry their own sets of ethical expectations and challenges. In these settings clinicians are expected, prior to conducting an assessment, to provide clear and informative disclosure around the limits to confidentiality and the risks involved. In clinical settings, however, patients’ willingness to be evaluated is usually inferred simply by their physical presence in the examining room. What is also simply assumed is that patients have thereby acquiesced to being given a particular diagnosis and to having that diagnosis enshrined in their medical record, shared with the community of careproviders who access those records, and communicated to third-party payers.

VIGNETTES

Case 1

A 26-year-old woman presents to the emergency department, accompanied by her fiancé, after an episode of superficial cutting. She has cut several times before, has felt suicidal at times in the past, and is in long-term therapy due to her difficulties with emotional regulation and maintaining intimate relationships. She is evaluated and cleared for discharge. Her fiancé, who has been fully aware of the patient’s difficulties and occasionally present at her therapy appointments, is at her bedside when the emergency room clinician announces that the patient will be discharged with a (new) diagnosis of borderline personality disorder. Both the patient and fiancé are startled and disturbed by this new diagnosis, and they protest, to no avail. In the days that follow, the patient finds her fiancé to be brooding and distant.

Case 2

A 52-year-old man is in long-term therapy with a psychiatrist at a major medical center. The gentleman is active in the community, highly religious, and a devoted family man who prides himself on his honor and probity. Having built a trusting relationship with his psychiatrist, the patient one day reveals that he has for years found himself sexually attracted to prepubescent girls, and although he has never acted on those urges in any way, he feels exceptionally guilty and ashamed. He and his wife have struggled with their relationship, largely due to the husband’s lack of desire and his emotional distance. After the session the psychiatrist grows concerned about potential future liability and so, after consulting his DSM-V, enters the diagnosis of pedophilic disorder into the electronic medical record. The patient returns the following week concerned that he had revealed too much and, after pointed questioning, the psychiatrist reluctantly acknowledges the new diagnosis that he gave. The patient leaves, upset, and the treatment ends.

Case 3

A 16-year-old adopted boy is brought in for an evaluation by his parents for defiance, dishonesty, fighting, and shoplifting. The parents are highly accomplished, hard-driven professionals who adopted the child when he was five years of age; they express disappointment in his mediocre academic accomplishments, growing frustration with his behavior, and worry that he may be a “bad seed.” The boy had early experiences of neglect, and he witnessed his mother die of a drug overdose at four years of age. The boy is very protective and solicitous of his 13-year-old sister, who was adopted by the same family and whose behavior is much less disruptive. At the end of the evaluation the clinician informs the parents (but not the child) that the boy meets criteria for conduct disorder, at which point the father turns to the mother and says, “See, I told you so!”

LIMITATIONS TO DIAGNOSTIC PATERNALISM

In practice, of course, the skilled mental health clinician will remain sensitive to how the patient might experience being given a specific diagnosis and will take pains to educate and even negotiate...
around these matters. Many diagnoses, such as narcissistic personality disorder in the context of long-term psychotherapy, may not be communicated at all. Others, such as schizophrenia, may be offered only after a substantial accumulation of data. In practice as well, however, are clinicians who for a variety of reasons take a more formulaic approach to diagnosis and who accord little weight to the patient’s perspective or the possible ramifications of their diagnostic choices. What seems remarkable in any case is how little formal expectation there is for dialogue between the doctor and patient on these matters, how powerless the patient is in times of disagreement, and how much silence surrounds the entire process.

Informed consent for “medical interventions” is codified as a fundamental aspect of ethical practice by the American Medical Association, and, by extension, the American Psychiatric Association. The American Academy of Child and Adolescent Psychiatry Code of Ethics calls for consent from the legal guardian before engaging in “actions” involving the child or adolescent. Beauchamp and Childress, in their widely cited textbook on medical ethics, describe informed consent as an “individual’s autonomous authorization of a medical intervention.”

The question, therefore, is whether conferring a psychiatric diagnosis upon a patient constitutes a “medical intervention”; if so, then the relevant ethical codes in regard to informed consent could reasonably be expected to apply in some way. Given the substantial and manifold risks of harm associated with a psychiatric diagnosis, it seems difficult to conceptualize it as anything other than a medical intervention. Another way to address the question is to ask whether patients experience the process of being diagnosed as a substantial “doing to” them of some sort, and whether many of them would wish to have the opportunity to have their perspective and interests meaningfully acknowledged in the process. Unfortunately, there is very little empirical data to help answer that question, and likely a great deal of confusion on patients’ part as to the negotiable aspects of the diagnostic process.

To the extent that a psychiatric diagnosis is like a medical diagnosis, there may be little room for dialogue; a kidney stone by any other name is still, irreducibly, a kidney stone. Indeed, many diagnoses widely used in psychiatry, such as Down’s syndrome or Alzheimer’s disease, do appear to have distinctive and identifiable etiologies, leaving little room for diagnostic hedging. For many patients, however, a psychiatric diagnosis can be thought of as a narrative, built upon a foundation of empirical data, that the clinician and patient can use together to understand and address the patient’s difficulties. If the narrative selected by the clinician is substantially discordant with the patient’s experience or with the way in which the patient would like to be able to think of her- or himself, the patient’s adherence to treatment may be compromised.

Other cornerstone ethical principles that may be implicated in the psychiatric diagnostic process are those of beneficence and nonmaleficence and the expectation that concern for the patient’s welfare is paramount in the clinical encounter. There may be times when skilled clinicians’ judgment leads them to protect their patients (and avoid doing harm) by modifying what they record as the primary diagnosis. Certain diagnoses, such as factitious disorder imposed upon another, or antisocial personality disorder, bring with them a host of knotty ethical considerations for the treating clinician who wishes to balance the need for truth-telling against responsibility toward the patient. A paternalistic approach to diagnosis, however, tends to preclude disclosure, and it limits conversations with the patient around such important considerations.

Rather than being a simple, by-the-book exercise in checking lists of symptoms, the process of psychiatric diagnosis may in fact be a more ethically complex endeavor than is often appreciated. Very little attention has been given, however, to questions of how to think through the difficult issues that arise in the process and how best to engage patients in diagnostic decision making. The unexplored ethical and practical challenges surrounding shared authority for psychiatric diagnoses are similar in many ways to those regarding treatment decisions 40 years ago. Jay Katz, in his classic book on informed consent for treatment decisions, wrote, “The insistence on authority has stifled any serious exploration of whether physicians and their patients could interact with one another on the basis of greater equality. Thus, the idea of informed consent—of mutual decision making—remains severely compromised.”

**SHOULD PATIENTS HAVE THE RIGHT TO REFUSE PSYCHIATRIC DIAGNOSES?**

One somewhat radical approach to engaging patients in the process of psychiatric diagnosis would be to fully extend the concept of informed consent to include both diagnosis as well as treatment, in an acknowledgment that the two processes are interrelated and that both implicate patients’ right to self-determination. In this model, patients
would have the right to refuse a psychiatric diagnosis (even if it were fitting), just as they have the right to refuse lifesaving treatment (even if it were medically indicated). And, in the same way that patients cannot choose just any treatment plan, patients here would not have the right to simply choose a diagnosis for themselves. Although the clinician might not believe it to be in the patient’s best interests to reject an apt and informative diagnosis, the competent patient’s preferences would be the final determinant.

One objection to a strong right-to-refuse-diagnosis approach is that some psychiatric patients lack insight due to their illnesses and therefore might be likely to reject an accurate diagnosis. Even in the absence of clear risk to patients, allowing delusional, irrational, or cognitively compromised patients to dictate their diagnoses would seem to offer little benefit, and would be a concession not to the patients’ autonomous interests, but rather to the limitations associated with the disorder. To avoid this situation, clinicians would need to be able to ascertain that patients were not competent due to an inability to understand or rationally think through the ramifications of the diagnosis and then override the stated preferences on that account.

A second objection to allowing patients to refuse psychiatric diagnoses is that it might jeopardize reimbursement from third-party payers, either if no diagnosis were given or if a more anodyne diagnosis than was warranted led to a more restrictive reimbursement schedule. This speaks, perhaps, to yet another of the various burdens that have been piled upon the narrow shoulders of the diagnosis, and it may represent a quite valid, if unfortunate, real-world concern.

The most troublesome objection to this approach, though, is that the diagnosis is not only something that happens between a clinician and a patient; it is also a primary mode of communication among clinicians. As such, it is expected to reflect an accurate recording of the clinical encounter. The clinician and the patient each have ownership of the diagnosis in different ways, with the clinician responsible for its accuracy and thoroughness and the patient the one who has to live with it. A clinician’s diagnosis is an attestation that the important aspects of a clinical encounter have been articulated, and, in many circumstances, a clinician’s silence would be misleading and potentially dangerous for a patient. For example, a psychiatrist who evaluated a patient in the emergency room for alcohol intoxication and a suicide attempt would be professionally obligated to communicate that information in the diagnosis, even in the face of the patient’s objections. In circumstances such as these, clinical care would be compromised at the patient’s expense if the given diagnoses were not forthright, which might justify overriding the patient’s preferences. More broadly, clinicians’ trust in the accuracy of the medical record might be seriously eroded if it was understood that critical conclusions could be withheld at a patients’ behest.

**PATIENTS’ ASSENT FOR PSYCHIATRIC DIAGNOSIS**

If full informed consent (with its accompanying right to refuse) is overly broad, and if traditional diagnostic paternalism is too narrow, is there a Goldilocks framework whereby a patient’s agenda and interests could begin to be invited and considered in a meaningful way? I would suggest that the concept of assent, particularly as has been developed and articulated with pediatric populations, would be a workable and reasonable approach.

Although pediatric patients are typically not legally empowered to give informed consent for medical interventions, children of a certain developmental level are able to offer their perspective, articulate their interests, and agree or disagree with a treatment approach. The process of assent for children involves a developmentally appropriate explanation of the options available, an invitation for them to ask questions and express concerns, and an opportunity for them to express a preference. While it is the adult guardians of children who provide the legally and administratively mandated permission for a treatment, the process of assent is more than just a pretense, in that children’s wishes carry real weight. Although children may not have full veto power in all cases, their preferences matter, and their opposition to a particular treatment plan may well be enough to scuttle it, depending on their developmental level and the gravity of the clinical problem at hand.15

The model of assent would set an expectation that clinicians have a meaningful discussion with patients prior to giving a psychiatric diagnosis and make a good faith effort to consider and give weight to the patients’ preferences. It would, no doubt, call for a certain amount of explanation as to the meaning of any particular diagnosis, as well as about the limitations of the *DSM-V*-based nosological approach. At the same time, it would ultimately allow clinicians to select the diagnoses that they felt were indispensable for accurate communication and good patient care.
An assent model for psychiatric diagnoses would not require clinicians to provide a misleading diagnosis in the medical record. Rather, clinicians might at times defer making a particular diagnosis in the face of patients’ resistance, choose a more benign or acceptable diagnosis from among a few reasonable options, or utilize one of the many unspecified diagnoses offered in the DSM-V.

In addition to demonstrating respect for patients’ autonomy, engaging with patients around diagnoses might well enhance clinical care. Patients who appreciate the significance of their diagnosis and who feel they have made a meaningful contribution to the diagnostic decision are more likely to sustain participation in treatment. And, to the extent that such a collaborative process helps to reduce patients’ sense of stigmatization, it would promote care-seeking behavior on their part.16 Given the enormous challenge of treatment avoidance and treatment non-adherence for serious mental illness, any lowering of the barriers to treatment would be likely to pay substantial public health dividends.17

POSSIBLE OBJECTIONS TO PATIENTS’ ASSENT FOR PSYCHIATRIC DIAGNOSIS

One possible objection to incorporating patients’ preferences into diagnostic decision making, as in the assent model, is that it would undermine the reliability of psychiatric diagnosis and thereby impoverish the communication between patients’ various treating clinicians.18 Even if the most critical diagnoses were retained, this argument goes, more subtle modifications in diagnosis (such as putting persistent depressive disorder in place of major depressive disorder) would hamper collaborative care and might distort treatment plans in unhelpful ways. However, the utility of psychiatric diagnoses for communication between clinicians has long been compromised by problematic reliability in clinical practice, episodic changes in diagnostic criteria, the pervasive influence of third-party payers, and the everyday, thoughtful deviations from diagnostic orthodoxy made by clinicians as they diagnose patients. For many patients with a lengthy psychiatric history, their medical records contain a motley array of diagnoses, made with varying degrees of rigor at different points in time. As such, the actual loss of accuracy involved in according patients more involvement in the diagnostic process may not be as great as might be feared. Secondly, it may well be that in primarily relying on a DSM-V-based diagnostic category to effectively and comprehensively communicate individual patients’ circumstances, we are asking too much of it. The primacy and assumed authority of the diagnosis has perhaps overshadowed the critical role that the clinical formulation should play in collaboration among careproviders.

A second possible objection to allowing psychiatric patients a role in their diagnosis is that it would set psychiatry apart from other fields in medicine. An obstetrician does not invite lay opinions on an ectopic pregnancy, and an internist has no use for patients’ thoughts as to whether or not they may have hypertension. After working so hard to establish itself as a legitimate branch of medicine with a scientific foundation, why should psychiatry veer away in this manner, acknowledging in effect that its diagnostic systems lack genuine validity? The answer is that psychiatric diagnoses at this point in time are indeed different from medical diagnosis in any number of ways. Not only are psychiatric diagnoses largely heuristic, but they frequently contain much greater value complexity than do medical diagnoses.19 As such, it is only appropriate that they be addressed differently. Further, it is not necessarily the case that allowing patients to have meaningful input around their diagnoses reflects the developmental immaturity of the field of psychiatry; it may well be that certain medical diagnoses carry their own underappreciated ethical complexities and that the field of psychiatry could take the lead in acknowledging and addressing the issues involved.

CONCLUSION

Current psychiatric nosology represents an effort to impose coherence on the confusing particularities of patients’ distress, much as celestial constellations attempt to make sense of the starry night skies. Psychiatric diagnoses, however, are highly prone to reification and can have substantial and harmful impacts on patients in a variety of ways. The paternalistic approach to psychiatric diagnosis, in which clinicians retain full authority in the diagnostic endeavor, leaves patients powerless and largely silent in the process and appears to take little regard for their autonomy. At the same time, clinicians bear responsibility for accurately documenting their clinical impressions and would be remiss in allowing patients to simply dictate their preferred diagnoses. An expectation that clinicians seek patients’ assent before bestowing a psychiatric diagnosis upon them would encourage a meaningful dialogue, demonstrate respect for patients, and likely reduce patients’ sense of stigma, while still allowing clinicians the latitude necessary for accurate recording.
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Response to “Psychiatric Diagnoses and Informed Consent” by Andrew Clark

David Brendel

ABSTRACT

A patient’s rights to informed consent and self-determination in psychiatric treatment are well enshrined, but the same rights have not yet been meaningfully extended to patients with regard to psychiatric diagnosis. Andrew Clark’s essay entitled “Psychiatric Diagnoses and Informed Consent” in The Journal of Clinical Ethics empowers both psychiatrists and patients to rethink who “owns” the process of clinical assessment and of bestowing diagnostic labels that may have far-reaching consequences. Clark’s article represents a noteworthy breakthrough in the field’s ongoing journey toward enhancing informed consent, personal dignity, and patients’ active involvement in their own care.

Andrew Clark’s essay in this issue of The Journal of Clinical Ethics is a remarkable contribution to the ethics and philosophy of psychiatry, and his key points are deeply relevant in a wide range of clinical settings. A patient’s rights to informed consent and self-determination in psychiatric treatment are well enshrined, but the same rights have not yet been meaningfully extended to patients with regard to psychiatric diagnosis. In the latter case, psychiatrists are still considered to be authoritative subject-matter experts whose conclusions carry the weight and objectivity of medical science. Clark importantly and compellingly problematizes this predominant view. In so doing, he empowers both psychiatrists and patients to rethink who “owns” the process of clinical assessment and of bestowing diagnostic labels that may have far-reaching consequences.

Most of the diagnoses included in the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-V) are clusters of symptoms, some of which are self-reported by patients and others of which are objectively observable. There is enormous overlap of symptoms across diagnostic categories. For many patients seen in office-based practice, stressful life events—such as those that occur in high-pressure work settings—can cause significant anxiety. When severe, this anxiety may present as distressing beliefs that the boss or coworkers are actively trying to undermine or otherwise harm the patient. The psychiatrist here faces the question of whether the current diagnosis is an anxiety disorder or a psychotic disorder with paranoid features. In my clinical experience, these situations are common and either diagnosis is often justifiable. How should a psychiatrist in such cases establish a diagnosis, share it with the patient, enter it in the medical record, and potentially disclose it on insurance forms or disability applications?
The decisions taken by psychiatrists in these situations can be momentous, for the many reasons that Clark deftly points out. For example, being diagnosed as “anxious” versus “paranoid” means different things to different people. Some patients may feel alarmed or ashamed to be labelled as psychotic, and thereby experience a worsening of their condition. In that case, the psychiatrist could have protected the patient’s fragile emotional state by more gently providing the equally justifiable diagnosis of an anxiety disorder. On the other hand, some patients may appreciate and benefit from being directly informed that they possibly or likely have crossed a threshold into psychosis. It may grab their attention in a productive way, engendering greater motivation for and adherence to a rigorous treatment plan, which may include short-term use of an atypical antipsychotic medication.

The consequences of sharing an anxiety disorder diagnosis versus a psychotic disorder diagnosis with insurance companies or other outside stakeholders also can also be profound. A psychotic disorder diagnosis may help a patient to receive appropriate short-term disability benefits, which may be critical for the patient’s financial stability as he or she recovers. But at the same time, it may compromise the same patient’s future applications for life insurance or long-term disability coverage. Because of these considerations, psychiatrists should exercise caution when documenting a psychiatric diagnosis in the medical record. The patient’s informed consent should be sought beforehand, after a thorough discussion of risks versus benefits. Clark is on point in suggesting here that the informed consent process is just as critical with regard to diagnosis as it is to treatment.

For this and other reasons that Clark elucidates, psychiatric diagnosis ought to be viewed as a complex process that should include serious consideration of the patient’s point of view, personal values, and understandable self-interest. At its best, the process of diagnosis in psychiatric settings is a kind of “thought partnership” between patient and clinician. Nuanced conversations about the implications of psychiatric diagnoses can empower both of them in their respective roles. When the patient is an active participant in these conversations, he or she is much less likely to be blindsided and stressed later by the implications of a particular diagnosis. A consensus about the diagnosis can also help the patient to achieve greater insight into the condition and “buy in” to the treatment plan. These conversations can also aid clinicians, because they may furnish more data about patients’ state of mind and openness to treatment. Informed consent around diagnosis can also protect clinicians from later complaints from patients that a diagnosis harmed them emotionally, socially, financially, or otherwise.

Some people come to see psychiatrists to talk over life stressors, emotional challenges, and relationship issues they are facing—not to receive a potentially stigmatizing diagnosis. It is essential, right up front, for the psychiatrist to ensure clarity about the goals and objectives of a meeting with a patient. If the patient does not seek a psychiatric diagnosis (or actively expresses a wish not to receive one), psychiatrists should take the request seriously and respect the patient’s wishes. Absent a formal diagnosis, insurance and payment questions may come into play if the patient is not paying out of pocket for the services. This can create a pesky problem, but one that should be addressed at the outset and with the fundamental goal of respecting the patient’s wishes. Unless such a patient presents an imminent safety risk based on a clear psychiatric disorder, no diagnosis should be imposed, entered in the chart, or shared with anyone else outside the consulting room.

Clark’s article represents a noteworthy breakthrough in the field’s ongoing journey toward enhancing informed consent, personal dignity, and patients’ robust involvement in their own care. It should breed continued discussion and debate about the logistics of engaging patients and their loved ones in critical conversations around the process (and potential consequences) of psychiatric diagnosis. Psychiatric training ought to include curricular material on this key aspect of patient-centered care, and education of the public should help patients and their loved ones to understand better what to expect when seeing a psychiatrist. We owe Clark a debt of gratitude for bringing this under recognized issue to light in such an articulate manner and for encouraging positive, real-world changes in clinical practice.

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ABSTRACT

The broad use of social networking and user-generated content has increased the online footprint of many individuals. A generation of healthcare professionals have grown up with online search activities as part of their everyday lives. Sites like Facebook, Twitter, and Instagram have given the public new ways to share intimate details about their public and private lives and the lives of their friends and families. As a result, careproviders have the ability to find out more about their patients with just the tap of a key or the click of a mouse. This type of online searching for patient information is known as patient-targeted googling or PTG.

This article provides an overview of the emergence of PTG, identifies the potential benefits and possible pitfalls of engaging in PTG, and explores current ethical frameworks that guide decisions about PTG. The article describes the development of a critical thinking tool developed by the Behavioral Health Ethics Committee at CHI Health, that can serve as a best-practice model for other hospitals and health systems. Called TTaPP (Together Take a Pause and Ponder), this tool is designed to help healthcare professionals across settings practice collaborative critical thinking skills as they consider the ethical questions of whether or not to engage in PTG. Finally, this article suggests areas for further study, including ways to prompt collaboration and appropriate documentation by maximizing electronic medical records systems, exploring the effectiveness of the TTaPP tool as a way to promote a culture of collaborative critical thinking practices, and the attitudes of patients and the public regarding PTG.

“I don’t think it’s right that she can’t say goodbye . . . something fishy is going on here and I think her family is keeping things from her. Let’s google them and see what the real story is. . . .”

It started innocently enough, a conversation within one of our treatment teams. They had a hunch about this situation, and it would be easy to simply search online for the information they wanted. Yet while this seemingly innocuous strategy to find out more was well intended, the consequences proved complicated. The information the team found online—that the young patient’s loved one had passed away, his bedside surrounded by several other family members, his funeral now an event of the past—could not be unseen. They now had information their patient did not have. They had not asked for parental permission to search online. They struggled with their relationship, given this new knowledge; and they grappled with their own conflicted feelings about grief, loss, and the “best” way to parent a child dealing with death. Ultimately, the trust within the therapeutic relationship was significantly compromised by their online search activities, and the treatment team eventually turned to our local behavioral health ethics committee for guidance.

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TTaPP: Together Take a Pause and Ponder: A Critical Thinking Tool for Exploring the Public/Private Lives of Patients

Leslie Kuhnel
Situations like this one are not uncommon in our ever-evolving social-networking age. Most healthcare professionals are a keystroke away from previously hidden details of their patients’ lives, and ready access to an abundance of online information has made the urge to “google search” quite tempting. To be sure, accessing online avenues can be beneficial to healthcare teams by providing more information to consider as effective care plans are developed. However, when curiosity overshadows caution, the risks associated with the instant urge to “google” must be considered.

Within this new social-networking world, concepts of privacy, the boundaries between public and private lives blur, and the role of professionalism within the therapeutic relationship is challenged in new ways. Known as patient-targeted googling (PTG), this type of online patient-information-gathering activity raises several ethical questions, including concerns related to respect for privacy and confidentiality, the accuracy and verifiability of information, and risks to the integrity of the patient-care-provider relationship.

These were the questions that the members of the ethics committee grappled with in an effort to respond to the treatment team. The goal was to find a way to balance the potential benefits and possible pitfalls associated with engaging in PTG. The result was the development of a critical-thinking tool for healthcare professionals called TTaPP (Together Take a Pause and Ponder, see the appendix). The TTaPP tool is designed to facilitate collaborative decision making about whether or not to engage in PTG. It is intended to prompt healthcare professionals to work together to pause and ponder their intentions and motivations, and to consider the benefits and potential consequences of searching online for information about their patients, before engaging in PTG.

This article provides an overview of the emergence of online search activities within healthcare, identifies potential benefits and possible pitfalls of engaging in PTG, and explores current ethical frameworks that guide decisions about PTG. This article also describes one organization’s response to the need for PTG activity guidelines (the TTaPP tool) and suggests further areas of research and study. Finally, the article suggests that the TTaPP tool can encourage healthcare professionals across disciplines and delivery settings to practice collaborative critical thinking skills as they consider whether or not to engage in PTG, and offers the TTaPP tool as a model practice for adoption by other hospitals and health systems.

HISTORY AND BACKGROUND OF PTG

The Evolution of the Web and the Emergence of Patient-Targeted Googling

The evolution of the social-networking age has seen the emergence of a plethora of user-generated content information. Social-networking sites and sophisticated online search engines have dramatically changed the way people interact with one another. In the past, finding out about personal behaviors and private encounters would have required driving by a person’s home, reading a person’s diary, or eavesdropping on a person’s conversations. In this social-networking era, however, catching a glimpse into a person’s private world is as easy as googling a name, visiting a Facebook page, or viewing an Instagram gallery.

As Brian K. Clinton and colleagues note, instant online searches and frequent social media browsing reflect the “omnipresence of the internet in our daily lives,” and the capability of conducting online searches is literally at the fingertips of most people. As a result, the once-private lives of others have become remarkably public.

Careproviders face unique opportunities and challenges in this social-networking era. PTG offers new windows into the personal lives of patients, their families, and their circles of friends. For younger generations of healthcare professionals, “digital natives” who have grown up with the internet, such online exploration is a natural and instinctive part of their everyday connection with others. “The vast majority of physicians I know google their patients,” says one young doctor; “To my generation, using a search engine like Google [in the professional setting] comes as naturally as sharing pictures of children or a recent vacation on . . . Facebook.”

This anecdotal demonstration of routine online activity by healthcare professionals is echoed in the empirical literature. For example, Gabriel T. Bosslet and colleagues found that 93.5 percent of medical students, 79.4 percent of resident physicians, and 41.6 percent of practicing physicians in the United States reported using online social-networking sites. Maxim Ben-Yakov and colleagues report that the majority of responding emergency physicians, residents, and graduate students were users of online social networks. Based on these studies, it appears that most medical professionals are frequent users of search engines and browsers of social-networking sites within the context of their private lives.

However, when it comes to professional perspectives regarding the appropriateness of engaging in PTG, medical professionals’ comfort levels changed.
Only 57.9 percent of physicians, medical students, and residents in the study by Bosslet and colleagues found it “ethically unacceptable” to visit the social network sites of patients. Likewise, only 12.1 percent of respondents in the second study searched on Google and 1.9 percent searched on Facebook for information about their patients. Nearly 30 percent of respondents in the study by Ben-Yakov and colleagues felt that engaging in a Facebook search was “very unethical” because such activities would violate confidentiality, respect for patients’ dignity, and standards of informed consent.

Attitudes and actions seemed to vary within the behavioral health context, however. A study of psychology graduate students by David K. DiLillo and Emily B. Gale found that while the majority of respondents felt it was “usually” or “always” unacceptable to search for online patient information using Google (76.8 percent) or Facebook (76.8 percent), as many as 94 to 97 percent engaged in PTG for at least one of their patients during the year prior to the study. These results seem to suggest that there may be something unique about information sharing within the therapeutic relationship in the behavioral healthcare setting. Cynthia Geppert writes that this may suggest that there is a need for guidance regarding engaging in PTG in the behavior healthcare context in particular.

It is likely that the frequency of engaging in PTG will continue to grow, given the ease of access to online information and the generational differences as younger careproviders become medical professionals. While this has the potential to benefit patient care in many ways, there are a number of possible risks as well. In anticipation of related ethical dilemmas, careproviders, scholars, and professional organizations recognize the need for deliberation about engaging in PTG. As resident Haider Javed Warraich noted, “it surprises me that more physicians don’t pause and think about what [PTG] means for the doctor-patient relationship.” Developing intentional practices and critical thinking skills that protect the integrity of this relationship is critical to the professional practice of medicine in an era of social networking.

POTENTIAL BENEFITS AND POSSIBLE PITFALLS OF PTG

Ready access to the social-networking landscape promises several potential benefits within the healthcare arena, since online databases and social-networking sites contain a wealth of information that may be helpful to patient care. For example, PTG may help identify an unrepresented patient’s potential representative, and may provide medical history and other relevant information for unconscious patients. PTG may allow careproviders who are concerned about the safety and well-being of their patients to monitor risks more closely. PTG may help locate research participants who were formerly lost to follow up, so that up-to-date treatment information can be shared. Social-networking sites and other online outlets can be valuable sources of information for patients for whom communication would otherwise be a challenge. Online platforms can be an essential information-gathering tool for patients with severe social phobias or communication disorders, and can inform patient care in significant ways.

Paul S. Appelbaum and Andrew Kopelman write that PTG holds significant promise as “rich sources of collateral data” that could otherwise remain undiscovered or might be misrepresented within a clinical setting. For example, Facebook posts and Twitter feeds may include items that suggest mental health symptomology, including depressive or suicidal thoughts, ongoing patterns of substance use, or other concerning behaviors. By using social-networking sites as a way to “access a patient’s mental state in real time,” Chantal Cox-George writes, PTG can provide a valuable method for gathering previously unavailable information.

In addition, online search activities conducted in partnership with a patient can be an effective tool in the therapeutic setting. For example, a careprovider may find it helpful to review social media posts with a patient who is struggling with boundary issues, or might be able to engage with a patient experiencing a public loss or tragedy by reviewing available online information together. Suggesting collaborative online search activities may prompt a patient to verbally share sought-after information, such that further PTG becomes unnecessary.

Although there are several potential benefits associated with online search activities, there are pitfalls as well. Consider, for example, how the locus of the control of information shifts in the online environment. Patients are no longer the primary owners of decisions about when and how to share their personal information within the therapeutic setting. Instead, control is now shared with—or even handed over to—their careproviders, who now have the ability to search for information with or without the permission of their patients. As a result of this shift, several ethical dilemmas have emerged. Areas of particular ethical concern are discussed below.
Privacy and Confidentiality, Part One: Information Control

One area of concern is the increased potential for breaching patients’ privacy and confidentiality when engaging in PTG. Here it is important to recognize the distinction between privacy and confidentiality. As Kayhan Parsi and Nanette Elster note, privacy is “typically focused on the person—how and when an individual may share of him or herself,” whereas confidentiality is “focused on information that has been shared with someone else in a relationship of trust.” In the context of the patient-careprovider relationship in this social-networking age, trust is paramount, with privacy dependent on the degree to which patients are allowed to decide what information to share and what not to share online, and confidentiality dependent on the degree to which a careprovider shares patients’ information discovered online with others.

Because the locus of information control has shifted from patient to careprovider to a certain degree, there is increased potential for breaches of both privacy and confidentiality. Windows into the once-private lives of patients can be opened by careproviders and others on the care team (often without permission), revealing information that was easily hidden in the past. This includes information patients would rather their careproviders not see, creating a new type of vulnerability for patients.

Access to patients’ personal thoughts and experiences may not be limited to decisions by patients about whether or not to share these with their careproviders. Instead, such information may be discovered through a careprovider’s decision to search within the “private” spaces of patients’ social-networking footprints.

For some patients, recognizing these new windows into previously private worlds may result in increased discretion about what content to share online. For other patients, though, this recognition may lead to a reluctance to engage within the healthcare system, even to the extent that the delivery of care may be compromised. To avoid this, patients must be able to trust that information sharing and searching is done within the context of respect for their privacy and confidentiality. Given the current conversations and investigations into privacy on social network sites, the final determination of both public and legal perceptions regarding the privacy of the information that is posted on social media sites remains to be seen. However, until such time as these questions are sufficiently answered, these legal and regulatory constructs around privacy remain relatively undefined.

Privacy and Confidentiality Part Two: Legal and Regulatory Constructs

One may ask how regulations and laws apply to privacy and confidentiality as they relate to engaging in PTG. Surprisingly, the regulatory and legal realms do little to limit such activities. First, as Daniel F. Shay argues, online postings are considered to be in the public domain. Second, as Geppert and Lorna L. Hecker and Roger Shindell write, because information posted on social-networking sites is created by a patient about himself or herself, and not by the careprovider about the patient, information is not covered by the typical privacy regulations such as HIPAA (Health Improvement Portability and Accountability Act). Currently there do not seem to be regulations that fully protect the privacy of most of the information that is available on social-networking sites.

Likewise, within the legal realm, determinations of privacy regarding information on social-networking sites are not as straightforward as some might assume. As attorney Margaret DiBianca writes, there is a general legal consensus that “ ‘private’ is not necessarily the same thing as ‘not public,’ ” and thus it cannot be expected that information posted on social-networking sites will automatically remain private. Given this, Shay says that currently there do not seem to be legal reasons that careproviders should refrain from online search activities, as long as the method of searching itself is legal.

Privacy and Confidentiality Part Three: Social Constructs

Although the regulatory and legal constructs of privacy and confidentiality do not limit a careprovider’s ability to engage in PTG, at least of yet, the social construct of privacy and confidentiality may create limitations for professionalism. Many consider the information posted on social-networking sites like Facebook, for example, to be relatively private. However, although privacy settings can limit some types of exposure, the frameworks of online platforms of many social-networking sites make it difficult to completely control all access to personal information. The messages one sends can be retweeted indefinitely. Pictures one posts online can be reposted by other persons on their sites. Friends of friends of friends may have unknown connections that lead to uninvited viewing of your information, and networks of connected users may stretch beyond recognized relationships to cross over professional or personal boundaries. All of this increases the vulnerability of patients, and the expectations of professionalism, including protecting the integrity
of the therapeutic relationship, becomes even more significant. For patients to continue to trust their careproviders, they must be able to rely on the social constructs of privacy and confidentiality that are inherent in patient-careprovider relationships.

The Accuracy and Validity of Online Information
Beyond privacy and confidentiality, another area of concern is the accuracy and validity of online information. Because postings and images that are discovered online can lead to a variety of assumptions, the accuracy and validity of the information itself, and perceptions about that information, must be carefully considered. In some cases, names that are similar and variations in spelling may lead to the discovery of information about the wrong person. For example, which Jane Smith was arrested for drunk driving three years ago? Was that Jane Smith or Jayne Smyth in that picture posted last New Year’s Eve? Or information that is found online is about the right person, but does not truly reflect that person’s actual lived experience. Thus, that is “the right Jane Smyth” in the photo, but the champagne glass she is holding is her friend’s, not hers.

The images and postings found online do not tell the entire story. As Shay notes, information posted online generally represents an isolated snapshot, a single moment in time.39 Jim Taylor writes that a person’s “online self” may or may not be grounded in the reality of that person’s actual identity, or may be the result of significant variations between the person’s “online” persona and “real-world” persona.40 Appelbaum and Kopelman note that the disinhibition effect, the asynchronous nature of online communication, and the sense of increased anonymity within the virtual world make it easy to create an inflated or fantasy online persona and to hide one’s true self.41 All of these factors make it difficult, if not impossible, to draw accurate conclusions based solely on information found as a result of PTG.

Transparency, Patient Consent, and Disclosure
Other areas of concern are transparency, patients’ consent, and disclosure. Whether or not careproviders are transparent about their intentions to search online, whether or not patients are given the opportunity to consent, and whether or not the information found online is disclosed to patients matters in terms of protecting the integrity of the patient-careprovider relationship.

Patients’ perceptions and expectations are the primary factors to consider here. For one, as Merle Spriggs notes, searching online without a patient’s consent changes the role of the careprovider “from someone who works with the patient to someone who observes and spies on them.”32 The perception has shifted from that of a shared relationship of a patient and careprovider interacting with one another, to an imbalanced relationship in which one person (the careprovider) acts upon the other (the patient). Again, trust is the central issue, and the potential for violation of that trust through searching online without the patient’s consent is significant. Cox-George and others have argued that because patients commonly expect the bulk of what physicians know about them to come from information the patients have shared personally, engaging in PTG without the prior consent of patients should be avoided unless there are significant health or safety issues at stake.33 Rebecca Volpe and colleagues offer a litmus test to use as guideline: Simply ask, Why would it be better to google a patient than to ask her or him directly for the information sought?44 Finding out more about patients’ perceptions of how online searches strengthen or weaken trust within the patient-careprovider relationship would add to this dialogue and confirm whether or not these perceptions are accurate.

Motivations of the Careprovider
Another area of concern is a careprovider’s motivation for engaging in PTG. Searching for information online can be quite tempting, given the abundance of easily accessible information. As Parsi and Elster argue, curiosity as a motivation rarely justifies PTG, particularly when the information sought is information a patient would rather not share.45 The urgency to find out more by searching online must be balanced with respect for the patient and respect for the integrity of the therapeutic process.

Allowing information to emerge organically (if it does emerge at all) may be a critical part of the therapeutic process. Rushing the process by prematurely inserting found information into the clinical encounter may pose a serious threat to the integrity of the patient-careprovider relationship. Rather than search online for information to answer questions not yet approached, Warraich writes, “a physician should instead pause and do what has worked . . . over time: simply sit down next to the patient and ask [the patient directly].”46 Should patients decide they do not want to share, argue Ben-Yakov and colleagues, then that decision should be respected: “if the only reason a doctor searches online is to gather personal information that patients don’t want to share with their physicians, then [searching online] is absolutely the wrong thing to do.”47

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There is a fine line between professional responsibility and potential voyeurism. The cloak of anonymity that may give patients a false sense of security within online encounters creates a strange space for careproviders as well, perhaps leading them to falsely believe that patients would not find out about online searches. Ben-Yakov and colleagues, along with others, argue that although the circumstances of a specific case may justify engaging in PTG, special caution must be taken to consider whether searching online is really about enhancing patient care in ways that cannot be otherwise accomplished, or if the act of online searching is driven by casual habit, curiosity, or voyeurism. Pausing to consider the motivation for engaging in PTG is an important way to navigate online environment while avoiding potentially damaging pitfalls.

**EMERGING GUIDELINES AND STANDARDS**

Questions about the appropriate use of online information in the healthcare setting have become a popular focus of conversations about professionalism. In 2010 Clinton, Silverman, and Brendel offered a set of questions that practitioners should explore when considering the ethical dilemmas associated with engaging in PTG. These included questions about the potential impact on the therapeutic relationship, the role of informed consent and disclosure, whether and how to document information found online, and the motivations for engaging in PTG.

Since then several professional organizations have developed guidelines for working within the online and social media context and engaging in PTG. For example, the American Psychiatric Association’s Ethics Committee states that “first and foremost, the ‘Googling’ of a patient should only be done in the interest of promoting patient care and well-being, and never to satisfy the curiosity or other needs of the psychiatrist.” The APA opinion also notes the importance of considering how online information will ultimately be used and how it might influence treatment and the therapeutic relationship. The opinion concludes with a recommendation that clinicians ask certain questions about their own motivations for engaging in PTG, the intended application of information found through PTG within the clinical setting, and the potential consequences resulting from PTG before engaging in this type of information gathering. In order to be considered ethically permissible, the goal of the online search activity must be aligned with the patient’s goals for his or her treatment, must be clearly in the best interest of the patient, and must not be for the sole benefit or convenience of the careprovider.

In contrast to the APA, although the American Medical Association (AMA) has expressed an opinion on the role of social media in relationship to medical professionalism, it has not specifically addressed ethical considerations related to engaging in PTG. Maria J. Baker, Daniel R. George, and Gordon L. Kaufmann refer to this as AMA’s “Google blind spot,” and criticize this lack, given both the number of practicing physicians who use social media on a daily basis and the number of medical students and new physicians who have grown up in the social-networking age. In response to the AMA’s lack of guidance, Baker and colleagues offer a list of 10 factors that would justify PTG. This list includes the duty to warn of possible harm, suspicion of “doctor shopping,” evasive responses to clinical questions, improbable claims about personal or family history, inconsistent statements from a patient or other family members, suspicions of physical or substance abuse, and concerns related to suicide risk.

In addition to conversations in the psychiatric and medical literature, other healthcare professionals have suggested or developed guidelines for PTG. Janet Green has written for nurses; Amy L. Hader and Evan D. Brown wrote for nurse anesthetists. Heck and Shindell wrote for wound care specialists; Frederic G. Reamer wrote for social workers; Kendra Gagnon and Carla Sabus for physical therapists; Ann McNary for risk-management professionals; C. Lee Ventola for pharmacists; and Thomas E. Taimann for dentists. While there are no universal standards for engaging in PTG for use across healthcare professions, there are several common recommendations found in these guidelines that professionals should consider before searching online for patient information, which include:

- Their intentions and motivations for engaging in patient-targeted googling activities
- The impact of PTG on the current and future therapeutic relationship
- The requirement of consent prior to engaging in PTG
- The accuracy and validity of online information
- The potential benefits or risks of PTG
- The appropriateness of disclosure of information found online to the patient and to current and future careproviders
- The process for documentation of relevant information

In addition, prior to engaging in PTG, professionals are commonly guided to pause and ponder...
the above considerations, either on their own or in collaboration with their colleagues and patients.

RESPONDING TO LOCAL DILEMMAS: DEVELOPMENT OF THE TTaPP TOOL

Conversations about whether and when to conduct online searches for information about patients emerged as a focus for our local Behavioral Health Ethics Committee in 2014. Members of our committee, representing various areas of behavioral healthcare, several professional disciplines, and our patient population, were asked to review the case described earlier: because of their concern that important information was being “hidden” from their patient, members of the team had decided to search online for more details. As a result of their search, they discovered the obituary of their patient’s loved one, and found pictures of other family members with the loved one in the days prior to the death. These findings led team members to conclude that the patient had been intentionally deceived, and prevented from saying good-bye in a way that they all felt was important.

Following the search, the dynamic of the therapeutic relationship changed in significant ways. Some team members became suspicious of most of the parents’ behaviors, and a few even questioned whether the situation should be reported as a type of parental neglect. Although the team initially wanted to know whether it would be ethical to disclose information about the family member’s death to the patient without the parents’ permission, it did not take long for the focus of the ethics committee’s conversation to shift to broader ethical questions related to engaging in PTG. This included concerns related to the confidentiality and privacy of the patient’s family, conflicts about whether or not to disclose discovered online information to the mother and the patient, and questions about searching online without asking for consent or permission. Members of the treatment team and the members of the behavioral health ethics committee struggled to determine the best way to respond to the resulting disruption within the therapeutic relationship.

Although this situation came to the ethics committee as an isolated case, several additional examples of healthcare professionals engaging in online searches emerged. In fact, it became clear that engaging in PTG was not uncommon in the behavioral health setting. Sometimes online searches were conducted because of safety concerns, and other times they were conducted simply out of curiosity about a patient’s background. This discussion prompted ethics committee members to think about ways to pro-actively address the ethical dilemmas associated with engaging in PTG. For experienced ethics committee members from older generations, the initial answer seemed to be prohibiting engagement in PTG altogether. However, as discussion continued and the possible benefits of searching for information online were explored, it became clear that strict guidelines prohibiting PTG in all situations would be too limiting. It also became clear that such prohibitions would not adequately respond to the social-networking practices of younger professionals—and of many patients. What was needed instead was a critical-thinking tool to guide collaborative decisions about whether, when, and how to appropriately engage in PTG within the clinical setting.

Building upon the pragmatic framework suggested by Clinton, Silverman, and Brendel, ethics committee members developed a critical-thinking tool called TTaPP (Together Take a Pause and Ponder—see the appendix). The TTaPP tool is intended to provide staff with a series of ethics-related questions to consider before engaging in PTG. The TTaPP tool guides professionals to talk with their colleagues, managers, and other care team members about the possible benefits, implications, and consequences of engaging in PTG. The TTaPP tool sets the expectation that healthcare professionals will pause and ponder questions together before making a definitive decision about whether or not online searching for a patient’s information is ethically justifiable.

Although the TTaPP tool was developed within the behavioral healthcare context, the questions have been carefully crafted for application across healthcare settings. By fostering critical thinking and collaborative deliberation about the practice of engaging in PTG in any context, the TTaPP tool can help professionals navigate the potential benefits and possible pitfalls that accompany expanded access to online information about the public and private lives of patients throughout all areas of healthcare.

OPPORTUNITIES FOR ADDITIONAL RESEARCH AND STUDY

There are several opportunities for additional research and study associated with PTG and the TTaPP tool. For example, an exploration of the attitudes of practitioners prior to and following their introduction to the TTaPP tool could help us understand variations among professions, generations, and service areas. Such a study might also help us understand whether the TTaPP tool creates a context in which critical thinking before searching becomes
a professional habit. Possible ways this could be done include the use of pre- and post-education surveys, focus groups, one-on-one interviews, and observations of practice patterns across a variety of professional disciplines.

A second area to study includes an exploration of ways to maximize the electronic medical records (EMR) functions related to PTG and the implementation of the TTaPP tool. Prompts for documentation of evidence that staff paused to ponder certain questions in collaboration with others before engaging in PTG, could provide useful information about online search practice patterns. In addition, maximization of EMR documentation tools may help us explore how information found through PTG impacts interactions with and the treatment of patients and their families. Although more complex than other types of analysis, a qualitative chart review could offer information about how PTG impacts patient-careprovider relationships within and across patient encounters, and may give us some idea of whether or not such activities are indeed helpful (or potentially harmful) within the context of patient care.

Finally, there is an opportunity to explore attitudes and perceptions of patients and the public regarding PTG. To date, most of the research on attitudes towards online search activities by healthcare professionals has focused on practitioners and learners. The perceptions of patients and the public tend to be drawn from anecdotal conversations and speculation. However, the general conclusion that patients may be skeptical about such activities has likely been drawn from observations like Shay’s: “while patients may appreciate the opportunity to research their doctors, often they are less enthusiastic about having the doctor research them.”

Surveys, interviews, and focus groups may help us determine if such conclusions and our presumptions about patients’ perceptions of PTG are indeed accurate. They may also give us insight into the opinions and attitudes of the general public related to acceptable reasons to engage in online searches for information in the healthcare context. Insights gained from this type of research could provide valuable information about potential benefits and possible pitfalls of PTG, and could expand our understanding of the ethical tensions that have been identified throughout this article.

CONCLUSION

With the continuing evolution of social networking, the increasing accessibility of online information, the integration of online activities within the fabric of everyday life, and the emergence of medical professionals who are, more likely than not, social-networking natives, the tendency to engage in PTG within the healthcare context will grow. By proactively considering the potential benefits and possible pitfalls of online searching, and by fostering critical thinking skills and collaborative deliberation regarding PTG, the integrity of the patient-careprovider relationship can be protected. This may not be easy, however, as new platforms are introduced and new dilemmas are uncovered. Introducing models like the TTaPP tool may help healthcare professionals remember to pause and to collectively consider the ramifications of their actions so that professionalism remains a priority.

BLINDING OF THE CASE

Details of this case have been altered to protect the identities of the patient and the patient’s family.

ACKNOWLEDGMENTS

I would like to thank the members of the CHI Health Behavioral Health Ethics Committee for their engagement in discussions about the ethical dimensions of patient-targeted googling, and for their contributions to the development of the TTaPP tool.

I would also like to thank the healthcare team for bringing this case and the related dilemmas to the attention of the ethics committee, and for their commitment to caring for the needs of patients and their families in a way that demonstrates compassion, sensitivity, and integrity.

Finally, I would like to thank Summer McGee and Michael McCarthy from Loyola University; Brenda Bergman Evans from CHI Health; and Susie Sisson, Wendi Chiarbos Jensen, and James Somers for their support during the writing and revision of this article.

NOTES

2. Ibid.
3. Ibid., 104.
5. Clinton, Silverman, and Brendel, “Patient-Targeted Googling,” see note 1 above.
**APPENDIX**

**Together Take a Pause and Ponder**

We live in a networked world and sensitive information about the people you serve may be just a tap on a keyboard or cell phone away. Though it can be tempting—and even helpful—to search Google, Facebook, Twitter and other online and social media sources to find out more, online searches on your work or personal computers and electronic devices have the potential to:

- Compromise the integrity of the therapeutic relationship.
- Cross professional boundaries.
- Jeopardize trust between patients and their care team
- Introduce false or inaccurate information.

The general guidelines is NOT to search online for patient information, before you do the following:

- FIRST, talk with your manager, another team member, and/or your patient’s provider
- THEN, Together Take a Pause and Ponder (TTaPP) the following questions.

**Questions to Ponder Together**

1) **How is my decision to search for online information guided by our Mission, Core Values, and Standards of Conduct?**

   - Would this search demonstrate or compromise my reverence for this person?
   - Does this search demonstrate hospitality, collaboration and respect for the dignity of this person?
   - Does this search demonstrate or compromise my integrity or the integrity of others caring for this person in terms of honesty, humility and stewardship?
   - How might this search strengthen or compromise my compassion for this person?
   - Does this search illustrate our commitment to person-centered care, creating healing environments and advocating for others?
   - Does an online search cross professional boundaries with this person or compromise the requirements of my professional licensure?

2) **Why do I want to search online for information about this person?**

   - Am I concerned about this person’s immediate safety and well-being, or am I just curious to find out what might be online?
   - Do I believe this online information is critical to providing effective treatment for this person?
   - Is my desire to search for online information based on my assumptions about this person, or influenced by any sources of stigma?
   - Does this online search cross professional boundaries within my relationship with this person?
   - How does this online search compare to other types of information-gathering activities? For example:
     - searching in a phone book
     - looking through a purse or wallet
     - reading a diary or journal
     - listening in on a personal conversation
   - How will I know if any information I might find online is true and accurate?
   - Is there no other way to find out this information (including directly talking with the person)?

3) **Could my online search either advance or compromise treatment?**

   - How will I use the information I find online within the treatment setting?
   - How will I keep this information private (or should I keep it private)?
   - How would any online information I might find impact this person’s treatment plan?

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This information was adapted by the CHI Health Behavioral Healthcare Ethics Committee from information found in the following resources:

• How might this online search be of benefit or cause harm to this person? To our therapeutic relationship?
• Is there a different way I could find the information I am searching for online that would pose less risk to this person’s confidentiality and privacy?
• Is there something about this situation that would justify searching for information online? For example:
  • Looking for an otherwise-unknown emergency contact.
  • Concern for the immediate safety and wellbeing of this person.
  • Concern for the immediate safety and wellbeing of others as a result of my interactions with this person?

4) Should I ask for permission from this person before searching online for information?
• Would asking this person about the situation or for permission before searching open up discussions about my concerns?
• Are there compelling reasons not to ask permission before searching for information online?
• Will this person feel hurt, angry or violated if I search online without permission?
  • If there is a low likelihood of benefit and a high likelihood that this person will feel angry or violated, then you should probably not search for information online.
• How can I preserve privacy and maintain trust with this person if I search for online information without permission?

5) Should I share online search results with this person?
• If I decide to search online for information, should I share what I found with this person and/or with others?
• What if I didn’t ask for permission to search online before-hand? What should I think about before I decide to tell this person about my online search after I’ve found something?
  • Consider talking with a legal, risk management or privacy specialist, or requesting an ethics consultation, to help you with this decision.
• If I decide not to tell this person that I searched online for information, or not to share the information I found, how will it change my interactions with this person?
• If I decide to tell this person about my online search, how can I do so in a way that preserves trust within our relationship?

6) If I do search online, should I document any information I find in this person's medical record?
• Is the information I found online relevant to the treatment plan?
• Have I considered that this person has a right to read information in the medical record?
• How might this person’s relationship with other members of the current or future treatment team be impacted by this information?
• How might unverified information found online and placed in a medical record impact this person’s current and future treatment and well-being?
  • For example, might documentation about a photo of this person holding a cigarette lead to a false assumption that this person smokes; and how might that impact future insurance coverage or employment opportunities?

7) How do I monitor my motivations along with the risks and benefits of searching online for information?
• Have I checked in with my manager or supervisor, another colleague or the primary provider before searching online for more information about this person?
• Have I identified and acknowledged my motivations for wanting to search online for more information about this person?
• Can I justify my desire to search online from a clinical and/or therapeutic perspective, or am I just being curious or “noisy”?
• Have I carefully considered how this person will be impacted by any information I find by searching online?
• Have I carefully considered how my perceptions will be impacted by information I find by searching online?

Your answers to the questions above will help you decide whether or not you should search for information online.


41. Ibid.

42. Ibid.


44. Ibid.


52. Clinton, Silverman, and Brendel, “Patient-Targeted Googling,” see note 1 above.

ABSTRACT

This article elucidates the premises and limited meaning of medical futility in order to formulate an ethically meaningful definition of the term, that is, a medical intervention’s inability to deliver the benefit for which it is designed. It uses this definition to show the two ways an intervention could become medically futile, to recommend an even more limited usage of medical futility, and to explain why an intervention need not be futile in order to be withdrawn over patient-based objections. If an intervention retains some benefit, then patients or surrogates might legitimately consider that benefit in their case and request the intervention. Physicians might still be justified in declining it on the grounds that the burdens greatly outweigh the benefits, but not on the grounds of futility. Finally, the article uses bioethics research and healthcare litigation to clarify the meaning of futility in practice and recommends alternative language when possible.

In 2009, I joined the ethics committee of a hospital in the southeastern United States. Every monthly meeting involved at least one discussion of medical futility. During one of these discussions, futility was attributed not only to an intervention, that is, “this intervention is futile,” but also to the situation and even to the patient; “the situation is futile” and “the patient is futile.” As an external member of the committee, I thought about how shocking these phrases would sound to patients and families. I was struck that medical professionals spoke these phrases without recognizing their human dimension. At the same time, I could understand why. They were using technical language to discuss the management of very difficult, persistent clinical problems. I found myself thinking, “I understand what you are trying to say, but medical futility is not the way to say it.”

As I listened to these conversations, I noticed that medical futility sometimes does the work it is supposed to do: to withdraw an intervention that should not be continued even though the patient, or more often the family or surrogate, insists on continuing it. At other times, the term confuses the ethical discussion and exacerbates the very conflict it attempts to resolve, creating situations that drain emotional energy and waste time and resources. Thankfully, invoking futility does not always aggravate conflict because the goodwill of medical professionals and families typically enables them to work together to resolve their differences.

The error comes about when medical professionals invoke futility to withhold or withdraw an intervention that may retain some benefit, but which nonetheless may not be worth continuing. Medical professionals need language to express this view, but medical futility does not describe what they really
mean in this situation. The term is used anyway because it is perceived as the strongest justification, and in some situations the only justification for withdrawing treatment over patient-based objections. The more that it is used as the only justification for withdrawing treatment, the more its definition expands to include whatever reasons a physician holds to justify withdrawal. The approach works until a physician invokes futility when an intervention is not really futile, the patient’s representatives recognize some benefit to the intervention or simply do not agree, and insist on continuing.

A medical intervention need not be futile in order to be withdrawn. In practice, it may be difficult to establish a neat dividing line between futile and non-futile but not obligatory interventions. Conceptually, however, there is an important ethical difference between interventions that are futile—rendered ineffective or incapable of benefit by the patient’s medical condition—and interventions that retain some marginal benefit despite excessive burdens. In the latter case, patients and their surrogates may consider what that benefit, although small, would mean to them and might legitimately request the intervention. Nonetheless, physicians might legitimately decline the intervention.

Medical institutions have long recognized the difficulty of these cases and have developed futility policies. These policies may help medical professionals correctly understand and apply the concept of futility. But the soundness of those policies depends upon the underlying definition and application of futility and how well the policy is understood among the members of the institution. A sound policy should help medical professionals distinguish interventions that are clearly futile from those that are clearly not and to recognize grey-area cases in which it is difficult to distinguish futile from marginally beneficial/overall burdensome interventions.

I share with many authors the essential convictions that it is possible to define and use medical futility, that only medical professionals possess the expertise to recognize futile interventions, and that they are justified in withholding or withdrawing interventions that are truly futile. I propose, however, to define medical futility in terms of an intervention’s designed benefit rather than its physiological or quantitative effects or qualitative benefit. These latter definitions, based upon the work of authors such as Lawrence J. Schneiderman and Nancy S. Jecker, tend to apply futility too broadly. Accordingly, this article elucidates the premises and limited meaning of medical futility in order to formulate a definition of the term and to demonstrate why physicians are justified in withdrawing truly futile interventions. It shows the two ways an intervention could become medically futile—immediate and mediated futility—and recommends more-limited usage of medical futility. Further, it explains why an intervention need not be futile in order to be withheld or withdrawn over patient-based objections. Finally, it uses bioethics research and litigation to clarify the meaning of futility in practice and recommends alternative language whenever possible.

MEDICAL FUTILITY IN CONCEPT

The Premises and Limitations of Medical Futility

Medical futility appeals to the meaning of the word futility in order to justify withdrawing a medical intervention. The basic meaning of futility gives persuasive force to various uses of the word, including colloquial, ethical, scientific, and medical uses. As a word in English, futile means “incapable of producing any result; failing utterly of the desired end through intrinsic defect; useless, ineffectual, vain.” Futility implies that a cause cannot produce its effect and, in ethics, that a particular deliberate act cannot achieve its objective. The word describes an act that a person could perform, but never successfully. Thus, medical futility describes an intervention that cannot cause its beneficial effect and for that reason should not be performed.

In the above definition as it applies to ethics, the words “effect,” “end,” and “result” refer to the benefit that an intervention is designed to bring about. They never refer merely to the intervention’s physiological effects. It is always possible to describe the various physiological effects—beneficial, detrimental, burdensome, and neutral—of a deliberate human act, including a medical intervention. But some physiological effects of an intervention are themselves the health benefit. An intervention becomes futile when it fails to bring about its beneficial effects. The beneficial effects may be called the intervention’s designed benefit or benefits. Thus, medical futility describes an intervention incapable of accomplishing its designed benefit.

Defining medical futility in relation to its designed benefit rather than its physiological effect better illustrates the concept’s persuasive force, as well as its limitations. Schneiderman’s definition of qualitative futility in the following passage refers to the effects of a number of common medical interventions as if they were merely effects and not simultaneously benefits: “Medicine today has the capacity to achieve a multitude of effects, raising and
lowering blood pressure, speeding, slowing, and even removing and replacing the heart, to name but a minuscule few. But none of these effects is a benefit unless the patient has at the very least the capacity to appreciate it, a circumstance that is impossible if the patient is permanently unconscious.\textsuperscript{5} The “multitude of effects” listed above, however, are not merely effects, but the designed benefits of specific kinds of interventions. The actual benefit to the patient does not depend upon the patient’s capacity to appreciate it, but on the intervention’s ability to deliver it, given the patient’s medical condition. If an intervention is not capable of “raising or lowering blood pressure,” \textit{et cetera}, then it is futile. If such an intervention is capable of achieving its designed benefit, then the benefit of performing the intervention comes along with the effect, even if the patient is not capable of appreciating it. In that case, the physicians or surrogate, or both, might judge that the burdens of the intervention outweigh the benefits and still decline the intervention, but not on the grounds of futility.

Typically the medical condition of the patient renders the intervention incapable of delivering its designed benefit and thus futile. For this reason, medical futility differs slightly, but importantly, from the dictionary definition of futility above, which attributes a futile act’s failure to an \textit{extrinsic} defect.\textsuperscript{9} The medical condition of the patient is a circumstance \textit{extrinsic} to the intervention. In order to establish medical futility, then, it may be necessary to show what factors, especially about the patient’s medical condition, render it futile.

Only medical professionals have the medical training and clinical experience to evaluate a patient’s medical condition and identify interventions rendered futile by that condition. This knowledge and experience, used correctly, justify withdrawing a futile intervention. Paul R. Helft and colleagues recall this principle at the origin of the futility movement:

The movement [in the 1980s] to establish a policy on futile treatment was an attempt to convince society that physicians could use their clinical judgment or epidemiologic skills to determine whether a particular treatment would be futile in a particular clinical situation. The idea was that once such a determination had been made, the physician should be allowed to withhold or withdraw the treatment, even over the objections of a competent patient.\textsuperscript{6}

Similarly, in “Medical Futility: A Conceptual and Ethical Analysis,” Mark R. Wicclair observes that “Physicians have scientific and clinical expertise that enables them to ascertain the likely physiological effects of medical interventions. . . .”\textsuperscript{7} Clinical judgment and epidemiological skills can judge how well an intervention is likely to achieve its designed benefit and thus to improve the patient’s medical condition. Most patients and their surrogate decision makers are not trained in medicine and, quite appropriately, cannot contribute to this kind of judgment. If the intervention will not work, there is no benefit for the patient or surrogate to consider, and the physician would be justified in withholding or withdrawing it unilaterally.

Clinical judgment and epidemiological skills can also recognize when an intervention is likely to bring some small benefit or to be excessively burdensome. This medical expertise contributes to an overall judgment that the burdens of an intervention far exceed the benefits, and thus that offering or continuing the intervention is not obligatory (even though not futile). In this case, however, the decision whether to offer or continue it also depends upon the value that patients, families, surrogate decision makers, and medical professionals find in performing an intervention of such small benefit. In the end, a physician might decline the request, but it is the value of not performing excessively burdensome and/or marginally beneficial interventions, rather than ineffectiveness of medically futile interventions, that provides the grounds for doing so.

The leading bioethics literature today has, to some extent, incorporated this lesson. A 2015 policy statement by the American Thoracic Society, the American Association for Critical Care Nurses, the American College of Chest Physicians, the European Society for Internal Care Medicine, and the Society of Critical Care (hereafter, the ATS policy statement) observes that “There is now widespread agreement that many of these disagreements, previously called futility disputes, do not hinge solely on technical medical determinations and instead also involve contested value judgments about what is appropriate treatment in patients with far advanced illness.”\textsuperscript{8} Presumably “contested value judgments” refers to disagreements between the physician and patient, family, or surrogate about the value of performing an intervention of little remaining benefit or disproportionately great burden rather than an intervention that is futile. The ATS policy statement therefore recommends that “The term ‘futile’ should only be used in the rare circumstance that an intervention simply cannot accomplish the intended physiologic goal,”\textsuperscript{9} or, in this analysis, its designed benefit.
The meaning of futility both justifies and limits the use of the term medical futility. Medical futility can describe an intervention rendered incapable of achieving its designed benefit by the medical condition of the patient, and perhaps by other related medical factors. Medical professionals possess the expertise necessary to judge how the intervention is likely to interact with the patient’s medical condition. Therefore, they legitimately withdraw truly futile interventions despite objections brought on behalf of the patient. The same expertise enables medical professionals to recognize when an intervention, although not futile, is likely to have marginally beneficial and/or excessively burdensome outcomes. This judgment should contribute to conversations with family and surrogate decision makers about the value of performing the intervention. At the end of such conversations, the physician might decide not to pursue the intervention further, but on the grounds of great burden and little benefit rather than of medical futility.

How Medical Futility Applies to Interventions

There are two ways that an intervention could be futile. First, the intervention does not work. A physician recognizes that the intervention cannot effectively deliver its designed benefit and declines to provide it. Cardiopulmonary resuscitation (CPR) is futile if it will not restore cardiopulmonary function; hemodialysis is futile if it will not adequately cleanse toxins from a patient’s blood; and tube feeding is futile if a patient’s body cannot assimilate nutrition. Interventions that are futile in this way might be rare, but the grounds for withholding them are obviously strong. An intervention is ineffective, and there is no benefit to consider. Few patients or family members will insist on something that has no immediate beneficial effect.

This version of medical futility is sometimes called physiological futility or quantitative futility, but the term “immediate futility” is more ethically relevant. Physiological futility sounds counterintuitive because an intervention that is not capable of delivering its designed benefit still produces other, sometimes burdensome physiological changes in the body. Seen another way, physiological futility might be taken to mean that the intervention produces only physiological effects. But the emphasis on producing physiological effects does not explain why the intervention is futile. Rather, it is the intervention’s inability to bring about its designed benefit. Similarly, Schneiderman, Jecker, and Albert R. Jonsen define quantitative futility as the very low probability, based on physicians’ experiences in similar cases, that the intervention will work. The standard of probable effectiveness may serve as a helpful guideline in some clinical situations, but it is more specifically a medical and scientific than an ethical term. Ethics evaluates an action in pursuit of some benefit, and medical futility, as an ethical term, claims that an intervention cannot deliver its designed benefit.

Immediate futility better describes the ethical reality meant by the physician. In its colloquial sense, immediate communicates that no benefit would be possible at the time the intervention was attempted, and therefore that it should not be offered. In a philosophical sense, immediate communicates that the intervention’s failure is not mediated by a worsening medical condition over time or by any other factor that would eventually render the intervention futile for a future goal of treatment. This philosophical sense becomes clearer when immediate futility is distinguished from the second way in which an intervention could be futile.

An intervention is also futile if it is somewhat beneficial but is expected to lose the beneficial effect before achieving currently held goals of treatment. The term “mediated futility” accounts for the fact that some factor, such as disease progression over time, will likely arise to render the intervention futile for the stated goals of treatment. Mediated futility resembles qualitative futility because both terms define futility in relation to a goal of treatment. But mediated futility depends upon a medical judgment about how effectively an intervention is likely to support a goal of treatment, and not upon a patient’s ability to appreciate the intervention as a benefit. Moreover, mediated futility is not based upon a physician’s view of appropriate goals of treatment, even though a physician’s view on this matter is sometimes helpful to patients and surrogates. Rather, mediated futility is based upon the physician’s integrating empirical, pragmatic, prudential judgments about the value of the intervention for achieving the goals of treatment.

The grounds for withholding or withdrawing interventions that are futile in this way are weaker. Determining mediated futility requires the patient or surrogate to articulate goals of treatment, and in this sense mediated futility cannot be determined by the physician alone. The intervention itself provides an immediate benefit, and the patient or surrogate might re-evaluate treatment goals and either replace impossible goals with possible ones or willingly forgo the intervention. In these circumstances, invoking futility may cut off an important route for peacefully resolving conflict. Moreover, futility in
tics primarily determine transplantation outcomes. In these cases of mediated futility, it is better to avoid using futility language altogether and instead be as clear as possible about what benefit the intervention could actually deliver.

The second kind of futility is by far the more common. To take a typical example, medical professionals employ a variety of interventions in the intensive care unit (ICU) that might be futile for the goal of discharging the patient, but not for allowing loved ones to visit a dying patient or for accomplishing another short-term goal. Burdensome or marginally beneficial interventions are not futile if they help achieve the latter goal, even if they are not obligatory. Schneiderman describes this scenario:

> What about the terminally ill patient who requests attempted CPR in hopes of surviving for one last visit from a distant loved one hastening to the bedside? Even though the physician is convinced that the intervention would have almost no chance of keeping the patient alive more than a day or so in the ICU, clearly the physician will want to make a compassionate exception to accommodate the short-term goal of the patient. It is important, however, to distinguish this compassionate act from an obligatory act.

Schneiderman rightly recognizes that the intervention is not obligatory, but it is not futile. In this case, CPR is effective and will prolong life until family can visit. It provides an immediate benefit, even if that benefit might be considered disproportionate to its burdens. The patient or surrogate has no obligation to pursue the intervention, but is certainly justified in requesting it. The physician could decline to provide it, but not on the grounds of futility.

Here is a less common example of mediated futility. Two recent articles about liver and kidney transplantation illustrate futility in relation to a specific treatment goal for an individual patient. One article argues against performing dual liver-kidney transplants in which the kidney transplant is likely to fail. The other article advocates for the current MELD (model for end-stage liver disease) allocation system and underlying “sickest-first policy” on the grounds that disease-related factors rather than demographic-, donor-, or surgery-related characteristics primarily determine transplantation outcomes. Both articles use futility to describe transplantation for a patient unlikely to survive more than three months post-transplantation. In other words, they consider the intervention futile for achieving a reasonable, defined goal of treatment: three-month post-transplant survival.

This kind of futility depends upon how somatic factors foreseeably compromise the efficacy of the transplant. These somatic factors are primarily the medical condition of the patient, as well as the quality of the donated organ and the impact of the transplantation method on both. For example, the article advocating the current MELD system recognizes futility on the basis of “disease-specific factors including laboratory MELD score, cardiac risk, previous septic shock, and comorbidities.” The article concerning dual liver-kidney transplants recognizes futility according to “pre-transplant illness severity,” dialysis duration, the quality of the donated kidney, and (longer) kidney ischemia.” In both cases, the intervention is futile because the patient’s medical condition and other somatic factors make it impossible for the intervention to achieve three-month post-transplant survival.

Futility cases sometimes involve many interventions, especially when the patient suffers from many combined ailments. Even when considering the combined benefits of a series of interventions, futility is still defined in the two ways outlined above. As a patient’s medical condition deteriorates, particular interventions become futile when they cease to work at all. A series of interrelated interventions might provide some immediate benefit, even though it may be considered futile because it fails to achieve the goals of treatment. This weaker sense of futility provides grounds for withdrawing or not offering the intervention, but the patient or surrogate might request to continue that series of interventions for more modest treatment goals. This position respects the fact that patients and surrogates might legitimately pursue interventions of some small benefit, even if medical professionals are not always obliged to provide them.

## Two Difficulties in Applying Medical Futility

Sometimes surrogate decision makers have no treatment goals at all. They want everything done so that their loved one will live. It is hard for them to believe that any intervention is too burdensome, even when they are aware of the burdens. In this situation, medical professionals might have a feeling of futility because the surrogate’s vague, unstated goal is to preserve life indefinitely, which no intervention will do. But resolving the conflict adequately requires establishing reasonable goals, which invoking futility does not accomplish.

There is another pitfall. Futility judgments should not relate an intervention’s effectiveness ar-
bitarily to treatment goals. For example, assisted nutrition and hydration (ANH) nourishes the body and contributes directly to prolonging life and providing comfort, and in that way contributes indirectly to further goals of care. ANH is immediately futile, and surely harmful, for a patient whose body cannot assimilate nutrition. If it can, then ANH is not futile. It might be withdrawn if the intervention will not prolong life or if it imposes significant burdens, such as great psychological discomfort or a significant risk of aspiration pneumonia.

Sometimes ANH is said to be futile for a patient in a persistently unconscious state (PVS) if the patient is unlikely to regain consciousness. This argument does indeed relate ANH to a reasonable goal of care, the restoration of consciousness, but in an arbitrary way. ANH is not designed to restore consciousness and promotes that goal indirectly by nourishing the body and prolonging life, thus allowing time for the reparative functions of the body to achieve what healing they can. As long as ANH nourishes the body and the patient is not actively dying, it should not be considered futile. The burdens of caregiving and financial burdens might influence what care can be offered, but those burdens, a low quality of life, and the undesirability of life in a disabled state do not render ANH futile for a PVS patient.

**MEDICAL FUTILITY IN CULTURE**

**Medical Futility as Perceived by Physicians**

In today’s healthcare culture, use of the phrase medical futility has broadened well beyond its legitimate meaning. Medical futility has so many different definitions that some believe it cannot be defined, but continue to use the term in process-based or mediation approaches to futility cases. For example, Jeffrey P. Burns and Robert D. Truog observe that efforts to define futility by clinical criteria have failed, argue that procedural approaches prove inadequate, and advocate for negotiation and mediation approaches. Thaddeus Mason Pope too observes the difficulty of defining futility and argues that the limitations of mediation give rise to procedural approaches. These authors all recognize that both procedure and negotiation are essential tools and differ in priority and application. But they also despair of the admittedly difficult task of defining futility.

Failing to define medical futility adequately is a serious problem. People always have an implicit definition for the terms they use. Consequently, any process-based or mediation approach to resolving futility cases must itself have some adequate definition of futility or default to the unwieldy position of confronting whatever definitions are asserted by the parties involved. In the worst-case scenario, each party to a conflict asserts the definition that falls to its favor, and medical futility, evacuated of any real meaning, cannot even justify withdrawing interventions that truly are futile. Faced with this difficult problem, some have suggested abandoning entirely the use of the term, and surely some institutions could do so with positive results. However, it is still widely used in culture and law, and therefore it is necessary to use the definitions outlined above to evaluate the different meanings given to futility in healthcare culture today.

In the article “What Does Futility Mean? An Empirical Study of Doctor’s Perceptions,” Ben White and colleagues offer a window into current conceptions of medical futility. These authors interviewed physicians in specialties routinely involved in end-of-life care. Conversational in style, each interview began simply by asking each physician to “describe a situation from your experience when a person got treatment at the end of life you didn’t think they should have had.” The interviews then asked about the definitions physicians gave to futility, cases they had managed, and reasons why they thought treatment should not have been given. Follow-up interviews looked for similarities and differences among the physicians’ views and “continued until a stable pattern of agreements and disagreements was established and no new topics emerged.” In this way, the research generated a list of perceived meanings for futility that physicians currently hold.

**Refining Perceptions and Avoiding Unnecessary Conflict**

Some of these meanings constitute futility. Others do not. Some physicians related futility to patient benefit and offered a variety of definitions: no benefit, insignificant benefit, burdens outweigh benefits, and inability to achieve treatment goals. In reality, only two of these meanings represent futility: the intervention has no benefit or does not achieve treatment goals. “No benefit” implies that the intervention does not work and therefore is futile. An intervention might also be somewhat effective but unable to support reasonable goals of care, and therefore futile in that sense. The other meanings in the list—insignificant benefit, burdens outweigh benefits—might justify not performing the intervention, but imply some benefit whose value patients and patient representatives might legitimately pursue. In those scenarios, interventions cannot be with-
drawn as if they were ineffective based on clinical judgment, even if physicians have other strong reasons for not performing them.

White and colleagues also found that doctors related futility to the patient’s quality of life. Here, the meanings of futility vary from no gain in functioning or length of life, to no quality of life, to insignificant quality of life. In reality, only “no gain in functioning” represents futility, because it implies that the intervention does not work. The other meanings—no or insignificant gain in quality of life—allow that an intervention could be somewhat effective, but not effective enough to restore bodily function to an acceptable level. The argument for not offering or continuing that intervention is based on what constitutes an acceptable quality of life and functioning rather than on the capability of the intervention to deliver its designed benefit. Declining such an intervention could not rest on grounds of futility.

Including all of these meanings under the one banner of futility introduces a contradiction that is impossible to overcome and likely to exacerbate conflict. Futility always claims that an intervention is ineffective in one of the two ways outlined above. Sometimes, though, physicians invoke futility when an intervention is somewhat beneficial. In this case, White and colleagues use the term “justifiable futility” to recognize both the benefit and the fact that physicians consider it not worth pursuing. At the same time, the authors recognize the inherent contradiction: “The term ‘justifiable futile treatment,’ containing, as it does, an internal contradiction, might be better rendered as ‘appropriate treatment, all things considered.’” The authors’ alternative, appropriate treatment, may avoid conflict as long as physicians explain the reasons why they think a marginally beneficial intervention should not be pursued.

**MEDICAL FUTILITY IN PRACTICE**

**The Courtroom**

Examining legal cases is instructive for a variety of reasons. They provide well-documented examples of true futility, of misattributed futility, and of grey-area instances in which it is better to avoid futility language altogether. They show typical features of futility cases and articulate the reasons physicians often give for withdrawing interventions that have a marginal benefit and a weighty burden. Moreover, legal cases offer the opportunity to explore both the complex situations in which futility arises and the ethically meaningful distinctions that may help resolve conflict. Finally, learning from legal cases provides realistic hope that sound ethical reasoning and strong attempts at honest, fair, and open communication may diminish the risks of litigation, of negative public reaction, and of damage to an institution’s reputation.

The case of 28-year-old Carl Winspear provides a clear example of an intervention rendered immediately futile by the medical condition of the patient. Both family and medical professionals recognized that CPR would have been futile, but the family brought legal action because they were not informed of the DNACPR order (do not attempt CPR). Winspear suffered from cerebral palsy and spinal deformities that made CPR futile, presumably because these pathologies rendered his skeletal structure incapable of supporting the CPR procedure. Moreover, performing CPR would have been terribly distressing and painful for the patient and therefore extremely burdensome. His surrogate, his mother, recognized that CPR was futile, but objected to the DNACPR order placed without their consent.

The case illustrates futility in its strictest sense, the strong justification for declining the intervention, and the increased likelihood that surrogates will recognize futility.

In *Rotaru v. Vancouver*, the physicians correctly recognized that an advanced pathology, declining medical condition, and very poor prognosis left the patient with a number of interventions with little immediate benefit and made them futile for bringing about the healing required for discharge. However, the surrogate seemed to have the goal of prolonging life indefinitely and insisted on continuation. The patient, Aleksandrina Priboi, suffered from global vascular disease and presented at Vancouver General Hospital in December 2007 with right leg ischemia caused by a popliteal artery occlusion, which was treated. Subsequently, her medical condition declined, and court records summarize the physician’s view:

Mrs. Priboi has global, irreversible vascular disease, with inoperable lesions resulting in compromised blood flow to vital tissues, particularly to the GI [gastrointestinal] tract. She has chronic ischemic colitis, with GI bleeding and inability to support enteric nutrition requiring TPN [total parenteral nutrition]. Her life currently is being sustained by artificial means. It is my opinion that she will not improve to the point that she will survive without these treatments, and I would expect that irrespective of our interventions that she will die. This is due to the burden of her disease state.
The medical staff saw progressive multi-system organ failure that rendered dialysis, ventilation, and TPN futile for the goal of allowing the patient time to heal and return home. Family members never engaged the futility discussion, but insisted on continuing ventilation and TPN. These interventions provided some small immediate benefit, were not futile in that sense, and out of compassion for the family were continued as long as they did not increase the patient’s suffering. Nonetheless, the family perceived the overall withdrawal of medical interventions as “death inducing actions” and sued for negligence.

In Marsala v. Yale New Haven Hospital, physicians also recognized that an advanced pathology, declining medical condition, and poor prognosis were progressively rendering interventions burdensome, marginally beneficial, or futile. In this case, the surrogate was not attempting to prolong life indefinitely, but did have moral objections to withdrawing ventilation, which remained immediately effective for prolonging life, yet futile for enabling the healing sufficient to return home. The medical record describes the declining medical condition of the patient, Helen Marsala, a 76 year old woman transferred from Griffin Hospital for multiple medical problems for further management. She has an extensive past medical history, which included [diabetes mellitus], moderate aortic stenosis, hypertension, hyperlipidemia. . . . She has had a long hospital course, which has included prolonged respiratory failure and failure to wean, shock requiring vasopressors, Morganella bacteremia requiring treatment with Impipenem, volume overload, and GI bleeding thought to be due to ischemic colitis.28

Physicians repeatedly but unsuccessfully attempted to stimulate respiratory function by weaning the patient from ventilation. They recognized that continuing ventilation would offer marginal and declining benefit, with increasing burdens as the patient’s medical condition deteriorated. Conflict arose when the physicians recommended changing her status to “do not re-intubate,” but the surrogate, husband Clarence Marsala, considered re-intubation obligatory for preserving life. Notably, the patient’s husband did consent to a DNR order because he believed his wife would not have wanted to be kept alive “at all costs.” The physicians had a strong case that continuing ventilation would be excessively burdensome, and could be withdrawn. Further, the physicians might have argued that continuing ventilation was futile for the goal of discharge and would only slow the dying process. Invoking futility would have likely appeared counterintuitive to the family, because ventilation was immediately effective. In the end, the family brought numerous legal claims, including “negligent infliction of emotional distress, intentional infliction of emotional distress, wrongful death, loss of consortium, and medical malpractice.”29 This case illustrates that it may be better to avoid invoking futility even when one could make a good case for it.

In the case of Baby Joseph Marachli, physicians invoked futility to withhold an intervention that was not actually futile in any sense. The baby’s family requested treatment that physicians found excessively burdensome, but the family had a different view of the burdens involved, and legitimately pursued the intervention. The baby was born with a rare, neurodegenerative disorder eventually diagnosed as Leigh’s disease. The ethical question was whether or not to perform a tracheotomy, which would have allowed the family to care for him at home until his death. The physicians called a tracheotomy futile because they thought it would cause much discomfort, increase the risk of infection and pneumonia, and impose arduous burdens of care on the family. They also thought that the baby had suffered enough and had no hope for recovery. But the physicians never claimed that a tracheotomy would not ease his breathing and realize the family’s goal of caring for him at home. The parents recognized the burdens and the benefits because they had had a daughter with the same disease just a few years before. In her case, they had requested a tracheotomy, which was performed, and had cared for her at home until she died. With certain knowledge that a tracheotomy was not futile, the family brought legal action, and the conflict drew widespread media attention.30

Better Language at the End of Life

Medical professionals need a broader set of ethical concepts and terms for legitimately withholding and withdrawing interventions. Futility does not apply when an intervention is capable of delivering its designed benefit. By contrast, the concepts “proportionate” and “disproportionate” describe the kind of reasoning that relates declining benefit to increasing burden and therefore that helps clarify when an intervention is not obligatory, even though not futile. A medical intervention is proportionate when its benefits outweigh its burdens. In such cases, the intervention is typically provided, and there may even be an expectation that the patient
accept the intervention if it is important for regaining health.

Disproportionate means that the burdens of an intervention outweigh its benefits, but benefits still remain. Achieving the benefit requires an excessively strenuous effort because the burdens are so heavy. Such burdens could include pain and suffering for the patient; psychological burdens on family and caregivers; and significant cost to the patient, the insurance plan, and the medical institution. Yet disproportionate treatment is not futile.

Disproportionate treatment should not necessarily be considered inappropriate. Although the recent ATS policy statement advocates “potentially inappropriate,” there are good reasons to avoid the term inappropriate altogether in conflictual, end-of-life cases. Some families might mistakenly think that they are behaving inappropriately in requesting an intervention, when the physician is really saying that the intervention could be considered inappropriate. Moreover, the term inappropriate does not convey why a medical professional counsels against an intervention, for example, because it is excessively burdensome. In this context, disproportionate has the sense of “off balance” or “out of equilibrium,” describing a poor benefit-to-burden outcome that could be maintained with strenuous effort for a limited time. Patients are not expected to accept interventions with disproportionate burdens, but might request them in pursuit of specific, usually short-term, goals. Medical teams are not required to provide them, but often do for various reasons, especially to show compassion for patients and their families.

It is not always necessary to label an intervention as proportionate, disproportionate, or futile. These terms accurately convey the relationship between benefits and burdens, but can come across as overly technical for use with patients and families. Many people have never heard of them, and courts have had difficulty understanding and applying them. Local cultures might possess better language for communicating the meaning behind these concepts.

Generally, the most useful terms are probably “beneficial,” “burdensome,” and “ineffective.” Ineffective communicates the reason why an intervention is futile while avoiding the complications surrounding futility in today’s healthcare culture. Beneficial means that, on balance, the benefits outweigh the burdens of the intervention. Burdensome or perhaps “excessively burdensome” means that, on balance, the burdens outweigh the benefits of the intervention. As different parties to an end-of-life conflict express their views of treatment, using these terms naturally leads to a discussion about why each thinks the balance tends one way or another.

CONCLUSION

It is better to avoid futility language in end-of-life conflicts, but some institutions have come to rely upon it, and the term has legitimate, although limited, purchase. Medical futility applies only to interventions and should be defined in terms of the benefit for which the intervention is designed. Medical futility occurs when the medical condition of the patient renders the intervention incapable of delivering its designed benefit, either immediately or in support of a reasonable goal of treatment. It should be properly related to goals of treatment. For example, ANH is futile if it cannot prolong life, but not because the patient will not regain consciousness. Nor does it apply whenever the medical team believes that the intervention should not be offered or continued, for example when it is excessively burdensome with marginal benefit. Although it may be difficult in practice to distinguish between futile and excessively burdensome interventions, in the latter case the patient or surrogate and family might legitimately state what that marginal benefit would mean to them. Physicians might still decline excessively burdensome interventions, but not on grounds of medical futility.

There is no guarantee that candid, compassionate discussion will prevent intractable conflict over end-of-life care. Many other factors, especially emotional states, influence end-of-life discussion more than the calculus of burdens and benefits. There is no language that automatically reconciles opposing views. Sometimes we can hope only that views are expressed and decisions are made with enough respect and transparency to avoid intractable conflict and promote resolution.

NOTES

1. Legal scholar Thaddeus Pope maintains a very useful website that provides an excellent view of the scope of futility legislation, jurisprudence, and policy: http://www.thaddeus pope.com/medicalfutility.html.


3. See articles by Schneiderman et al., which propose quantitative and qualitative futility, in note 2 above.


5. Schneiderman, “Defining Medical Futility,” see note 2 above.


9. Ibid., 1319.

10. Regarding physiological futility, see D. White and T.M. Pope, “Medical Futility and Potentially Inappropriate Treatment,” in *The Oxford Handbook of Ethics at the End of Life*, ed. S.J. Youngner and R.M. Arnold (New York: Oxford University Press, 2016), 72; regarding qualitative futility, see articles by Schneiderman et al., which propose quantitative and qualitative futility, in note 2 above.

11. Schneiderman, Jecker, and Jonsen, see note 2 above, p. 951.

12. Sulmasy, see note 2 above, pp. 73-4.


16. Ibid., 1191.


23. Ibid., appendix 1, “Interview Guide.”

24. Ibid., 318e2.

25. Ibid., 318e4.


29. Ibid.


ABSTRACT

This article proposes an action guide to making decisions regarding the ethical allocation of resources that affect access to healthcare services offered by community-based healthcare organizations. Using the filter of empirical data from a study of decision making in two community-based healthcare organizations, we identify potentially relevant conceptual guidance from a review of frameworks and action guides in the public health, health policy, and organizational ethics literature. We describe the development of this action guide. We used data from a prior empirical study of the values that influence decision making about the allocation of resources in particular types of community-based healthcare organizations. We evaluated, organized, and specified the conceptual guidance we found in 14 frameworks for ethical decision making. The result is an action guide that includes four domains that are relevant to the context of the decision to be made, eight domains that are relevant to the process of the decision to be made, and 15 domains that are relevant to the criteria of the decision to be made. We demonstrate the potential use of this action guide by walking through an illustrative resource allocation decision. The action guide provides community-based healthcare organizations with a conceptually grounded, empirically informed framework for ethical decision making.

INTRODUCTION

Community-based healthcare organizations provide access to health services that are tailored to the needs of their local community members. Many of these organizations form the backbone of a safety net system intended to serve uninsured and other vulnerable individuals whose needs are not otherwise met within the fragmented American healthcare system. Examples include federally qualified health centers, local health departments, public clinics and hospitals, and nonprofit healthcare organizations that are not affiliated with an academic medical center. Administrators of these organizations at times wonder what is the right policy or resource allocation decision, given the potential impact on the population they serve. Such community-based organizations are not unique in this regard, but their administrators may have unusual latitude to make decisions that are based on the values of the community or organization, rather than based on regu-
lutions or principles to maximize profit. A robust scholarly literature addresses general ethical questions about how to allocate healthcare resources in accordance with philosophical theories of justice. It would be of little use, however, to simply hand this literature to an administrator of a community-based healthcare organization who is considering a specific policy change—for example, to facilitate equitable access to specialty healthcare services. Accordingly, ethics frameworks have been developed to help decision makers translate theory into practice in the context of specific problems. Yet among the many frameworks on offer, none are comprehensively useful specifically to stakeholders within community-based healthcare organizations that provide access to health services. We sought to address this need. Our effort was informed by data that we collected within two of these organizations regarding policy decisions with morally important consequences, such as who will receive care and how much care they will receive, given limited resources.

We reviewed existing ethics frameworks published for use by organization-level decision makers. We identified potential normative elements of the frameworks that had been empirically demonstrated to be relevant to the type of community-based healthcare organizations we characterized in our prior research. We used this empirical data to evaluate, organize, and specify the conceptual guidance available in 14 of the existing frameworks. The result is a conceptually grounded, empirically informed action guide that future empirical research can test and refine in a community-based healthcare organization practice setting. In this article we first describe the methods by which we created the action guide, then present the action guide, next provide a sustained example of how the action guide could be used, and finally discuss implications for future research and practice.

**METHODS**

We reviewed the literature relevant to ethical healthcare resource allocation or policy decisions to identify guidance or frameworks relevant to meso-allocation decisions (that is, decisions made at the organizational level) as distinct from macro-allocation (that is, decisions made at the country level or multisystem level), or micro-allocation (that is, clinical rationing). We consulted three main bodies of literature: public health ethics, health policy ethics, and organizational ethics. In recent years, frameworks have proliferated in the public health ethics literature, as Nancy Kass wrote, to help “professionals identify and respond to moral dilemmas in their work” designing and maintaining programs that promote population-level health. Because many public health ethics frameworks are oriented towards either macro-allocation or emergency circumstances, however, we also reviewed the health policy ethics and organizational ethics literatures for similar action-oriented guides relevant to dilemmas experienced by community-based health organizations. Health policy ethics examines the values underlying public program and policy decision making. Organizational ethics helps organizations to sustain ethical cultures and make decisions consistent with their fundamental aims, examining issues such as integrity, responsibility, and choice.

From the literature we reviewed, we selected 14 ethics frameworks for further analysis: five frameworks from public health ethics, five from health policy ethics, and four from organizational ethics (see figure 1).

An ethics framework should be grounded in theory but also be “approachable” enough for a professional decision maker to use it without specialized ethical training. One way to satisfy both criteria, relative to a specific type of decision-making context, is to work back and forth between the normative literature about how decisions ought to be made and empirical data on how decisions actually are made in that context. We used our empirical findings about decision making in a particular type of community-based healthcare organization as a lens through which to filter, aggregate, and specify the normative ethical literature.

Normative frameworks sometimes distinguish between substantive normative criteria for decision making and an ethical process of decision making. For example, Georg Marckmann and colleagues include both elements in their framework, whereas Norman Daniels’s “Accountability for Reasonableness” focuses exclusively on process. In addition to those two categories of decision-making elements—criteria and process—we empirically observed that organizational decisions are impacted by the social context of the decision, much in the same way that individuals’ behaviors are influenced by social context. Hence our three analytic categories were context, process, and criteria.

To develop the action guide, we first re-analyzed our empirical findings to create a table of the example decisions and the factors and values affecting them, which we categorized by context, process, and criteria for decisions (see figure 2). Second, we similarly categorized the normative considerations...
FIGURE 1: Summary of inclusion/exclusion criteria for literature review and selected frameworks

<table>
<thead>
<tr>
<th>Literature review for guidance on ethical organization-level healthcare resource allocation decision making (meso-allocation)</th>
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<tbody>
<tr>
<td><strong>Excluded (n = 49)</strong></td>
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<tr>
<td>Overarching ethical theory (n = 34)</td>
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<td>• Bioethics (n = 2)</td>
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<td>• Public health ethics (n = 5)</td>
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<td>• Health policy ethics (n = 25)</td>
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<td>Frameworks for micro-allocation decisions (n = 3)</td>
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<td>• Public health ethics (n = 4)</td>
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<td>Frameworks for macro-allocation decisions</td>
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<td>• Health policy ethics (n = 2)</td>
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<tr>
<td>Frameworks for public health emergencies (n = 4)</td>
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<tr>
<td>Public health ethics (n = 5)</td>
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<tr>
<td>• Kass¹</td>
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<tr>
<td>• Childress et al.²</td>
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<td>• Baum et al.³</td>
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<td>• Nuffield Council⁴</td>
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<td>• Markmann et al.⁵</td>
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<tr>
<td>Health policy ethics (n = 5)</td>
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<td>• Daniels and Sabin⁶</td>
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<td>• Caplan, Light, and Daniels⁷</td>
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<tr>
<td>• Emanuel⁸</td>
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<tr>
<td>• Wynia et al.⁹</td>
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<td>• Clark and Weale¹⁰</td>
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<tr>
<td>Organizational ethics (n = 4)</td>
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<td>• Ozar et al.¹¹</td>
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<td>• Iltis¹²</td>
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<td>• Winkler and Gruen¹³</td>
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<td>• Nelson and Wadsworth¹⁴</td>
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NOTES

within the 14 selected ethics frameworks as relevant to the context, process, or criteria of decision making in our empirical data. Third, we compared the considerations within the normative frameworks to each element of the empirical findings with the goal of identifying a normative foundation for each empirical element (see table 1). When we found multiple normative considerations that aligned with an empirical element, we chose the normative consideration that required the least specification to be relevant to the empirical element; if all normative consideration options were similar, we chose the version in the most recent publication. When a normative consideration seemed related to a concept that appeared in the empirical data but had not been previously listed as an empirical element, we re-examined the empirical data to see if that concept was prevalent enough to warrant drawing it out as a separate empirical element.

We excluded from further analysis any normative considerations that were not relevant to any empirically observed elements of the context, process, or criteria for making decisions. Fourth, we reviewed the chosen normative foundations in comparison to the empirical element, and specified those normative foundations for use in community-based healthcare organizations. No single conceptual framework adequately accounted for all of the elements that we found to be involved in the allocation of resources by community-based healthcare organization and in processes to make policy decisions. Only by combining normative considerations from all three sections of the ethics literature (public health ethics, health policy ethics, and organizational ethics) were the empirical elements sufficiently supported. In addition, not every empirically observed element had a normative foundation (for example, some elements were purely political). Consequently, our final version of the action guide uses only 10 of the 14 frameworks; the 27 domains include both normative and practical decision-making considerations (see table 2).

To refine the action guide for ease of use by decision makers in community-based healthcare organizations, we formatted each element as a question that decision makers could ask of themselves or their leadership teams. We tested the usability of the action guide by developing an example decision with data from one of the 10 example resource allocations that we have described elsewhere.16 We also used the illustrative example decision to check for redundancies in the action guide domains and to

![FIGURE 2. Process of creating the action guide](image-url)
# TABLE 1. Comparison of empirical findings and normative considerations

<table>
<thead>
<tr>
<th>Empirical data on factors involved in resource allocation decisions</th>
<th>Ethics framework</th>
<th>Normative consideration from framework</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relevant to context of the decision</strong></td>
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</tr>
<tr>
<td>Trends at the local, state, or federal level (e.g., Site 1 founded during a recession and election health reform debate. Site 2: movement toward managed care, attention to pill mills and narcotics addiction).</td>
<td>None</td>
<td>“Consider political feasibility and community acceptance”</td>
</tr>
<tr>
<td>Political factors (e.g., not allowing undocumented or people over 500% of the federal poverty level to be eligible at Site 1 or covering birth control at Site 2 due to perception or statement that doing so would jeopardize the program).</td>
<td>Baum et al.</td>
<td>“Establish a mission, i.e., a set of fundamental commitments and values” Understand “the implications of those commitments for various aspects of organizational life”</td>
</tr>
<tr>
<td>Economic factors (e.g., when financial viability was threatened, organizations created policies to limit access to either a certain number of people (Site 1) or for a certain amount of participation (Site 2).</td>
<td>None</td>
<td></td>
</tr>
<tr>
<td>Mission referenced at both sites as a source of core values and goals.</td>
<td>Itlis</td>
<td></td>
</tr>
<tr>
<td><strong>Relevant to the process by which the decision will be made</strong></td>
<td></td>
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<tr>
<td>Common value of “organizational excellence” across sites defined as acting in a way that is aligned with their values, e.g., preserving access to care for the most poor or ill members even during organizational financial hardship.</td>
<td>Itlis</td>
<td>Integrate “organizational mission into decisions at all levels of an organization” Develop “a plan to resolve situations in which an organization’s values call it to act in incompatible ways”</td>
</tr>
<tr>
<td>Varied stakeholders were recruited to advisory boards at both sites, including clinicians, members, local business leaders.</td>
<td>Marckmann et al.</td>
<td>“Populations affected by the . . . intervention should be able to participate in the decision about the implementation”</td>
</tr>
<tr>
<td>Participants referred to a goal of making decisions transparent.</td>
<td>Marckmann et al.</td>
<td>“Decision process including database and underlying normative assumptions should be transparent and public”</td>
</tr>
<tr>
<td>Participants believed that their members should be treated decently, with compassion, respect, and dignity, and that members should be empowered.</td>
<td>Childress et al.</td>
<td>“Building and maintaining trust”</td>
</tr>
<tr>
<td>Every participant explicitly discussed trade-offs made during decision-making processes.</td>
<td>Caplan, Light, &amp; Daniels</td>
<td>“Keeping promises and commitments”</td>
</tr>
<tr>
<td>Participants discussed the importance of making responsible decisions and using public dollars wisely; subdomain within common organizational value of stewardship.</td>
<td>Clark &amp; Weale</td>
<td>“Comparability . . . all funds expended for health care should be explicitly gathered into a budget so that they can be weighed against other, competing social needs”</td>
</tr>
<tr>
<td>Participants discussed how several decisions were revised as data or conditions changed.</td>
<td>Marckmann et al.</td>
<td>“Implementation of . . . interventions should be open for revision (e.g., if data basis changes or certain aspects have been neglected)”</td>
</tr>
</tbody>
</table>
Participants discussed how decisions were based on evidence about the characteristics of the county uninsured, best practices in healthcare delivery, and data from utilization review before and after policy changes.

Relevant to the criteria by which options will be evaluated

<table>
<thead>
<tr>
<th>Core value of ensuring or facilitating access to healthcare for members, e.g., based on belief in universal right to affordable care (Site 1) or maximizing access to a temporary bridge to services (Site 2).</th>
<th>Baum et al.</th>
<th>“Demonstrate evidence of need and effectiveness of actions”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants said they wanted to provide access to care that was described as: high quality, preventive, primary comprehensive, coordinated, medical/home-based, and culturally appropriate.</td>
<td>Caplan, Light, &amp; Daniels</td>
<td>“Universal access—coverage and participation: Any fair health care system must make all needed and effective services equally available to everyone regardless of their health conditions or risks”</td>
</tr>
<tr>
<td>Participants discussed potential impacts of decisions on various desired outcomes, e.g., reducing inappropriate use of pain-management specialists or changing mandated use of health coaching service.</td>
<td>Nuffield</td>
<td>“Ensure that people have appropriate access to medical services”</td>
</tr>
<tr>
<td>Sites sought to provide culturally appropriate care, e.g., Site 1 modified health coaching program to more effectively serve those with limited English proficiency but who wanted to participate.</td>
<td>Markmann et al.</td>
<td>“Expected health benefits for target population</td>
</tr>
<tr>
<td>Subdomain of organizational value of service to others was to providing a safety net and helping the most vulnerable people, e.g., even when limiting access to care, Site 2 made exceptions for the very least-well-off, ensuring pain management is still available for acute needs, and chronic care available to those with blood cancer or sickle cell</td>
<td>Wynia et al.</td>
<td>“Compassionate. The design and administration of health benefits should be flexible, responsive to individual values and priorities, and attentive to those with critical needs and special vulnerabilities”</td>
</tr>
<tr>
<td>The organizational value of fairness encompassed a goal to treat individual members or providers the same way as other members or providers, e.g., Site 1 revised a policy mandating involvement in health coaching because members with limited English proficiency could not participate.</td>
<td>Clark &amp; Weale</td>
<td>“The principle of solidarity implies a commitment to the idea that all members of society will stand together and will not leave any one behind, no matter how needy or disadvantaged”</td>
</tr>
<tr>
<td>Participants described considering who was in need that might not receive care, e.g., if colonoscopies not covered (Site 1), if chronic pain management services were completely excluded (Site 2).</td>
<td>Clark &amp; Weale</td>
<td>Justice/equity: “patients who are alike in relevant respects should be treated the same, and those who are unlike in relevant respects should be treated in appropriately different ways”</td>
</tr>
<tr>
<td></td>
<td>Marckmann et al.</td>
<td>“Potential harm and burdens</td>
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<table>
<thead>
<tr>
<th>Empirical data on factors involved in resource allocation decisions</th>
<th>Ethics framework</th>
<th>Normative consideration from framework</th>
</tr>
</thead>
<tbody>
<tr>
<td>One domain within a common organizational value of service to others was empowering members to be self-reliant.</td>
<td>Marckmann et al.</td>
<td>“Impact on autonomy”&lt;br&gt;• health-related empowerment (e.g., improved health literacy)&lt;br&gt;• respect for individual autonomous choice (e.g., possibility of informed consent, least restrictive means)&lt;br&gt;• protection of privacy and confidentiality (e.g., data protection)”&lt;br&gt;Autonomy “used to refer to the ability of individuals to be self-directing and make decisions for themselves about important matters . . . those choices will be one’s own and thus also one’s own responsibility”&lt;br&gt;Clarke &amp; Weale</td>
</tr>
<tr>
<td>Common organizational value of supporting member independence and self-sufficiency.</td>
<td>Clarke &amp; Weale</td>
<td>“Equitable financing—by ability to pay: All direct and indirect payments and out-of-pocket expenses scaled to household budget and ability to pay”&lt;br&gt;Clarke &amp; Weale</td>
</tr>
<tr>
<td>Affordability was a subdomain within the common organizational value of access to care.</td>
<td>Caplan, Light, &amp; Daniels</td>
<td>“How can the benefits and burdens of a program be fairly balanced?”&lt;br&gt;Caplan, Light &amp; Daniels</td>
</tr>
<tr>
<td>A subdomain of organizational value of fairness included a goal to treat individual providers alike, e.g., Site 2 wanted to ensure that the provision of care for the indigent was spread evenly across their provider networks.</td>
<td>Kass</td>
<td>Benefit to the community&lt;br&gt;Kass</td>
</tr>
<tr>
<td>Common organizational value of community well-being compromised a belief that providing people access to care would benefit the health of the entire community.</td>
<td>Ozar et al.</td>
<td>Advocacy for social policy reform&lt;br&gt;Ozar et al.</td>
</tr>
<tr>
<td>One domain within a common organizational value of service to others was advocating for public policies that would benefit their members.</td>
<td>Ozar et al.</td>
<td>Organizational solvency/survival&lt;br&gt;Ozar et al.</td>
</tr>
<tr>
<td>Decisions always included consideration of the impact of the organization’s financial viability, solvency, or sustainability (subdomain within common organizational value of stewardship), e.g., Site 2 was created to sustainably fund indigent healthcare.</td>
<td>Baum et al.</td>
<td>“Assess expected efficiencies and costs associated with proposed action”&lt;br&gt;Baum et al.</td>
</tr>
<tr>
<td>Sites constantly considered where to set limits on access to services based on need, costs, and degree of staff resources needed; e.g., Site 1 decided to pay for colonoscopies because of substantial need in population and lack of access otherwise.</td>
<td>Baum et al.</td>
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</tbody>
</table>
organize the domains of each category according to the order in which they were relevant to the example decision. We present below the resulting illustrative example decision.

RESULTS

The Action Guide

The result of our analysis is the action guide (see table 2). The action guide asks decision makers to consider the context of the decision, the process by they wish to make the decision, and what criteria they will use to choose between options or evaluate the quality of the options. Although we will present the action guide as if it is being used prospectively to make a decision, it could also be used retrospectively to evaluate the ethical quality of a decision. We anticipate decision makers would use the guide iteratively both to analyze the problem with which they are struggling and to evaluate proposed solutions.

The Action Guide in Action

The following example illustrates how administrators in a community-based healthcare organization could use our action guide to review and revise a policy concerning the healthcare services available to the organization’s members. We have developed this example as a hypothetical scenario, informed by historical data to make it as realistic as possible, presented from the standpoint of administrators at a community-based healthcare organization. The example combines data on what actually occurred with our analysis of what ought to occur in similar circumstances. To follow a realistic sequence of decision making, we demonstrate the iterative use of the action guide through multiple stages of a decision, from analyzing a problem in light of existing policy, to developing a revised policy, to implementing and monitoring the outcomes. As a result, we present five stages of using the action guide—one for context, two for process, and two for criteria—with the categories of process and criteria subdivided to reflect considerations relevant to revising a policy and to implementing it. The domains of the action guide are bolded in the text of the example and the domain number appears in parentheses.

Identification of a Potential Policy Problem

In the course of conducting a routine review of how an organization’s members have utilized available healthcare services, the organization’s administrators notice that 2 percent of the organization’s annual budget of roughly $3 million has been spent on pain-management specialty services, including expensive procedures (for example, local anesthesia followed by an injection into the spine to administer anesthetic and anti-inflamma-
TABLE 2. Action guide for resource allocation and policy decision making affecting healthcare services in community-based healthcare organizations

Consider the context of the decision:
1. What are the fundamental commitments, goals, and values of the organization? How do they impact various aspects of the community health organization?
2. Are there policy priorities at the local, state, or federal level relevant to the decision?
3. Are there economic factors relevant to this decision that could impact the process or outcome of the decision?
4. Are there political factors that could impact the community feasibility and acceptability of the decision?

Consider the process by which the decision will be made:
5. How will the decision-making process enable the participation and contribution of affected stakeholders with different interests?
6. What is the quality of the data and evidence used in analyzing the problem or solution?
7. How will trade-offs be explicitly examined and compared, for example, using a budget that includes all funds and resources?
8. How will the decision-making process and result be made publicly transparent, including data and assumptions?
9. How will this decision build or maintain trust with members and other stakeholders, for example, by treating them with compassion, respect, dignity, and decency?
10. How will the decision-making process reflect organizational excellence and values, goals, and commitments? How will situations be resolved in which an organization's values call it to act in incompatible ways?
11. To whom will the organization be accountable for the process or outcome of the decision, justifying and taking responsibility for activities and prioritizations?
12. How will the decision be revised if conditions or data change?

Consider the criteria by which you will choose between options or evaluate the quality of options:
13. How will this decision impact access to care, given that all members should have access to comprehensive and uniform benefits?
14. To ensure ethical stewardship of the organization's resources, what are the expected efficiencies and costs associated with proposed action? Where should the organization set limits on services?
15. What is the expected clinical effectiveness of interventions, including expected health benefits or care outcomes? How will the decision impact the likelihood of effectively achieving those goals?
16. How will the organization define what type and quality of care will be available to ensure all members have appropriate access to medical services?
17. How will this decision impact the organization's ability to serve the diverse needs and preferences of its members given that the care provided to members should be compassionate, flexible, responsive to individual values and priorities, and attentive to those with critical needs or special vulnerabilities?
18. Does this decision prioritize or impact the most vulnerable population served, especially in terms of those who are the least well-off in terms of health?
19. Will this decision cause burdens or harms to any subpopulation of members?
20. Will this decision treat similar members alike? How are considerations such as age, personal responsibility, lifestyle choices, or family situation taken into account implicitly or explicitly in setting priorities? Are subpopulations of members treated fairly by this decision?
21. Will this decision help members be self-directing and achieve independence by taking responsibility for their own health or health outcomes?
22. Will the decision empower members or help them achieve their desired ends? Does it respect individual autonomous choices of members?
23. Will this decision maintain or improve equitable financing and affordability of healthcare for members by ensuring costs to members match their ability to pay?
24. Will this decision change the organization's financial viability, solvency, or sustainability?
25. Will the benefits and burdens of this decision be fairly balanced, for example, across clinician/provider partners?
26. How will this decision benefit the health of the community?
27. Will the decision broadly promote social policy reform or wellness?
torily medication as guided by live X-ray imaging). No restrictions on the organization’s members’ access to these services are in place; all claims that are submitted by service providers are paid in full by the community-based healthcare organization. The administrators seek to examine why these costs were high, to create a plan to manage the costs of pain-management services, and potentially to revise the organization’s policy on access to pain-management services to address possibly inappropriate utilization.

Consideration of the Context of the Current Policy

The administrators begin by re-establishing the fundamental commitments, goals, and values of the organization (domain 1). Based on the organization’s mission statement, key considerations include how the policy affects members’ access to care (especially for vulnerable populations), the quality of the care available, and the efficiency with which the organization’s resources are used. These administrators are not alone in their concern about how pain-management specialty services are being accessed. After a number of years focusing on the undertreatment of pain, since 2008 attention at the state and local levels (domain 2) has turned to the overtreatment of pain and associated rates of narcotics use and abuse, which have been blamed in part on the evolution of treatment practices in the management of chronic pain. At the time this policy is being reviewed, the organization’s home state is identified as having the highest number of prescriptions written for opioids in the U.S., and rapid increases in the number of opioid-related deaths, problems blamed on the large number of specialty pain clinics and a lack of associated regulation. When considering economic factors (domain 3) relevant to a potential policy revision, the administrators are concerned that the relatively high proportion of funds being used for specialty pain-management services may have been driven by the resale value of narcotics on the street. To assess the political feasibility and community acceptability (domain 4) of revising the organization’s policy, the administrators ask organizations in neighboring counties whether and how they provide access to pain-management services to medically indigent residents. They learn that these counties have completely stopped coverage.

Consideration of the Process of Reviewing and Preparing to Revise the Policy

The administrators want to facilitate the participation and contribution of representatives from the various stakeholder groups who will be affected by the changes in policy (domain 5) in the process of reviewing and revising the policy. The administrators start by consulting with the medical committee of their oversight board—which includes the medical directors who are affiliated with their four member networks—and asking them to help determine whether the current utilization of pain-management services is reasonable and appropriate or whether changes are needed. In addition, the administrators speak with all of the primary care providers in the four networks, representatives from the local medical community, the local public safety committee (that is, the leadership of the Police Department and judges), the Sheriff’s Office, and organization’s two oversight boards, regarding whether those stakeholder groups would want pain management to change in the county, and what their suggestions might be for doing so. The oversight boards themselves have diverse representations of stakeholders, from medical professionals to community business owners to members receiving healthcare services through the organization. By engaging the members of the stakeholder groups, the administrators learn that the primary care providers do not feel comfortable prescribing narcotics for the members of the organization who ask for pain medication, and that all of the stakeholders are interested in changing the existing system of pain management. The administrators also begin to engage other community partners with whom they anticipate needing to collaborate in the implementation of any policy changes or revisions—for example, a detox unit and substance abuse inpatient programs.

The next step in examining the existing policy and preparing for potential changes is to review the best quality data available to inform the decision (domain 6). The administrators examine claims data on the utilization of services by current and past members; qualitative data from key informants who have network, pharmacy, or medical expertise; and systematic reviews from the peer-reviewed literature on recommended practices in pain management. Based on their analysis of the claims data, they see groupings of separate claims for a series of expensive procedures that do not align with the best practices reported in the peer-reviewed literature. They also see claims for ongoing high-dose narcotics prescriptions, sometimes with higher doses after procedures that were intended to reduce pain. Pharmacy and medical experts opine that the pattern of the claims data suggests that pain-management specialists were trying to bill the organization for a number of high-cost services, since the proce-
dures were not reducing the utilization of narcotics. In-network physicians provide anecdotes of patients reporting that when they asked pain-management specialists for narcotics prescriptions, they were required to get these expensive procedures first, perceiving that if they refused the procedure no prescription would be provided. Based on these data—which are of the highest quality practically available on a short timeline—the administrators decide to amend the current policy, which allows unfettered access to pain-management services. They create a supporting document that enables them to easily compare the costs of different services so that trade-offs can be explicitly examined (domain 7). The remainder of the process domains (domains 8 through 12) in the action guide are left to be evaluated at a later stage, as part of implementation of the revised policy.

**Consideration of the Criteria for Revising the Policy**

The first criterion to consider is how revising the policy will impact access to care (domain 13). As noted earlier, neighboring counties simply decided to no longer provide coverage for pain-management services. Because the administrators believe there will always be patients who need access to those services, for example, for cancer pain, they want to preserve access whenever possible. In an effort to be ethical stewards of their resources, they also consider potential impacts of setting new limits on access to care (domain 14): their goal is to reduce expenditures but not to the point of creating undue burden on those in need of pain-management services. Next, they look at the evidence on the clinical effectiveness of treatments in achieving their desired goals (domain 15)—of relieving members’ pain and reducing the frequency with which long-term narcotics are prescribed. In addition to consulting the peer-reviewed literature, the administrators speak with experts in best practices for pain-management services, and seek information on how other healthcare organizations and insurers structure access to these services.

The administrators use their analysis of factors contributing to the problem and the evidence on the clinical effectiveness of the treatment to define what type and quality of care will be available to ensure appropriate access to medical services (domain 16). They want to encourage members to use their primary care providers as the main source of pain-management services, but also still allow access to pain-management specialists. For this reason, the administrators decide to require prior authorization of referrals to specialists before commencing treatment, and to limit access to an initial evaluation and no more than two follow-up visits per problem-based referral. Based on their understanding of clinical effectiveness compared to costs, they decide to cover procedures to diagnose or treat pain only in cases of acute injury, dental pain, and pre- and post-surgical events, and to reimburse for a limited number of steroid injections restricted to specific diagnoses. Finally, the administrators decide to provide only those members who have a diagnosis of cancer, or a blood disorder such as sickle cell, with access to chronic pain-management services, defined as treatment for longer than 60 days, or 90 days post-surgery. The administrators will remove euphoric narcotics from their pharmacy formulary to address concerns about members who request narcotics because of addiction, or for purposes of drug diversion, rather than for pain treatment proper. They believe that this proposed policy revision will allow the organization to continue to serve the diverse needs and preferences of its members by being compassionate, flexible, and responsive to individual values (domain 17).

As they think ahead to implementation, the administrators consider how this proposed policy revision will impact those who are most vulnerable in the sense of being least healthy (domain 18), defined as members who are receiving high doses of pain-management drugs and who may be addicted. The administrators designate a 60-day transition period for the implementation of the policy. They also develop mechanisms to wean members off pain medication, including a collaboration with the organization’s community partners to provide access to a detox unit or substance abuse inpatient program, in addition to the organization’s existing coverage of substance abuse and some mental health treatment. This proposed policy revision may cause burdens, or harms, to the subpopulation of members (domain 19) who are currently receiving pain medication. If they do not fall into one of the protected categories, some members may be physically and mentally reliant on the treatments and may experience substantial emotional and physical distress as a result of the proposed revised policy. Other members may be engaged in the illicit diversion of pain medication; for them, the proposed revised policy might cause an economic setback from a loss of income. Nonetheless, the administrators believe that the proposed policy decision treats similar members alike and fairly treats subpopulations of members without consideration of age or family situation (domain 20). They believe it prioritizes access to symptom-mitigating care for those patients who
are taking responsibility for their own health and aiming to become independent (domain 21). The administrators further believe that the decision will help empower members to achieve their desired ends (domain 22) of receiving adequate pain management while reducing opportunities for addiction, or helping members to overcome addiction. While the policy does not restrict autonomous choices made by members (domain 22) about pain-management treatment, the proposed revised policy provides financial coverage only for a subset of those potential choices (for example, for short-term pain-management specialty treatment except for members with particular diagnoses). Under the proposed revised policy, the organization will continue to provide all covered services to members for free, thus matching costs to members with their ability to pay (domain 23). As a result of this proposed policy revision, the administrators anticipate that spending on pain-management services will drop significantly, thus improving the organization's financial viability and long-term sustainability (domain 24) and allowing funds to be re-allocated as needed. The remainder of the criteria domains (domains 25 through 27) are left to be evaluated as part of the criteria for implementing the revised policy.

Consideration of the Process of Implementing the Revised Policy

Having drafted the revised policy, the administrators enable the participation and contribution of stakeholders with varied interests (domain 5). For example, they present the data they have used to analyze the problem, their assumptions, and their proposed revised policy at public meetings of their oversight boards in order to seek reactions and recommendations, and in order to make the input from the meetings and the process publicly transparent (domain 8). The administrators also seek feedback from other stakeholders who were consulted earlier in the process. They make the final policy publicly available (domain 8) and actively educate members and providers about the changes. In the process of revising and implementing the policy, the administrators have sought to maintain trust with members and to treat them with compassion, respect, decency, and dignity (domain 9), by continuing to provide access to services for people in need, including those with blood disorders like sickle cell. They have strengthened their relationship with addiction treatment service providers to whom they can refer members who have, as an unintended consequence of the previously open coverage policy, developed addiction problems.

The administrators believe that the resulting decision reflects the organization's fundamental values and goals, and their commitment (domain 10) to providing access to care for the medically indigent in their community, while supporting responsible stewardship of the organization's resources. The administrators will hold themselves accountable for the process and outcome of the decision (domain 11) to their oversight boards and to the general public whose taxes financially support the program. The administrators will closely monitor key outcomes of the revised policy: specifically, overall costs of pain-management services for members, patients' utilization of the organization's services (for example, whether patients will remain members of the organization or switch to other forms of insurance like Medicaid), and the continuing provision of services to members by pain-management specialists. The administrators will implement transparent procedures for members and providers to appeal pain-management coverage decisions under the revised policy. After six months, the administrators will reconvene to assess whether, based on outcomes, appeals, or other conditions, the policy should be revised (domain 12).

Considering the Criteria for Implementing the Revised Policy

Analyzing whether the benefits and burdens of the policy revision are fairly balanced (domain 25) requires examination of its effect on both members and providers. The burdens will accrue only to those members who experience pain-management needs, while benefits will accrue to all members if the organization can re-allocate its resources to improve member services. Members who experience pain-management needs will bear an increased burden in the form of needing to seek referrals from primary care providers before being able to access pain-management specialists. As a result of the policy change, members who are illicitly diverting and selling narcotics for personal gain will no longer enjoy a type of economic benefit that would be inappropriate for the organization to subsidize. Particular benefit will accrue to those patients who are undergoing the serious health crisis of addiction (unwittingly facilitated or precipitated by the old policy) and who are willing to receive help from the newly supplemented services. Considering the impact on providers, the burdens of the decision will primarily fall on pain-management specialists—who will lose some income as a result of the policy change—and on primary care providers, who will now be required to take on greater responsibility for manag-
ing patients’ pain and monitoring referrals. Burdens will commensurately fall on pain-management specialists to the extent that they were engaging in problematic practices. The health of the community will benefit (domain 26) if this policy revision reduces the prevalence of addiction. The net benefit to community health would be reduced, however, if this policy change exacerbates violence committed by criminal organizations. In order to mitigate this unintended but foreseeable adverse consequence, the administrators have explicitly alerted law enforcement regarding the possible impact on the local market in illicit narcotics. On the whole, if the new policy is successful, this decision will promote social policy reform and wellness (domain 27) by demonstrating the feasibility of providing responsible access to pain-management services for the medically indigent, in contrast to the more draconian option of not covering these important services at all.

In summary, this action guide provides decision makers with a conceptually grounded guide to making or evaluating changes in policy within their community-based healthcare organization. The action guide is responsive not only to those items classically included in ethical frameworks for decision making, but also to the values and mission of organizations themselves, and to practical considerations such as the political landscape within which a decision is made.

DISCUSSION

In developing this action guide, we have taken a novel approach both to its construction and its elaboration. The most common guides or frameworks for ethical decision making are conceptual and provide guidance either at the level of macro-allocation, useful for leaders of countries or states (for example, to guide healthcare reform), or at the level of micro-allocation to guide clinical rationing at the bedside, often during emergency circumstances. For organizations that operate at the level of meso-allocation, like community healthcare organizations, professional societies are a more common source of ethics guidelines. Conceptually grounded action guides that are useful to administrators are rarely generated in the academic literature, and even more rarely are they informed by empirical data about the process of decision making. In developing our conceptually grounded, empirically informed action guide, we aimed to adapt the strong conceptual foundations available in the academic literature to the needs and context of community-based healthcare organizations, and thereby to create a product that could be used “off the shelf” with no additional training. Our illustrative example shows what it might look like to use the action guide, and simultaneously models the process by which future empirical research can refine it.

Additional empirical research is warranted to continue to improve the action guide and to study how community-based healthcare organizations can effectively deploy it. One line of research should test whether the elements of decision making that we identified in the subcategory of community-based healthcare organizations appear in other types of community-based healthcare organizations, and whether there are additional elements that need to be included. This line of work could also examine how different sets of organizational values (part of the context of a decision) impact the trade-offs made by organizations. Such work would form the basis of a hierarchy for addressing decision-making trade-offs. A second line of research should test the pragmatic utility of our action guide for making health policy decisions at the level of meso-allocation. Using survey development techniques, researchers could cognitively test the language of the action guide for clarity and utility. Research should also be conducted to obtain feedback from community-based healthcare organization decision makers to improve the usefulness of the action guide—for example, to find out whether there is an order of the subdomains that would be particularly useful. Research could also be conducted to assess the extent to which the use of an action guide promotes explicit consideration of organizational values and ethical tensions and dilemmas, or whether the results of the deliberations produce resource allocation and policy decisions that are better aligned with ethical norms.

A community-based healthcare organization that incorporates routine use of the fully developed action guide into decision making could, at minimum, expect to see improvements in the degree to which decisions are made systematically, transparently, and in accordance with the organization’s own stated mission and values. In addition, organizations could use the action guide to evaluate whether policies made in accordance with it are carried out consistently by frontline staff.

CONCLUSION

Nancy M. Baum and colleagues argue that the value of providing a tool for ethical decision making is in helping public health practitioners clarify the ethical tensions in their work, balance the ex-
clusive use of economic analysis, and promote the explicit analysis of values and transparency. These same benefits can be expected from a tool developed for community-based healthcare organizations. In this article we have drawn upon our prior empirical research to evaluate, organize, and specify applicable elements of existing conceptual frameworks, so as to provide comprehensive, actionable guidance for resource allocation decision making that affects healthcare services available to members of community-based healthcare organizations. The action guide presented here represents a first step toward providing community-based healthcare organizations with a conceptually grounded, empirically informed framework for ethical decision making.

ACKNOWLEDGMENTS

The authors gratefully acknowledge the contributions of our study participants. While conducting the first stage of this analysis and completing doctoral training in the Department of Health Policy and Management in the Johns Hopkins Bloomberg School of Public Health, KLH was supported by the AHRQ NRSA Health Services Research and Policy Traineeship (T32-HS00029) and the Victor P. Raymond Memorial Fund Health Policy and Management Endowment Award. Subsequent analyses were conducted while KLH completed postdoctoral training at the University of California, San Francisco, supported by the National Institute of Aging, T32-AG000212. KLH presented an early version of this work as a poster at the annual meeting of the American Society of Bioethics and Humanities, 24-25 October 2013 in Atlanta, Georgia; the poster was entitled “Going forward: Prototype guidance for addressing ethical challenges in health care resource allocation and policy decision-making.”

NOTES


17. Harrison, Forks in the Road, see note 5 above.


Medical Decision Making for Medically Complex Children in Foster Care: Who Knows the Child’s Best Interests?

Rebecca R. Seltzer, Rachel A.B. Dodge, and Renee D. Boss

ABSTRACT

Approximately one in 10 children in foster care are medically complex and require intensive medical supervision, frequent hospitalization, and difficult medical decision making. Some of these children are in foster care because their parents cannot care for their medical needs; other parents are responsible for their child’s medical needs due to abuse or neglect. In either case, there can be uncertainty about the role that a child’s biological parents should play in making serious medical decisions. Here we highlight some of the ethical challenges inherent in making these decisions for children in foster care, as seen through the lenses of a child welfare provider, an inpatient care physician, and a primary care pediatrician.

INTRODUCTION

Nearly 440,000 children are in foster care on any given day in the United States, of whom an estimated 10 percent are medically complex. Some of these children enter foster care due to abuse or neglect that is unrelated to their medical conditions; other enter foster care because their medical needs exceed their parents’ ability to care for them. In either case, child welfare and foster care providers become responsible for assuring that the child’s medical needs are met. Child welfare administrators and foster care parents are generally authorized to make routine medical decisions for these children, for example, vaccines or an antibiotic for a minor infection. But when serious medical decisions arise, for example, whether or not to place a surgical feeding tube for failure to thrive, there is often confusion about whether a biological parent’s legal authority should be the only factor to consider when determining who can meaningfully judge and advocate for a child’s best interests.

In this article we present a case that highlights some of the ethical challenges inherent in making...
serious medical decisions for children in foster care, as seen through the lenses of a child welfare provider, an inpatient care physician, and a primary care pediatrician.

**CASE**

“Darlene” is a nine-year-old female admitted to the hospital for spinal fusion surgery to correct severe scoliosis.

Darlene has cerebral palsy and cognitive/developmental deficits secondary to non-accidental head trauma at age three; she is also tracheostomy and gastrostomy-tube dependent. She is nonverbal, unable to sit up unassisted, and incontinent of both bowel and bladder. Darlene has lived in a medical foster care home since the initial trauma; her mother’s and father’s parental rights were terminated.

Following scoliosis surgery, Darlene’s post-operative course is complicated by infection, respiratory failure, and uncontrollable seizures. On post-op day 14, she is not responding to any external stimuli or interacting with her environment. Although she has some spontaneous breathing, the assessment of the PICU (pediatric intensive care unit) team is that she is likely to remain ventilator dependent. They plan to discharge her to a rehabilitation facility once she becomes medically stable. It is uncertain whether the foster parents with whom she has been living can handle her care now that she is ventilator dependent.

The PICU team recommends that Darlene should have a do-not-resuscitate (DNR) order in place (with no intention of withdrawing existing care). At the request of the child welfare agency legal counsel, the hospital ethics committee is consulted. The ethics committee agrees that a DNR order is ethically permissible. Darlene’s appointed lawyer also supports the institution of a DNR order. While the child welfare agency has medical decision-making authority for Darlene, consenting to a DNR order requires the authorization of a juvenile court.

Darlene’s biological parents, who have not had legal or physical custody of Darlene in six years, are notified about Darlene’s condition and upcoming court hearing. They attend the court hearing and express their opposition to a DNR order based on their Christian religious beliefs. They also argue (through their lawyer) that Darlene, their daughter, could potentially survive for many years and that the possible short-term pain associated with CPR (cardiopulmonary resuscitation) would not, in their view, outweigh the potential significant benefits of being alive. Despite the recommendations of the doctors, lawyers, and ethics committee, the judge does not allow the institution of a DNR order.

Given this scenario, one ethics question is: Should parents whose rights have been terminated have a say in decisions about providing or withholding life support for Darlene?

**CASE COMMENTARIES**

The Perspective of Child Welfare

Darlene had a scoliosis surgery that resulted in deterioration of her respiratory and mental status. This deterioration led to concerns by her healthcare team that a DNR order should be considered, and this was presented in court. Unless all parties are in agreement that a DNR order is in the child’s best interest, the courts are typically reluctant to authorize the withholding or withdrawing of life-sustaining therapies for children who are in state custody. The reasons for judicial reluctance are understandable. They are reluctant custodians for medically complex children, a role that they have taken on out of necessity in recent years.

The child welfare system was designed to provide protection and shelter for children whose homes are no longer safe. Although most children enter the system because of abuse or neglect, the child welfare system is increasingly responsible for children with medically complex needs whose parents are unable or unwilling to provide the care they need. Child welfare has had to design programs and recruit families to care for medically complex children. For some children, it is impossible to find a permanent adoptive family willing to take on the high burden of that care.

Children like Darlene, who require surgeries or complex medical technologies, often require complex medical decisions that involve prognostic uncertainty and substantial risk. Such decisions are usually made by healthcare professionals and parents in a process of shared decision making. This process is difficult or impossible in the child welfare system, since that system was never designed to bring its own moral values or interests into the process.

For children whose biological parents have had their rights terminated, or whose parents are not accessible, the child welfare system becomes the default decision-making authority. Case workers who visit a child one to two times per month, who have minimal involvement in the child’s daily care, and who rarely interact with the medical team, are given responsibility for providing consent for medical treatments. Case workers also change frequently, re-
dminating longitudinal understanding of a child’s evolving medical needs. To reduce the lack of continuity that comes with changing case workers, many child welfare systems assign authority to give medical consent to supervisors or directors. But they are even more removed from the child than case workers. This raises multiple questions about whether the individuals who are given the legal authority to make these decisions for children have a meaningful and informed understanding of the child’s best interests.

This concern is heightened as the stakes of the medical decisions become greater and the oversight becomes more rigorous. Decisions about withholding or withdrawing life-sustaining treatments for a child in foster care require court approval by a judge. Judges generally have no pre-existing knowledge of the child and no particular expertise related to making decisions for medically complex children or end-of-life care for children. When DNR orders are being considered, a judge may request an ethics consultant as part of the process. An ethics committee is tasked with considering the medical decision at hand and determining whether a DNR order is considered ethically permissible after spending time with the child and other involved parties to better understand the child’s medical condition and quality of life.

In Darlene’s case, the medical team, the ethics committee, and her appointed attorney all agreed that a DNR order was in her best interest. Her biological parents were the only parties who testified against the DNR order. But why are parents who have no legal authority to make either routine or serious medical decisions for their child notified of court hearings and allowed to participate in making end-of-life decisions? While they are not technically a party in the case, due to their termination of parental rights, it is up to the discretion of the judge to consider their opinions or testimony.

We do not know why the judge ruled against the DNR order for Darlene and what role, if any, the parents’ testimony played in the final ruling. Perhaps the judge felt the parents offered something that clarified Darlene’s best interest. While judges are meant to remain impartial (that is, to be rule-based regarding a child’s best interest), it would likely be challenging to override parents’ pleas, regardless of legal status, and take action that may ultimately result in the child’s death.

The Perspective of the Inpatient Care Team

Increasing numbers of patients in neonatal and pediatric ICUs are medically complex. Their clinicians must guide decisions regarding treatment intensity as the children experience declining function and quality of life. We assume that spinal fusion was intended to improve Darlene’s quality and length of life, so that she could return to her foster family with fewer daily care needs and greater comfort. Children and families do report increased quality of life after spinal fusion for neuromuscular scoliosis, although children with cerebral palsy, like Darlene, often have more limited functional improvements and a higher risk of post-surgical complications. It is unclear how Darlene’s increased risk of adverse surgical outcomes informed pre-operative counseling and consent, or whether the child welfare representative who provided consent had a good understanding of Darlene’s medically complex needs.

Darlene did have post-surgical complications, with severe functional deterioration that was predicted to persist. Her extremely limited quality of life is what unified the PICU team, Darlene’s lawyer, and the hospital ethics committee in their recommendation against CPR in the event of an arrest. Although there was not consensus in the medical team, some clinicians advocated to reduce Darlene’s treatment intensity via withdrawal of medical technology and nutrition. Those individuals worried that pain and distress are difficult to diagnose and treat in children who have severe neurologic impairment, and that if Darlene had intractable pain, anxiety, or distress, the value of mechanical ventilation or tube feedings may no longer exceed their burdens. In the end, the PICU team proceeded with a request for a DNR order, but without any intention to withdraw existing therapies.

Among all of the persons involved in the medical decision, Darlene’s biological parents were the only ones who stated opposition to the DNR order. We must question what motivated Darlene’s parents to show up to make their opinion known. It is unclear what the legal implications would be of Darlene’s death for her parents, given the history of non-accidental trauma. If her death could lead to criminal charges against one or both of them for murder, they may have had an irresolvable conflict of interest in making decisions for Darlene. Absent such concerns, determining whether the biological parents were appropriate decision makers for Darlene should include consideration of their understanding of the benefits and burdens of her current daily care and how those could change after attempted CPR.

As the judge did hear testimony from the biological parents in the decision about a DNR order, it is important to consider the strength of the reasons...
supporting the parents’ opposition. We know that persons’ religious and spiritual beliefs are often central to their decisions about end-of-life care. And while supporting a family’s values is essential, that support should include exploring how a family’s values map onto the current medical decision to be made and how they weigh against other benefits and burdens. Patients and families can misinterpret the rules of their religion related to end-of-life care; exploring parents’ beliefs may help clarify any misunderstandings and verify the presence of true value conflicts.

The Perspective of the Primary Care Pediatrician

A stable medical home for children like Darlene is a high priority for child welfare staff and pediatricians. Pediatricians for medically complex children can coordinate care with multiple subspecialists and appreciate the “whole picture” of a child’s medical needs. Assuming Darlene has had one consistent medical home (that is, one pediatrician who has continually followed her care), then Darlene’s primary care pediatrician (PCP) would have a longstanding relationship with her, her foster parents, and others who may attend primary care appointments, including child welfare case workers and home nurses. If her medical home predated foster care placement, the PCP would have a prior relationship with Darlene’s biological parents and potentially with her siblings. The PCP is therefore well-suited to weigh in on Darlene’s medical needs, her social needs, and the competing interests of the multiple individuals involved in her care.

We are not told whether Darlene’s PCP was involved in the decision-making process or if he or she is in support of the DNR order, which seems to be an evident omission in the case. For children like Darlene, advance care planning often begins in the inpatient/PICU setting, when an acute illness has occurred or death is imminent. In one study, 71 percent of clinicians felt that such discussions happen too late in the clinical course, and 92 percent believed that discussions regarding the goals of care should occur upon diagnosis or during a period of medical stability. While PCPs recognize their responsibility for initiating discussions regarding the goals of care, they note that time constraints, family readiness, and a provider’s lack of skill in such discussions are barriers.

Since Darlene is in medical foster care, the common disconnect between those who know Darlene best and those who are authorized to make medical decisions may have undermined advance care planning up until this point. For children in foster care, the ambiguity about parents’ and family members' involvement can be an additional barrier to advance care planning. Pediatricians are accustomed to deferring to parents’ assessment of their child’s best interest, based on the assumption that they care about their child, understand the child’s unique needs, and hold common family values.

The PCP’s assessment of Darlene is largely dependent on information gained through interactions with her foster parents, as they are the ones who regularly attend medical visits with her and provide updates about how she is doing. Decision-making authority is less of a question in the primary care setting, where routine decisions such as vaccines, bloodwork, and referrals do not require separate consent from the child welfare agency. On the contrary, when discussing surgeries or higher stake medical decisions in the inpatient/PICU environment, the legal need to escalate a decision to the child welfare agency or courts not only can remove foster parents from the decision-making process, but can also remove input from the pediatrician who has known the child over time.

The medical foster parents, whose opinion about a DNR order is notably absent from the court proceedings, are arguably those who are most knowledgeable about Darlene’s care needs and have provided her with a safe and nurturing home environment for six years. During that time, they have had the legal authority to decide when Darlene needs medical care, have scheduled and attended her medical appointments, and have made routine medical decisions with her PCP. But without seeking adoption or guardianship, they cannot make nonroutine medical decisions about procedures or life-sustaining therapies.

So what about the biological parents? Should all biological parents, by virtue of blood alone and regardless of circumstance, be entitled to the same opportunity to speak on behalf of their child in court? In Darlene’s case, in which the abuse from her parents resulted in her current medical severity, and assuming they have been uninvolved for most of her life, we would say no. If the judge’s decision is meant to be informed by those who care for Darlene and can speak to her best interests, we question why Darlene’s biological parents had an opportunity to provide testimony in court and her foster parents and PCP did not.

CONCLUSION

This case and associated commentaries highlight the need to further explore how medical decisions
are made for medically complex children in foster care. As Darlene’s biological parents’ rights were terminated six years ago, it is unlikely that they have had meaningful interaction with Darlene over the years. They appear to have no substantive moral authority to represent Darlene’s best interest and should not have been included in the decision about instituting a DNR order. By better understanding and identifying who the meaningful decision-makers are for children in foster care, we may be able to inform policy and practice on how to approach serious medical decisions for this population.

The current decision-making process for children in foster care involves multiple systems, including the legal, child welfare, and healthcare systems. These systems tend to work in siloes, which can prevent approaching the child’s needs and medical decisions through a more integrated model. By intentionally enhancing communication and collaboration between these systems, there is potential to learn from one another in order to address these more challenging decisions.

Unfortunately, little to no data exists on decision-making experiences or outcomes for medically complex children in foster care to guide our conversations. Additionally, court rulings in such cases are typically kept confidential, leaving us uncertain as to why the judge ruled the way he or she did. This is not surprising, as foster youth have special protections in place due to their designation as a vulnerable population. This designation creates barriers that limit data collection and research related to youth in foster care, including learning more about medical decision making. Such challenges and potential solutions will be discussed in the paper that follows, “Medically Complex Children in Foster Care: Do Research ‘Protections’ Make This ‘Vulnerable Population’ More Vulnerable?”

**FUNDING SOURCE**

RSR was supported by the U.S. Department of Health and Human Services (HHS) under HRSA (Health Resources and Services Administration) T32HP10004 and HRSA T32HP10025. This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by the U.S. HRSA, HHS, or the U.S. government.

**BLINDING**

Some details of this case have been altered to protect the identities of those involved.

**NOTES**

13. Ibid.

Medically Complex Children in Foster Care: Do Research “Protections” Make This “Vulnerable Population” More Vulnerable?

Rebecca R. Seltzer, Megan Kasimatis Singleton, Erin P. Williams, and Renee D. Boss

ABSTRACT

Children in foster care are considered a “vulnerable population” in clinical care and research, with good reason. These children face multiple medical, psychological, and social risks that oblige the child welfare and healthcare systems to protect them from further harms. An unintended consequence of the “vulnerable population” designation for children in foster care is that it may impose barriers on tracking and studying their health that creates gaps in knowledge that are key to their receipt of medical care and good outcomes. These gaps in knowledge have implications for justice, beneficence, and maleficence and serve to undermine “protection” of this population. Here we review the challenges of research regarding children in foster care, particularly medically complex children, and offer specific recommendations to include children in foster care in medical research.

INTRODUCTION

Children in foster care are considered a “vulnerable population” in clinical care and research, with good reason. These children face multiple medical, psychological, and social risks that oblige the child welfare and healthcare systems to protect them from further harms. An unintended consequence of the “vulnerable population” designation for children in foster care is that it may impose barriers on tracking and studying their health that creates gaps in knowledge that are key to their receipt of medical care and good outcomes. This is a particularly important issue for those children in foster care who have serious and chronic health problems.

While the intention of foster care is to improve the well-being of children at risk, current restrictions placed on the conduct of research with this population undermine our ability to assess, refine, and improve foster care. These gaps in knowledge have implications for justice, beneficence, and maleficence and serve to undermine “protection” of this population. Here we review the challenges of research regarding children in foster care, particularly children who have complex medical needs, and of-
fer recommendations to include children in foster care in medical research.

CASE

“Bridget” is one year old and has a history of extreme prematurity, severe intracranial hemorrhage, developmental delay, chronic lung disease, and dependence on a tracheostomy and feeding tube. She is currently admitted to the hospital for pneumonia.

The medical team discovers that Bridget has missed many doctor visits and has had no weight gain over the last three months. They question her parents’ ability to care for such a medically complex child. Child welfare is contacted due to concern regarding medical neglect. They begin to investigate whether Bridget can safely go home with her parents or whether she requires an out-of-home placement such as in foster care.

One morning on rounds, the attending physician says to the team, “It’s clear that Bridget’s parents are not adequately caring for her medical needs. I’m sure she will do better if we place her with a medical foster care family.” A pediatric resident on the team replies, “I searched the literature regarding medical outcomes for children placed in medical foster care, but I found almost no relevant studies. How do we know if foster care will improve Bridget’s health outcomes?”

VULNERABLE POPULATIONS IN PEDIATRIC RESEARCH

In the United States, regulations regarding research in children have evolved since the 1970s, when The Belmont Report highlighted the tension between two ethical imperatives: that children not be unfairly excluded from benefits of research, and that children are protected from the risks of research.1 In the 1980s, “Subpart D” of the requirements for the “Protection of Human Subjects” outlined in the U.S. Code of Federal Regulations permitted research with children that involved no more than minimal risk.2 These regulations permit the inclusion of children in research that presents greater risk if the research potentially offers the child a direct benefit or provides vital information about the child’s medical condition. “Subpart D” also requires, in most cases, that parents or legal guardians provide permission for the child to be involved in research and, when reasonable, that the child provides assent. These added research protections for children reflect their designation as members of a “vulnerable population,” a status conferred to them based on concerns that children could be misled or mistreated in research.3

Children in foster care are often considered to be particularly vulnerable, which reflects a history of research abuse in the U.S. in orphanages and concerns that populations in institutions may be oversampled in research because they may be readily available to researchers. For example, allegations that foster children in New York City were inappropriately enrolled in clinical drug trials during the early years of the HIV/AIDS epidemic were highly publicized and led the public and patient advocacy groups to question whether foster children should be allowed to participate in clinical trials.4 While these allegations were determined to be largely unfounded, they elevated concerns regarding participation in research by children in foster care.5

MEDICALLY COMPLEX CHILDREN IN FOSTER CARE

Restrictive application of these research protections has created barriers to understanding the role of foster care on health outcomes. On any given day in the U.S., nearly 440,000 children are in foster care.6 The majority of these children have been exposed to abuse or neglect and have high rates of physical, developmental, and emotional health problems.7 An estimated 10 percent of children in foster care are considered to be medically fragile and have medical problems that are complex.8 Medically complex children in foster care are a uniquely vulnerable population due to their combination of significant medical and social risks, a combination that has been reported to increase the odds of poor health outcomes and high rates of utilization of healthcare services compared to medical risk alone.9 These children often require intensive daily care due to multiple medications, dependence on technology (for example, feeding tubes, ventilators), and frequent doctor visits and hospitalizations. Once medically complex children enter state custody, they may be placed in a medical foster home with foster parents who receive specialized medical training, or in a group home or institution.

While the goal of foster care is to secure the well-being of at-risk children like Bridget in the case above, it is unknown how health outcomes for children in foster care compare to children with similar medical problems who are not in foster care. Following the outcomes of those with the greatest medical need is critically important to improving care and directing resources.
BARRIERS TO HEALTH OUTCOMES RESEARCH FOR CHILDREN IN FOSTER CARE

There are several key barriers that limit our understanding of how medically complex children do in foster care and how foster care placement impacts their health status. Here we review three essential barriers to research regarding medically complex children in foster care.

Limited Existing Databases

The Children’s Bureau within the U.S. Department of Health and Human Services supports state and tribal child welfare agencies in the development of data reporting systems, but encourages local agencies to “build information systems that meet their unique business needs.” So while each state agency maintains a data reporting system, much variability exists, and reports regarding health indicators are typically limited in scope and specificity. As such, available databases lack the variables necessary to study health outcomes for medically complex children in foster care.

“Vulnerable” Status Triggers Multi-Layered Review Processes

In addition to federally mandated reviews of research involving children by IRBs (institutional review boards), research involving foster children in the U.S. is commonly subject to additional review by state agencies. In some states, the district circuit court may even have to approve a research study involving children in foster care. Such state agencies are rarely equipped efficiently facilitate research review processes.

While U.S. federal regulations for human subject protections only require that additional protections be applied to selected studies involving children in foster care (that is, those studies that pose greater than minimal risk without direct benefit), agencies often interpret that these additional requirements should be extended to all research involving children in foster care. Those human subject protections posed as considerations and not imperatives may be over-interpreted by the IRBs or state agencies responsible for research review as formal “requirements.” This restrictive application of regulations may impede important minimal risk research, for example, a survey study, by requiring arduous and time-consuming reviews.

Challenges to Obtaining Consent

Identifying who is legally permitted to provide research consent for a child within the foster care system is also challenging. Often times that person is the biological parent or a child welfare administrator, neither of whom may be actively involved with the child’s care or who may be inaccessible. The barriers to obtaining consent can result in the exclusion of these children from research participation. Additional provisions in “Subpart D” of the requirements for the “Protection of Human Subjects” permit waivers of parental permission for neglected or abused children under certain conditions, although state agency requirements may prohibit that waiver for children in foster care. As IRB review is generally dependent on securing any other applicable approvals required by federal, state, or local law, an IRB would defer to the state agency requirements, and parental permission may be required.

RECOMMENDATIONS

Change is needed to support high quality research in this area. Without this change, we cannot know whether medical foster care is the best placement option for children like Bridget whose biological parents cannot meet their healthcare needs. Here we highlight initial strategies to accomplish this goal by focusing efforts on projects involving minimal risk, such as data collection and review.

Linked Child Welfare and Health Systems Databases

First, we need to expand child welfare databases to capture nuanced health information for children in foster care. The specific variables (for example, ICD codes, medications, hospitalizations, et cetera) that track outcomes for other children with complex medical needs should also be available for this same patient population who happens to be in foster care. In addition, consistently including “foster child status” in the medical problem list within electronic medical records would permit retrospective and prospective tracking of health outcomes for quality improvement and secondary analysis research.

Make “Vulnerable” Status Protections Meaningful and Not Prohibitive

“Vulnerable” status should not be an all-encompassing black box that prevents meaningful research due to excessive logistical and regulatory hurdles. Rather, being a child in foster care should trigger reasonable but achievable oversight policies and protections. A collaborative research approval process for studies of foster child health could incorporate hospital IRBs and child welfare research per-
sonnel. This joint perspective on research protections could prevent duplication of efforts and contradictory requirements.

Alternative Consent Strategies

Because locating the person currently allowed to provide research consent for a child in foster care can present a barrier to participation in research, a broad research consent from biological parents at the time a child enters the foster care system would allow for the collection of research data. There are already models in place for this: biological parents often sign a broad medical consent allowing a child welfare agency or foster parents to make routine medical decisions for children\(^19\) (for example, vaccinations, bloodwork, scheduling doctor appointments, et cetera). A similar consent could enable decision making for a child’s participation in medical research that involves benefit and minimal risk to the child.

CONCLUSION

Making a Vulnerable Population More Vulnerable

Health outcomes for medically complex children in foster care are now invisible. This undermines any effort to improve the quality of care we provide to children and families in the child welfare system, raising the possibility that our application of research protections is actually making this population more vulnerable.

For the case above involving Bridget, we have limited data to help us answer the question of whether foster care will improve her health outcomes. She is a child with significant medical complexity, who requires intensive daily care. It is not currently possible to answer the question of whether her growth, her dependence on medical technology, or her neurologic development are likely to be better if she is with her parents or with a medical foster family. Due to lack of available research, the medical team must make a decision that is not informed by evidence or data. Essentially, it is a “flip of a coin.” While multiple strategies will be required to track, assess, and optimize outcomes for children like Bridget, targeted healthcare research is a fundamental component.

BLINDING

Some details of this case have been altered to protect the identities of those involved.

FUNDING SOURCE

RSR was supported by the U.S. Department of Health and Human Services (HHS) under HRSA (Health Resources and Services Administration) T32HP10004 and HRSA T32HP10025. This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by the U.S. HRSA, HHS, or the U.S. government.

NOTES


18. ICD10, the International Statistical Classification of Diseases and Related Health Problems, is a medical classification list by the World Health Organization (WHO) that includes diseases, signs and symptoms; abnormal findings; complaints; social circumstances; and external causes of injury or diseases. ICD11 was released in 2018. http://www.who.int/classifications/icd/en/.

The Work of ASBH’s Clinical Ethics Consultation Affairs Committee: Development Processes Behind Our Educational Materials

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ABSTRACT

The authors of this article are previous or current members of the Clinical Ethics Consultation Affairs (CECA) Committee, a standing committee of the American Society for Bioethics and Humanities (ASBH). The committee is composed of seasoned healthcare ethics consultants (HCECs), and it is charged with developing and disseminating education materials for HCECs and ethics committees. The purpose of this article is to describe the educational research and development processes behind our teaching materials, which culminated in a case studies book called A Case-Based Study Guide for Addressing Patient-Centered Ethical Issues in Health Care (hereafter, the Study Guide). In this article, we also enumerate how the Study Guide could be used in teaching and learning, and we identify areas that are ripe for future work.
INTRODUCTION

Conducting healthcare ethics consultations can be intellectually and emotionally challenging. Frequently, ethics consultations involve seemingly intractable conflicts between stakeholders on personal, value-laden ethical issues, such as end-of-life decision making, confidentiality and privacy concerns, informed consent, surrogate decision making, and professional or institutional responsibilities. Healthcare ethics consultants (HCECs) must possess knowledge about core bioethics topics to be able to provide recommendations that are in keeping with ethical consensus (when it exists), but core knowledge alone is insufficient to master ethics consultation.

To do ethics consultation well, HCECs should possess and exhibit a range of advanced skills that extend beyond familiarity with ethical issues. For instance, HCECs should be familiar with national standards in clinical ethics, including consensus and policy statements promulgated by major healthcare professional organizations. Additionally, HCECs must be approachable and interpersonally comfortable working with patients, families, and healthcare professionals. They must be empathetic and able to interpret and respond to others’ verbal and nonverbal cues, yet remain objective enough to avoid partiality. HCECs must be able to communicate with people who are not familiar with contemporary healthcare systems and use language that is accessible to people from many different backgrounds, which may require at least moderate degrees of interpersonal versatility and self-awareness. Additionally, HCECs must possess strong analytical and critical-thinking skills, and be able to think and respond promptly to situations that change incrementally over time. In crises, stakeholders’ emotions can change quickly, clinical status can change abruptly, and courses of action must shift—all of which require agility of mind, or discursive agility.

Given the range of skills required to conduct ethics consultations, there has been some debate and uncertainty about the ideal method of teaching and learning ethics consultation. An internet search suggests there is a wide variety of teaching modalities available, such as online videos on ethics consultation, modules, webinars, and intensive courses. The range of topics is diverse as well, often including some teaching on mediation and conflict resolution skills, underscoring the importance of cultivating strong interpersonal skills and discursive agility.

The available instructional materials on ethics consultation undoubtedly assist individuals in learning core bioethics topics and may help cultivate critical-thinking skills. However, most materials on ethics consultation can only go so far in demonstrating the integration of knowledge and practice. That is, available materials are limited in that they usually cannot provide the experiential learning that comes through in-person practice. A 2007 survey suggested that many HCECs learn ethics consultation through on-the-job experience, which presumably means that HCECs find experiential knowledge essential to becoming clinical ethicists. These HCECs may feel they become stronger over time after conducting several (if not numerous) ethics consultations.

If it is true that HCECs learn primarily through on-the-job training and experience, then conceivably there may be missteps or (potentially) errors in the beginning of consultants’ learning. Although some learning through practice in a real environment is likely inevitable in ethics consultation, an “on-the-job-training model” may not be ideal for the initial application of knowledge to actual clinical encounters.

We sought to create teaching materials that could augment experiential learning through a distinctive, case-based methodology in a protected, artificial teaching environment. We call our case-based methodology an “unfolding approach,” which is described more fully below. The purpose of this article is to describe the educational research and development processes behind our teaching materials, which culminated in a case studies book called A Case-Based Study Guide for Addressing Patient-Centered Ethical Issues in Health Care, hereinafter, the Study Guide. In this article, we also enumerate how the Study Guide could be used in teaching and learning.

The authors of the Study Guide and of this article are previous or current members of the Clinical Ethics Consultation Affairs (CECA) Committee, a standing committee of the American Society for Bioethics and Humanities (ASBH). The committee is composed of seasoned HCECs, and is charged with developing and disseminating education materials for HCECs and ethics committees. The CECA Committee members are appointed for one-year committee appointments, renewable annually up to a maximum of three years by the president of the ASBH. Candidates for CECA Committee appointments are typically evaluated according to the following criteria: substantive involvement conducting ethics consultations on a range of ethical issues in a variety of healthcare contexts, demonstrable leadership and professional development in clinical ethics consultation, experience writing and publishing clinical ethics scholarship or other academic
contributions to the field, and active engagement in quality enhancement initiatives within clinical ethics consultation. CECA Committee members come from a wide variety of disciplines and geographic areas. A majority of the members direct or previously directed high-volume ethics consultation services in tertiary academic or community settings or work as full-time HCECs. Many committee members conduct research on ethics consultation and frequently publish on best practices for HCECs and ethics consultation services.

**BRIEF HISTORY**

In 2000, ASBH established a Clinical Ethics Task Force (now the CECA Committee) to build on the Core Competencies for Healthcare Ethics Consultation report. Through research, the group members found that some ethics consultations were being carried out by people who did not have formal education or training in ethics consultation. To fill in this gap in ethics education, the CECA Committee designed a self-education program guide in 2009, Improving Competencies in Clinical Ethics Consultation: An Education Guide. The second edition of the Improving Competencies was published in 2015.

In 2014, the CECA Committee surveyed the purchasers of Improving Competencies to identify what those users would find helpful in a follow-up educational report. Survey respondents indicated that it would be helpful for the CECA Committee to create a supplement to Improving Competencies that featured case studies, but respondents did not provide any details beyond stating that case studies would be helpful.

Based on these survey data, the CECA Committee members set out to write case studies, but we were not sure of the appropriate format. We learned through conducting education psychology research that most learners think inductively rather than deductively, which makes examples an effective teaching methodology for developing critical-thinking skills. However, the same studies that touted the benefits of case studies also suggested that case-based teaching is often done poorly.

**AVOIDING THE PITFALLS ASSOCIATED WITH CASE STUDIES**

A case study is a descriptive document based on a real-life situation, problem, or incident, and case studies are frequently used to enhance lectures and group teaching. There are at least five distinct reasons why case-based teaching has been criticized in the higher education literature. One common critique is that most case presentations are too lengthy and often laden with medical intricacies, redundancies, and unnecessary details that are not critical for medical (much less ethical) analysis. Conversely, other cases have been criticized for being too short and open ended that readers cannot conduct adequate analyses. When there are too many unanswered questions at the outset of a case presentation, it is argued, learners become “stuck” in conditional framings of the case and circuitous logic, creating elaborate “what if” or “if then” statements that prevent them from moving forward beyond “issue identification.” When this happens, learners cannot adequately conduct a thorough analysis in order to achieve a case resolution.

A second common critique of case-based teaching is that the cases fail to actively involve learners during case presentations. It is only at the end of a case presentation that learners are asked to “conduct an ethical analysis,” which essentially allows readers to disengage throughout the case presentation. When this occurs, readers may miss critical information or may perseverate on ethically irrelevant facts. A third critique of case-based teaching is that cases do not give adequate detail about psychosocial considerations or other dynamics that make a case truly “rich” with description. Rich description is often necessary for complete analysis.

A fourth critique, particularly applicable to clinical ethics consultation, is that cases rarely contain “ pivots,” that is, facts that are introduced midway through a case that should shift learners’ analyses in substantive ways. Pivots are essential to learning ethics consultation, because pivoting facts help cultivate discursive agility and creativity. Only through pivots do learners enhance their ability to move in nonlinear ways to manage cases.

A final critique (not found in the literature, to our knowledge, but rather our own thinking) is that cases rarely present procedural elements, that is, the consultative activities that HCECs use to manage cases. As the Core Competencies enumerate, as part of ethics consultation, HCECs engage in a number of activities for fact gathering or facilitation purposes. Specifically, HCECs meet one-on-one with patients and families to elicit morally relevant perspectives on a case. Ethicists may mediate or facilitate staff-only meetings involving only the care team, or HCECs may facilitate family meetings involving patients’ families and the care team to, for instance, discuss prognostic information or treatment options. HCECs document cases, and they talk with a number of stakeholders at various points in time.
each consultative activity, new facts and information emerge that have the potential to impact ethical analyses and the appropriateness of some courses of action. The consultative process, and the underlying reasons for the consultant’s activities, should be described in cases so that learners may rehearse how cases unfold from beginning to end. By operationalizing the procedural elements of ethics consultation, learners may gain a better sense of how consultative activities play an integral role in fact gathering and analyses.

Thus, as the CECA Committee, we knew we needed to develop case studies to meet HCECs’ needs, but we wanted to avoid the common critiques and pitfalls associated with case presentations. In practice, that meant the length of each case had to be just right—not too long and not too short. The cases presentations needed to actively engage the reader, and the case descriptions needed to introduce elements that make ethics consultation complex: dynamics, pivots, and conversations with multiple stakeholders.

DEVELOPMENT PROCESS FOR THE STUDY GUIDE AND ITS CONTENT

Drafting and Piloting Processes

The drafting processes consisted of having one member of the CECA Committee write a case, with a few members writing more than one case. Then, the principal author of each case shared it with a randomly assigned reviewer who was also part of the CECA Committee. These two individuals (principal author and reviewer) then submitted their case to the chair of the CECA Committee (CRB) who further revised the case in two rounds of edits.

At this stage of development, we were ready to pilot the cases. Through the efforts of using a principal author, a second reviewer, and the committee chair, the authors were able to create 14 full “draft” cases to pilot. To ensure that the cases were medically accurate and representative of actual clinical-ethical dilemmas, we then piloted each draft case with at least one physician-reviewer and one trainee (medical student, nursing student, or clinical ethics fellow), all of whom had an interest and at least minimal expertise in ethics consultation. Typically, these “outside” reviewers were members of ethics committees, ethics course students, or secondary faculty members affiliated with ethics departments or centers within the Texas Medical Center. The cases were assigned to outside reviewers based on specialty interests, to the greatest extent possible. Thus, for example, a case involving neonatal ethics was sent to a neonatologist for review, and a case involving heart failure treatment options was sent to a cardiologist.

After outside reviewers edited and commented on each case, the CECA Committee dropped two drafted cases because of negative feedback from reviewers. Then, the principal authors of the 12 remaining cases conducted additional edits to fully respond to the outside reviewers’ comments. Next, the principal authors returned their cases to the committee chair, who further refined each case. Finally, we sent the full manuscript to 11 additional outside reviewers. This second-round of outside reviewers were selected using a combination of two methods: purposive sampling of clinical ethicists who were willing and able to review the manuscript within a short time frame, as well as drawing on the newly appointed 2016-2017 CECA Committee. As newly appointed committee members, these reviewers were not involved in the writing of the Study Guide.

After the committee chair made additional edits to respond to the second set of outside reviewers’ comments, the manuscript was then reviewed by the ASBH Board of Directors. The CECA Committee chair made final edits in response to the board’s comments and suggestions.

In all, the cases were refined through at least six rounds of revision using multiple reviewers, at least two rounds of which involved outside reviewers. The end result is a 121-page book consisting of 12 cases—nine involving adult patients and three involving minors—on various topics in clinical ethics, including decision-making capacity, informed consent, advance care planning, end of life, and privacy and confidentiality, among many other topics. The cases are actual cases (the patients’ names have been removed and some facts were changed to preserve anonymity) and represent the authors’ collective experience in performing ethics consultations. The 12 cases we ultimately chose include complex patient and family narratives that are interwoven with ethically relevant medical, surgical, and psychosocial-spiritual features.

The Unfolding Approach

To actively engage readers, as well as to introduce dynamics, pivots, and procedural elements, we present the cases in what we refer to as “the unfolding approach”: a process in which we “interrupt” each case at several junctures to ask questions of the reader. Then, the case continues until the next break, when we ask more questions. We chose the term “unfolding” (a term that, to our knowledge, has not been used elsewhere) to describe what we hope
will become a new pedagogical advancement in how case studies are written.

In designing the unfolding approach, we drew on the work of Daniel Kahneman’s cognitive science work described in his *Thinking, Fast and Slow*, that posits that our brains are comprised of two systems.15 “System 1” operates reflexively, intuitively, often automatically—like when we drive or make facial expressions. On the other hand, “System 2” requires deliberating, reasoning, computing, and analyzing data. Examples of System 2 thinking might include recalling memories of childhood, formulating a presentation, or analyzing a math problem. The two systems often conflict with each other, and each of them have limitations. System 1 relies on heuristics and may be susceptible to factual inaccuracy. System 2 can suffer from being overly analytical and slow. In reality, the ideal mode of thinking is likely a combination of both, recognizing situations in which mistakes are likely and avoiding serious mistakes in high-stakes situations.16

Recognizing that strong clinical ethicists can likely navigate System 1 and System 2 thinking with little trouble, we wanted to create a case studies environment that could foster the balancing of both systems. We believed that an unfolding approach could help cultivate critical thinking in a way that could balance both systems. Specifically, in most books and e-modules including case studies, the author presents the contours of a case, and then, at the end of the case presentation, encourages readers to “analyze the case,” giving the false impression that cases proceed in a linear fashion and that the facts are as they are written at the outset of a case. In reality, cases rarely occur neatly, discretely, or linearly, and new facts are introduced as the cases evolve. Thus, to be clinically accurate and representative of actual clinical-ethical dilemmas, we used pivots in each case to introduce new facts, and we ask readers questions involving our new factual pivots.

In using pivots in this way—presenting new fact pivots throughout the case and asking readers questions involving the pivots—we hoped to encourage readers to abandon at least part or some of their current mode of analyses and approaches, in which they have to shift to an entirely new frame of thinking to conduct subsequent steps in an ethics consultation. The pedagogical benefit of our unfolding case presentation is that the pivots deliberately press readers to think quickly, yet thoroughly—engaging System 1 and System 2 thinking. Readers are pushed to re-evaluate their positions and options, sometimes ultimately taking on a new position that was not ethnically feasible at the outset of a case. For example, in one case involving issues of confidentiality, the most ethically appropriate action for an HCEC would be to wait until an unconscious patient regains capacity and is able to communicate his preferences regarding disclosure of confidential information. However, this course of action becomes impractical because the patient’s family arrives. In this case, the HCEC is confronted with the issue of whether and how much to inform the patient’s family when the patient is unable to communicate his current wishes. The HCEC must think both quickly (engaging System 1) yet very deliberately (engaging System 2).

We also purposefully interrupt cases at high “points”—times in a case presentation when we anticipate that emotionality, greenness, or uncertainties may tempt HCECs or trainees to lose confidence or become hurried, emotionally vulnerable, or unsteady. In other words, we use the unfolding approach at times when we anticipate that an HCEC might be drawing too heavily on System 1 thinking to encourage HCEC readers to become more deliberative.

The pedagogical benefit of using interruptions at high points is to help elicit and foster HCECs’ interpersonal skills, including their overall confidence in their ethical assessments and in their presentations of their assessments. Thus, in one case, a patient’s family becomes very angry, if not hostile, towards the HCEC. A natural but inadvisable position would be for the HCEC to respond reflexively and defensively. In our questions, we ask how the HCEC should ideally respond and what strategies could be used to help de-escalate the situation. In our answers to these questions, we provide trade-offs (outlining challenges and benefits) of a variety of frequently employed mediation strategies.

**Questions Embedded Throughout the Text**

As part of our unfolding approach, we present questions at the beginning of each case, throughout the case, and at the end of each case. The questions are a combination of knowledge questions, reflective questions, and procedural questions.

Knowledge questions are usually based on rote memorization. The knowledge questions are specifically designed for students and/or novice HCECs. For example, knowledge questions might be: “What are the elements of decision-making capacity? What is the difference between *capacity* and *competency*?” Reflective questions, on the other hand, go beyond knowledge questions by encouraging critical thinking, such as: “Why is guardianship not an option in this case?” or “Are there any circumstances in which
chemical or physical restraints might be warranted to provide treatment for an incapacitated patient who refuses treatment?"

The difference between knowledge questions and reflective questions is that, for the latter type of question, readers are primed to think about specific facts of cases and evaluate how those facts fit within larger ethical and legal frameworks. Knowledge alone is insufficient for navigating complex cases. Reflective questions challenge readers to integrate knowledge and apply this knowledge to the circumstances at hand. Our goal in asking reflective questions is to encourage HCECs to become intimately familiar with areas for which there is ethical consensus (or lack of consensus), and to encourage HCECs to become self-aware of areas in which they may lack expertise. We think the reflective questions will be most useful to novice HCECs or seasoned HCECs who would like to reflect on their practices.

The final type of question we ask in the Study Guide are procedural questions. These are questions that focus on ethics consultative activities, or processes—how HCECs should “move” cases, that is, the persons they should talk to, for what purpose, how they should frame the conversation, questions to ask other stakeholders, et cetera. For example, in one of the cases, we ask, “HCECs should value the importance of building rapport with patients. What are two concrete strategies, questions, or statements that might help the HCEC build rapport?” In another case, we ask: “Which treatments being provided to Mr. Garcia are life-sustaining treatments? What specific questions should the HCEC ask the clinicians to help them articulate the risks, benefits, and burdens of these interventions and the alternatives to them?”

Our reason for asking procedural questions is to encourage even the most seasoned HCECs to reflect on their approaches, including particular steps they should take in each case, for what purposes they should take those steps, and the justifications or motivations behind each step. We contend that HCECs should be systematic and deliberate in their approaches to ensure consistency, fairness, and thoroughness, as well as to minimize the possibility of short-circuiting ethical analyses. We aim to continuously nurture self-reflection regarding HCECs’ consultative activities and the techniques they use during ethics consultations to advance their skills and expertise.

At the end of each case, we provide robust answers, including extensive explanations, for each question we ask. We arrived at the answers using a consensus approach among the writers and reviewers of the book. In our answers and explanations, we often provide a range of several different, ethically acceptable answers and provide justifications for ethically less supportable (and even unacceptable) courses of action. We very rarely identify only one course of action and state that it is the only ethically acceptable answer. However, we also acknowledge that our answers are not exhaustive, and it is also possible that reasonable minds may disagree on our evaluation of the ethical feasibility of various options. There may be well-justified answers and options beyond what we provide in the book.

THE INTENDED AUDIENCE

Our goal in developing the book was to encourage HCECs to build their competencies from basic skills used to address common ethical issues to advanced consultative skills that can be used to address complex ethical concerns. To that end, the primary audience for the Study Guide (and this article) is students, as well as new and seasoned HCECs.

Much of the Study Guide, however, is applicable to any healthcare professionals who emphasize interpersonal communication and ethical analyses skills in their profession, including most clinicians, chaplains, social workers, and others. For instance, we include tips related to communication and decision making in medicine, such as strategies for guiding fruitful patient interviews, elucidating patients’ or surrogates’ concerns or perspectives, and conducting family meetings. We provide guidelines and strategies for the “ideal” overall structure of a family meeting, including its content and flow, and we support these recommendations with empirical findings to anchor our suggestions. We offer model questions that clinicians could use to elicit patients’ values, goals, and preferences, and we provide examples of questions we would suggest that clinicians should try to avoid using in such efforts. For every tip and practical suggestion we provide (as well as our tips on phrases or actions to avoid), we include justifications from the empirical literature to help ground our statements and contextualize our positions.

HOW TO USE THE STUDY GUIDE

The Study Guide can be used in myriad teaching settings. For instance, the Study Guide may be particularly useful for nascent ethics committees or ethics committees when there is a low volume of ethics consultations in order to provide its mem-

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bers with experiential learning. We also contend that the Study Guide could be used in core clinical ethics curricula in order to provide an experiential, practical, clinically based approach that may be lacking in clinical ethics curricula.

The Study Guide could also be used in quality enhancement practices. For instance, we can envision using the Study Guide to see whether there is consistency or legitimate deviation in consultative practices between different consultants on one ethics service, or differences between consultants on various ethics consultation services. For example, an ethics consultation service could consider using one of the cases with all of the HCEC on the service, asking them some of the questions we provide in the book. If one HCEC consistently provides a response that is not covered in our responses (and yet continuously asserts that he or she is correct), we can say with some confidence that such an HCEC likely could benefit from additional training. Likewise, if all of the HCECs on the service select very different responses and rarely come out similarly in analyzing the cases, it can likely be argued that there might be too much inconsistency or variability between the HCECs in their approaches and procedural activities.

Several of us have found it helpful to use cases to evaluate prospective job candidates for HCEC positions in order to discern their critical-thinking skills and their approaches. For instance, one of us used part of a case with prospective job candidates, asking the candidates to listen to the case and then answer two questions we provided in the book. A couple of the candidates gave shortsighted answers, barely scratching the surface of the case and providing overly legalistic and dogmatic responses. One candidate who received very high marks on this portion of the interview provided a response that touched on several of the elements and options discussed in the “answers” section of the book, showing mental agility. Thus, by using cases with job candidates, we could learn more about their interpersonal skills and critical-thinking skills.

Finally, the Study Guide could play a role in the professionalization movement of clinical ethics. It is designed to evaluate a number of skills that are integral to conducting high-quality ethics consultation, including discursive agility and interpersonal skills. Therefore, the Study Guide, conceived as an accompaniment to the Education Guide, could serve as an essential resource for material that can be integrated as part of the HCEC certification written examination currently being developed by the ASBH HCEC Certification Commission.

LIMITATIONS AND FUTURE DIRECTIONS

We acknowledge that there are important topics and strategies unaddressed in our Study Guide that could be developed through future work. For instance, we focused on the inpatient consultations in the Study Guide, and we did not move beyond hospitals to include other healthcare settings. Future work could explore issues that are particularly salient in other contexts. Additionally, our primary focus on properly conducted ethics consultations and limited attention to common missteps that can occur during consultations may represent a missed opportunity. HCECs also learn from cases that do not go well, and future work could focus on developing case materials involving poorly conducted ethics consultations.

Future efforts could develop video simulations to accompany our Study Guide. For instance, we can envision a video simulation on any of our family meetings within the book, pausing and asking the reader to assess the family meeting thus far, or asking the reader how the HCEC should proceed. Another timely project might be the development of instruments or evaluation tools used to formally assess novice HCECs’ skills in conducting certain procedural elements of ethics consultations. For example, in our book we list several important procedural elements of family meetings, such as introductions, elicitation of values, and closures. Novice HCECs can be assessed on whether they helped to ensure that these elements occurred and were satisfactorily met during family meetings. We can envision a tool consisting of definitions, Likert-item scales, and evaluative criteria to help novice HCECs differentiate their skills.

CONCLUSIONS

In this article, we describe our rationale and development process for the case studies book, A Case-Based Study Guide for Addressing Patient-Centered Ethical Issues in Health Care. We contend that this book addresses gaps, concepts, and strategies that have, thus far, been underdeveloped in clinical ethics.

As for future plans, the CECA Committee will continue to be flexible and responsive to the needs and preferences of HCECs. One way to provide support is to develop educational materials that HCECs or prospective HCECs could use to prepare for the ASBH HCEC certification written examination. However, our plans may evolve or shift, depending on learners’ needs. This Study Guide represents only
one step (albeit a significant one) towards achieving ASBH’s goal to develop and disseminate education materials for HCECs and ethics committees.

NOTES


6. Core Competencies for Health Care Ethics Consultation (Glenview, Ill.: ASBH, 2006).


13. Core Competencies, see note 2 above.


The Development and Rationale for CECA’s Case-Based Study Guide

George J. Agich

ABSTRACT

This article discusses the approach of the Clinical Ethics Consultation Advisory Committee (CECA) in developing A Case-Based Study Guide for Addressing Patient-Centered Ethical Issues in Health Care. This article addresses the processes used by the CECA, its use of pivot questions intended to encourage critical reflection, and the target audience of this work. It first considers the salience of case studies in general education and their relevance for training ethics consultants. Second, it discusses the enfolding approach used in presenting the case material designed to engage the trainee in the details of the case while stimulating critical reflection. And, third, this article briefly comments on the target audience with the caveat that even superbly developed cases are prone to misuse, although that prospect should not deter their development.

Writing cases for use in any educational context is challenging. For the education of ethics consultants this is particularly so, because ethics consultation is such a complex and dynamic practice. It is quite easy and common to say that “x” should have been included in a case, where the sense of should reflects a unique interest or concern. The reality is that no single case can include every relevant concern. Judgments about the adequacy of a case are thus often dependent upon the complex ways that teachers and students utilize the material. Thus, it is worth noting that a wide array of nuanced cases for teaching ethics consultants is sorely needed, so A Case-Based Study Guide for Addressing Patient-Centered Ethical Issues in Health Care, produced by the Clinical Ethics Consultation Affairs Committee (CECA) of the American Society for Bioethics and Humanities (ASBH) is welcome for that reason alone. In any event, assessing the individual cases or the Study Guide is beyond the scope of this brief commentary, which will focus on an article written by the authors of the Study Guide, Courtenay R. Bruce, Jane Jankowski, Barbara L. Chanko, Anne Cordes, Barrie J. Huberman, Lisa-Marie Johnson, Deborah L. Kasman, Aviva Katz, Ellen M. Robinson, Katherine Wasson, and George E. Hardart, published in this issue of The Journal of Clinical Ethics.¹

This article by Bruce and colleagues provides a forthright account of the developmental process behind the creation of A Case-Based Study Guide for Addressing Patient-Centered Ethical Issues in Health Care.² This account will be helpful to users...
of the Study Guide not only to understand and appreciate the challenges that the CECA faced, but also the care with which they approached their task. In addition, the article is of interest as a contribution to the literature on the pedagogy of case-based teaching. In my commentary, I offer a reflection on these processes and comment on the approach taken. There are three aspects of this article by Bruce and colleagues that are worth considering. First, the processes that the CECA followed in developing the cases, second, the questions embedded in the text and, third, the intended audience.

**DEVELOPMENTAL PROCESSES**

The processes followed in developing the Study Guide are fully described in the article. It is especially noteworthy that the CECA started this project with a thorough investigation of the literature on case-based learning. Rather than undertaking the writing of cases with a blind enthusiasm, the CECA adopted a more critical and, indeed, responsible approach. This resulted in a nuanced understanding and statement of some of the main challenges associated with writing and using cases. Combined with the CECA’s appreciation of the complexity of clinical ethics consultation, there is much to laud about the approach taken.

The article by Bruce and colleagues includes a summary and a very competent characterization of some of the pitfalls associated with case-based teaching that are drawn from the criticisms of such teaching in higher education. The article is by no means a literature review. Anyone interested in such will need to look elsewhere, but the summary statement of this literature shows that the CECA approached their task with a serious intent. The five points that the article summarizes about the pitfalls of case-based learning, it should be stressed, were made primarily for classroom education, and they are certainly relevant in a general way, but Bruce and colleagues do not discuss to what extent the criticisms of case-based learning in higher education apply to the clinical settings that are unique to ethics consultation or to the skills that clinical ethics consultants need to develop. Nonetheless, they report that they took the criticisms to heart and regarded them as signposts, warning about dangers and weaknesses that needed to be accommodated in how they went about writing cases. The cases that were produced were developed with multiple points of input, including at least six rounds of revision, which shows that the CECA was sensitive to and willing to accommodate criticisms and suggestions.

**QUESTIONS EMBEDDED IN THE CASES**

Bruce and colleagues characterize the cases that comprise the Study Guide as exhibiting an approach they call “unfolding.” This characterization is not intuitively obvious from their description, since the key element in this approach seems to be the use of what they call “pivots,” that is, points at which a case narrative is interrupted and questions are posed to the reader. Whether another term would have been more intuitive to characterize the approach, however, is a minor point. The use of pivots to interrupt a case is framed theoretically in terms of a vision of cognitive performance that was articulated in the well-known work of Amos Tversky and David Kahneman, but was specifically summarized in Kahneman’s book Thinking, Fast and Slow.3 In brief, this view is that our cognitive processes are the result of two systems: “System 1” uses association and metaphor to produce a quick and dirty draft of reality that “System 2” draws on to arrive at explicit beliefs and reasoned choices.

The research begun by Tversky and Kahneman, which led to what has been called behavioral economics, is focused on choice. A hallmark set of findings is how bias ineluctably creeps into our judgments. This occurs because our deliberative system is lazy, and we suffer from what has been called “ego depletion,” which results in biased and erroneous judgments about a range of phenomena that have been studied by cognitive scientists. These processes seem to be the nature of human cognition and cognitive judgment. So, it is surprising to hear that the CECA took the position that their strategy of “unfolding” could remedy or, perhaps more modestly, directly address this weakness. As I understand the thrust of the research, the tendency to error is hardwired and not something that can be readily corrected. Nevertheless, Bruce and colleagues say, “We believed that an unfolding approach could help cultivate critical thinking in a way that could balance both systems.” That is a lot to expect from a set of case studies, no matter how well wrought.

This criticism aside, the unfolding approach does seem to bring a useful heuristic approach to case-based education. Even one skeptical of the broader claim that the use of these cases can truly help to develop critical reflective capacity, especially mature consultative capacities that are essential for competent ethics consultants, can appreciate that these cases are intended to be a far more nuanced exercise for learning about ethics consultation than are currently available.
The unfolding approach is also touted not only to develop critical reflective skills, but also interpersonal skills. In their article about the development of the Study Guide, Bruce and colleagues write, “The pedagogical benefit of using interruptions at high points is to help elicit and foster HCECs’ interpersonal skills, including their overall confidence in their ethical assessments and in their presentations of their assessments.” It is even harder to understand why the authors think that this is will occur than it is with respect to critical reflective skills. Surely, anyone familiar with the distinction between knowing that and knowing how will see that recognizing and cognitively pointing to an appropriate response or way of communicating is hardly the same as acquiring the ability to respond or to communicate appropriately and effectively in actual emotionally stressful situations. That said, there can be no doubt that it can be useful in a general way for ethics consultants to recognize the need and the type of actions or behaviors that are most appropriate, although to think that working through paper cases can enable one to acquire the capacities and the propensities to exhibit the communicative skills in emotionally charged circumstances is a very large claim. Recognition of the importance and discussion of strategies for communicating in difficult situations certainly might motivate one to undertake to develop the interpersonal communication skills needed in similar clinical situations, but it would be a mistake to think that paper cases can do the job. Even though the authors do not explicitly claim this, a caveat is in order because there is a real danger that many ethics committees might be prone to adopt quick fixes and utilize the Study Guide as a relatively easy way to claim competence without achieving it in practice.

The unfolding approach relies on key “pivot” points around which the heuristic of the cases revolves. Three types of questions are raised at the pivot points: knowledge, reflective, and procedural questions. The meaning of these questions is straightforward, and each is obviously important in the education of ethics consultants. Procedural questions get the most attention in the article, and it is easy to concur with the authors that these questions encourage ethics consultants to reflect on their approaches and the specific steps they should take in each case. Nurturing such self-reflection by ethics consultants about the activities and techniques used in the process of doing an ethics consultation is an important factor in advancing skills and competence. I have little doubt that well-constructed cases can provide useful illustrations of common challenges that clinical ethics consultants face, and that they can be effectively used to learn about and to gain some degree of sophistication in doing ethics consultation. This does not mean that utilizing these cases will, by itself, nurture the skills necessary.

It is well recognized that experience in performing ethics consultations over time is essential for growth in competence. Yet, experience simpliciter is not the answer. Repetitively doing ethics consultations badly, or not as well as one might, can simply reinforce biases. That is why the supervision of consultative work and critical review and analysis of actual ethics consultation cases by one’s peers is essential. Hopefully, the case-based Study Guide might motivate and model these enlarged efforts.

INTENDED AUDIENCE

It is natural that the CECA envisions a wide audience for the Study Guide, namely students as well as new and seasoned HCECs. Surely, in the hands of able instructors, good cases can be effectively used in the education of a broad audience. The worry is that any segment of this broad audience might tend to see these cases as providing a sufficient grounding in ethics consultation or as the primary or only tool for quality improvement in existing consultation services. That is not a weakness in the conception of the Study Guide for the construction of the cases, but a concern that other important and useful pedagogies should not be marginalized.

CONCLUSION

Ethics consultation is a practice that is complex and multifaceted. I have argued that ethics consultation should be regarded as a reflective practice, and certainly that concept welcomes well-structured and well-constructed clinical cases for teaching ethics consultation and for developing skills and essential reflective capacities. As a reflective practice, however, it is important that individual consultants and consultative services develop an openness to critical reflection about cases. Doing so using cases that are specifically designed for educational purposes has the advantage of creating an emotional distance from the case details; from the actual healthcare workers, family members, or patients involved; and, more importantly, from the personal attitudes, beliefs, and emotional mechanisms that consultants inevitably bring into the performance of ethics consultations. That is an advantage that paper cases have over the review of actual cases. Although nuanced, constructed cases cannot replace critical review of
actual cases, they can motivate and model how one might openly confront with colleagues the cognitive judgments, communicative actions, and emotional reactions deployed in providing ethics consultations.

NOTES


Can Islamic Jurisprudence Justify Procurement of Transplantable Vital Organs in Brain Death?

To the Editor:

Aramesh, Arima, Gardiner, and Shah reported on diverse international legislative approaches for justifying procurement of transplantable vital organs in brain death. They stated, “In Islamic traditions in particular, the notion of unstable life is a way to justify organ donation from brain-dead patients that we believe has not been fully described previously in the literature.” This commentary queries the extent to which this concept is valid in accordance with the primary source of Islamic law, that is, the Quran.

Firstly, contrary to the claim of Aramesh and colleagues, the Quran has established the biological criteria of death 14 centuries ago. The required tests for death determination in the Islamic tradition should fulfill these criteria (see table 1). The experts or physicians are required to apply a medical standard that establishes the fulfillment of the death criteria with absolute certainty (yaqin). A case in point, Aramesh and colleagues pointed out that the Islamic Organization of Medical Sciences, consisting of medical scientists and scholars, concluded that the medical standard based on brainstem criteria equated with unstable life and not legal death within the Islamic law.

Secondly, the secondary sources of Islamic law such as ijma (consensus of Islamic scholars), aghl (reason) in Shi`ite, or qiyas (analogical deductions) in Sunni are not intended to override or clash with the two primary sources (that is, the Quran and the Sunnah). The majority of practicing Muslims would consider fatwas (legal opinions) or governmental legislations invalid if these fatwas are likely to clash with the Quran and the Sunnah. Therefore, it is arguable that legislations permitting the procurement of transplantable vital organs based on death determination with neurological instead of biological criteria should not be enforceable in Muslim communities. Aramesh and colleagues did not mention that the Islamic Fiqh Council of Islamic World League (in Makkah, Saudi Arabia) issued a resolution in 1987 stating that “a person is not declared legally dead unless heart and breathing fully stop working.” This resolution voided the earlier resolution of the Third International Conference of Islamic Jurists (in Amman/Jordan) that equated brain death with legal death in Islam. Therefore, it is surprising that Islamic organizations in the United States and United Kingdom issued contradicting fatwas that equated brain death with human death after the 1987 resolution. These fatwas clashed with the requirement of death determination by biological criteria in accordance with the primary Islamic sources.

Thirdly, conflating the dying with the truly dead is not permissible in the Quran. Aramesh and colleagues postulated that brain death, from a Shiite perspective, can be considered an unstable intermediate state between life and death. They elaborated on the justification of procurement of vital organs in brain death by drawing the analogy with stable and unstable states of life described in hunted or decapitated animals. Islamic jurists advanced this

<table>
<thead>
<tr>
<th>TABLE 1. Description of the phenomenon of death in the Quran</th>
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<tbody>
<tr>
<td>The characteristics of the phenomenon of death</td>
</tr>
<tr>
<td>• God created the phenomenon of death</td>
</tr>
<tr>
<td>• The phenomenon of death is universal and singular</td>
</tr>
<tr>
<td>• The definition of death is uniform and constant across generations and geography</td>
</tr>
<tr>
<td>• The determination of death requires absolute certainty(yaqin)</td>
</tr>
<tr>
<td>• The process of dying must be distinguished from the state of death</td>
</tr>
<tr>
<td>The criteria in the determination of death</td>
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<tr>
<td>• The soul (ruh) has separated irreversibly from the body</td>
</tr>
<tr>
<td>• The ruh is present in the body as long as the brain and the heart retain capacity for recovery of function</td>
</tr>
<tr>
<td>• The ruh has departed when ceased vital functions can no longer be reversed regardless of any external intervention (absolute irreversibility)</td>
</tr>
<tr>
<td>• The biological criterion (disintegration) confirms death</td>
</tr>
</tbody>
</table>

two-state of life as an argument for justifying the permissibility of consuming these animals legally without violating the Quranic rules. This proposal would permit the consumption of hunted or decapitated animals, if a human life is threatened by harm or death from starvation. Extrapolating the analogy of unstable states of life in animals to legitimize the procurement of transplantable vital organs from brain-dead patients is problematic. The argument for stable and unstable states of life is restricted to animals in the Quran. Elsewhere, the equivalence of brain death to physiological decapitation has been refuted. Therefore, brain-dead patients are not equivalent to decapitated animals. Assigning an unstable state of life to brain-dead patients would also imply that they are not truly dead. Indeed, some brain-dead patients may be considered in a stable state of life based on the proposed criteria of an unstable state of life: (1) imminent cessation of cardiac and respiratory functions, and/or (2) irreversible cessation of capacity for consciousness. Brain-dead patients continue to retain autonomous capacity for integration of biological functions and homeostasis and are unlikely to sustain imminent cessation of spontaneous cardiac activity. There are no scientifically validated and reliable tests that can directly ascertain the irreversible absence of capacity for consciousness in these patients. If brain-dead patients are not truly dead, then the procurement of vital organs would be the proximate causation of death. In these circumstances, applying the principle of public good (maslaha) to justify the procurement of transplantable vital organs from these patients would clash with the Quranic absolute prohibition of assisted suicide and euthanasia. The Quran prioritizes the prevention of harm over the promotion of good.

In conclusion, the equation of brain death with legal death or an unstable state of life for the procurement of vital organs would still clash with the Quran and Islamic law.

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8. Ibid.


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ISSN 1046-7890

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