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At the Bedside

Beyond Shared Decision Making

Edmund G. Howe

ABSTRACT

Shared decision making (SDM) is the state of the art for clinicians' communication with patients and surrogate decision makers. SDM involves give and take, in which all parties interact to maximize the autonomy of patients. In this article I summarize the core steps of SDM and explore ways to use it to benefit patients to the greatest extent. I review three articles included in this issue of *The Journal of Clinical Ethics* that highlight additional approaches we can use to help patients and parents to see what may be in their own or their child's best interest. I describe how these approaches can be used in most other medical fields. I explore ways to share information with patients that are outside the usual scope of SDM. Finally, I discuss how we might look, together with patients, at what all parties are feeling before we begin the process of SDM.

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Three of the articles included in this issue of *The Journal of Clinical Ethics (JCE)* consider how we may help parents make the best choices for their children and help patients to make the best choices for themselves. Ruth Tallman, in "Helping Children Hurt Themselves: Why Pediatricians Ought to Support Adolescent Football Players in Their Athletic Goals," discusses how pediatricians can help adolescents appreciate that they risk brain damage when they play tackle football.¹ Lainie Friedman Ross, in her article, "The Pediatrician's Moral Obligation to Counsel Directly Against Youth Playing Tackle Football," responds to Tallman and takes a different tack.² Ross, a pediatrician, recommends discussing this risk with parents even when their child is too young to play football. Ross includes additional concerns that pediatricians should discuss with parents, including the use of helmets for bike rides and "body image issues" for "young dancers." A third article in this issue of *JCE*, "Psychiatric Advance Directives as an Ethical Communication Tool: An Analysis of Definitions," by Billy Table, Jaime Thomas, and Virginia A. Brown, outlines how we can best try to persuade patients to do what is in their own best interest.³ These authors researched how clinicians, social workers, chaplains, attorneys, and other counselors may best

benefit patients with such serious psychiatric illness that they may later need to be hospitalized. The authors seek to increase patients' use of psychiatric advance directives (hereafter, PADs). They assert that, should a patient who has a PAD need to be hospitalized, the patient's transition will be more seamless—to the greatest degree possible.

The insights that these authors offer regarding communication with patients with serious psychiatric illness apply to our communication with all patients. This is because *what* we say, and *how* we say it, may be more important to patients' outcomes than any other factor. Whether patients choose to do what we advise may depend largely—or in some cases wholly—on whether we have earned their trust.

In the present introduction to this issue of *JCE* I will discuss these issues further, in three sections. In the first section, I will discuss these three articles and I will focus particularly on how the insights they provide apply in other medical contexts. In the second section, I will review key aspects of shared decision making (hereafter, SDM), since it is the core on which the authors' and my subsequent comments are based.⁴ After my review of SDM, I will consider how we should go beyond it, thus the title of this article, "Beyond Shared Decision Making." In the third section I will explore two ways that we may go further than the SDM model.

PERSUADING PARENTS AND PATIENTS

In their articles in this issue of *JCE*, Tallman and Ross share their concerns that adolescents may suffer concussions when they play football and other hard contact sports. Concussions may cause permanent brain injury, and, as Ross points out, long-term harm may result from multiple small contact injuries. Linemen, Ross points out, may particularly be at risk. Tallman stops short of raising this concern too robustly because she fears it may cause adolescents to lose trust in their pediatrician. Ross is willing to take the risk. As we shall see, her sheer conviction may persuade some parents when pediatricians who convey less passion may not.

In their article in this issue of *JCE*, Table, Thomas, and Brown seek ways to move patients with serious psychiatric illness to write a PAD. They performed an extensive review of the literature and report their findings. I will discuss two of their findings that are particularly valu-

able in any field, and involve issues that may take place without our realizing it. These are the words we use when we talk with patients and how some patients' conditions affect us in ways outside our awareness. These factors may affect how we are able to help patients.

Tallman: Maintaining Trust

Medical students are taught to look to patients' future needs in addition to their immediate needs. Clinicians seek to do this as well. At present, there are comprehensive ways to screen for outside stresses on patients.⁵ Minimally effective medical practices attend to external factors that affect patients, such as whether they have enough to eat and what they eat. Additional external factors could include whether patients can afford the transportation they need to access care, and whether they can afford a baby-sitter while they receive the treatments they need with the frequency required. We are not expected to resolve these concerns, but we are expected to refer our patients to others who can. Our practice of medicine occurs within a social environment.

Tallman's approach to adolescents who play football speaks to this long-term view. She looks beyond immediate results and seeks to retain a maximal ground on which we may later prevail. She says, "Give them facts, show them pictures, and tell them stories." Yet, she says, if pediatricians go too far, patients will "simply find another doctor . . . without a lecture" that won't make them feel badly. This "shared decision making," she says, "is essential in interactions with adolescent patient-athletes."

In writing this, Tallman models how to start from the empirical reality of where patients are "at" and, in so doing, to prioritize retaining their trust. Patients may change their mind if given sufficient time and space, consistent with the tenets that underlie motivational interviewing.⁶ Tallman recognizes that, above all else, it is important to retain patients' trust.⁷ Patients' trust is critically important because they must be willing to hear what we recommend if they are to maximally benefit from it.

Ross: Look for and Prevent Discriminatory Effects

Ross presents an unbounded commitment to patients and their parents. She exception-

ally models several strengths we should seek to emulate. The first is her willingness to go beyond the guidelines of her pediatric specialty organization. Her position contradicts that of the American Academy of Pediatrics, and it takes some courage to say what she does. Second, Ross models how to anticipate possible harms and how to act early on to try to prevent them. She recommends that discussions with parents take place when children are younger, as a preventive intervention that screens for harmful external factors. In the same vein, Ross notes that if children play flag football when they are very young, even though it involves no tackling, they may acquire a love for football and want to continue playing it later, when it involves tackling. In the same way, parents may come to love football. This may be particularly important due to the social pressures and influences on children and parents for children to play sports, especially sports like football, with higher social and media status. The panoply of products that feature athletes illustrates this. Children's social identity may be created (or diminished) by the sports they play.

The need for prevention applies widely in medicine. It exists also in ethics consultation. That is, once an ethics consultation has resolved the issues it was called to address, ethics consultants and members of ethics committees should consider how they might prevent whatever occurred from recurring in the future. I recall the time a new attending came onto an internal medicine ward and canceled a plan that had been made, well in advance, for a patient to go off a respirator, with the understanding that the patient would then die. The new attending canceled the plan because he was new to the ward and did not know enough to assess whether, ethically, the planned withdrawal was a procedure that he should approve. The cancellation caused the patient and his loved ones hard-to-imagine grief. A preventive solution that the ethics committee could have considered is that, when an attending will be coming to a ward, the attending is alerted well in advance to pending actions the committee has approved.

Ross also looks to the groups that might be most damaged from playing football. She finds the risk unequal: there is evidence that African-Americans suffer concussions disproportionately.⁸ Perhaps if Ross informed members of this group, it might increase their incentive

to stop playing. Finally, and admirably, Ross recognizes and respects why children and their parents may not want to stop the child from playing and put the child at risk. Ross does her best, using SDM to help parents—and her patients—to make informed decisions.

Table, Thomas, and Brown: Words and Countertransference

Table, Thomas, and Brown seek to reduce the trauma that patients with serious psychiatric illness may undergo when they are hospitalized. For many patients, such trauma is unforgettable and may darken their lives ever after. For example, a middle-aged woman was delusional, and, without any treatment, was getting worse. Her adult daughter cared for her a great deal and was deeply pained to see her in this condition. The daughter sought to have her mother committed involuntarily. Late one afternoon I obtained the court order the daughter sought, and I arrived in the early evening at the mother's front door with two psychiatric attendants, both in white medical white lab coats. The woman had been in her bathroom and was in her bathrobe when she opened the door. Her surprise and dismay were obvious. That we interrupted her when she was in the bathroom indicates the intrusiveness of our arrival, out of the blue, to carry her out of her home and to the hospital. My feelings of guilt about this, warranted or not, cause me to wince as I recall it.

Table, Thomas, and Brown seek to guide us in the process of helping a patient to write a PAD, even advising us regarding the words we use. They suggest saying, for example, "So, you said that as a *patient*, you want your voice to be heard. Could you say more about that?" The authors then offer additional practical and insightful suggestions. The two examples I would like to briefly amplify here are their attention to the words we use and some sources of countertransference feelings that may tend to remain hidden for most of us.

The Words We Use

Table, Thomas, and Brown tell us that, when we want to explain something to a patient, it is more clear to use a metaphor rather than a simile. Some of us, like me, may have forgotten the meanings of these words—if we ever knew them. Metaphors and similes both compare two different things. A simile uses the

word “like” or “as,” and a metaphor does not use either. For example, we might use a simile to explain the function of a PAD in this way: “A PAD is *like* an advance directive at the end of life.” Or we could use a metaphor: “A PAD *is* a tool that helps your careproviders know what you want should you become ill.” The words that are used make a difference. Researchers report that using “is” rather than “like” is more clear. Researchers also report that it is preferable for careproviders to not compare PADs with advanced directives (ADs), because ADs may be negatively associated with the end of life.

All of us should be aware that it is possible that these kinds of connotations—how we frame what we say, with the words that we use, and the tone that we employ—may, in many clinical and other contexts, take precedence over or even erase the content of what we actually say to patients. Every word we use may have a connotative effect, relative at least to other words we could use. An example is the use of the word “suffocation” rather than the phrase “air hunger.” Clearly suffocation is more frightening. We could use either when we speak to a patient or family about what the patient might experience in the future, should the patient need a sedative and analgesics, but not receive them. In this instance, conceivably, the words we use could, due to their connotative effect, move the patient or family to decide, or not, to continue life-prolonging treatment.

It might seem that we do not have the time to anticipate the possible connotations of every word we use. Surely this is true. We might, however, keep in mind that the words we use and how we speak may affect whether or not patients can understand and “hear” what we say.

Countertransference

A second point that Table, Thomas, and Brown make that may be new to many of us is that we may respond differently to patients who have different conditions, to a greater extent than we know. The example the authors use is how we may respond differently to patients with autism spectrum disorder than we do to patients who are blind. We may have implicit biases regarding certain illnesses.

The particular examples of illnesses and the point that we may treat patients differently, based on their illness, resonated with me. I recall seeing a patient with far-advanced autism,

who was aged. He said mostly the same things again and again. I wondered whether my seeing him was the best use of my time, because I felt that I had little to offer. It seemed all that I was able to offer him was that I was able to listen. Although I (and others) shared with this patient how we were frustrated at his repetition, he continued to do it, as though his uninterrupted speech was driven and beyond his control. Perhaps it was. I began to consider whether I should stop seeing this patient, so that I could devote more time to seeing other patients who were likely to benefit more, but then he said that his sessions with me were the most meaningful times in his life. So we continued our sessions as we had been.

In contrast, I worked with a patient who was blind. He was an adolescent. He became blind as a child, when he had a brain tumor removed. As a result of the surgery he lacked an increase in testosterone, and he had missed the need to adjust to a hormonal surge in his early adolescence. We were thus tasked with having to make this adjustment as best we could, but in months rather than years. For us both this course of treatment was thrilling, as we could laugh together about what he was newly experiencing due to the testosterone.

The contrast in my feelings about my two patients highlights a point that Table, Thomas, and Brown make when they posit that how we describe our patients may express how we view them. We might examine how we describe our patients, especially if we find them to be “difficult” or inscrutable. This may allow us to see patients, and ourselves, in deeper, truer ways.

Table, Thomas, and Brown relate that we may unwittingly use what they call “person-first” language (for example, “a patient with autism”), in which the person is placed in front of the impairment, rather than use what they call “identity-first” language (for example, “a blind person”), in which the impairment is placed first. They suggest our language may show unintentional discrimination, and, even when it is unintentional, it may further the stigma that surrounds an illness. Should we always use person-first language, for example, “the patient with diabetes” rather than “the diabetic patient”? It may help us to avoid unconsciously distancing ourselves from our patients.

It is important to recognize possible differences in how we view our patients, and it is as important to know what we can do about it.

Music therapists Maya Marom, Avi Gilboa, and Ehud Bodner work with children with autism who, like my aged patient with autism spectrum disorder (ASD) repeated or, as the authors say, “echoed” the same words over and over again. They write about the countertransference feelings they experienced and what they found often offered them a remedy. What these authors mean by “countertransference feelings,” in this case, are their emotional responses to the patients’ “echoing.” The literature suggests, the authors say, “that the unique interpersonal condition created in therapy with clients with ASD may elicit powerful countertransference in therapists. Clinicians who attempt to contain the client’s autistic states may experience a slew of reactions—both emotional (e.g. boredom, sadness, or hostility), and behavioral (e.g. restlessness and hyper-activity).”⁹

A common countertransference reaction, they write, includes “a sense of being mentally paralyzed from thinking creatively.”¹⁰ This was, I believe, what I experienced with my aged patient that led me to think I might have more to offer as a therapist to other patients in the same amount of time, since I could be more creative with them.¹¹ Marom, Gilboa, and Bodner write that they learned to help resolve this sense of being mentally paralyzed in a way that can help patients the most. They state, “Studying communication hurdles such as echolalia from the perspective of the therapist is significant for all therapists who work with clients with ASD. . . . These are not always easy to admit to, and therefore may be left unaddressed. Rarely have they been studied methodically. . . .”¹²

Marom, Gilboa, and Bodner continue, “A sure signal of countertransference is when the therapist . . . will be highly directive, authoritative, and expert-like and not defer to the client’s wishes, often under the guise that the client is too defensive, wounded, or confused to make such decisions. . . .”¹³ They suggest, “Audio-recording the sessions can be very valuable. While listening to the session, try to pay attention to the quality of your own voice: what characterized the contour of your voice when you spoke? How loud did you speak to this client? How fast? Was it much louder/softer, or faster/slower than your client’s speech?”¹⁴

These music therapists work with patients who are emotionally sensitive in the extreme. We should try to do the same with our patients: listen to what we say and how we say it.

SHARED DECISION MAKING

Clinicians’ failures in communication with patients are well documented. In the past clinicians were highly paternalistic, but it was determined that patients did not need to be protected from making their own decisions, or did not need to be protected as much as had been assumed. In response, clinicians were directed to remain neutral above all else, and provide only information to patients, and leave it up to them, for the most part, to determine what to do with the information they received.

Some continue to view this approach as optimal, but it may risk leaving patients feeling emotionally abandoned. For example, patients often ask clinicians what clinicians would do in a given situation. Clinicians who hold a give-information-only-view may respond, “I won’t tell you. I can’t because I am not you,” in as many words. In response, patients may feel they have been abandoned, and may feel shame for having asked. They may feel as though their clinicians are saying that they should have known better than to ask.

Patients may feel anxious about what to do when they lack the gains and/or reassurance they might have received from an answer from their clinicians. Patients may want, most reasonably, to hear how their clinicians would integrate their medical knowledge—typically far greater than the patients’—and their careproviders’ clinical experience in answering this question. Those who are concerned that we might influence patients too much by answering their questions may reduce this risk by asking patients whether they want to consider the pros and cons of our saying what we would do, before we decide whether we should answer.

The main con is that if patients decide to do what we say we would do, and it turns out badly, they may regret that they did not make the decision on their own.

In any case, SDM is now the optimal model. But is it possible to go too far to avoid paternalism, to the point that some patients may be deprived of the benefit of clinicians’ knowledge? Should we take the initiative to offer patients our insights, when there may be an important aspect of their decision that they may have missed? I will discuss this in the rest of this section and in the next section. I will share what I see as the core tenets of SDM that are now considered to be the state of the art, and dis-

cuss whether we should alter what we currently do, and whether we should go even further still.

Step One: Ask Patients Whether They Want to Discuss Their Decision

A first step is to ask patients whether they want to discuss their options with us. For example, we can ask, “Is it okay if we talk about your options together?” In my view, this is an ideal way to start interactions. Asking this implicitly recognizes that some patients may not want to discuss their options. Asking them makes it easier for them to answer, “No thanks.” A difficulty many patients may have in saying “No” is hard to overestimate. But it’s no wonder: patients may fear that if they offend us, it could influence decisions we make, and our decisions could affect their life or death.

A very small number of patients may decline our invitation. This may present an ethical dilemma: Should we alter and adapt what we say and do to meet the needs of this (presumably) very small group? What if it turns out that there is only one patient who declines? Are patients who want us to decide with them likely to be better off than those who don’t? Are the patients who don’t want us to decide with them less well-off and more vulnerable? These last two questions may help us to answer whether we should gear our initial intervention to patients who don’t want our assistance, by asking, “Is it okay if we talk about your options together?” rather than saying something like, “Let’s discuss your options together.”

Step Two: Share Options

A second possible step is to tell patients what we see as their “medically reasonable” options. For example, we can ask, “Would you like me to share with you what I see as your *most reasonable* medical options?” Note that I have phrased this as “*most reasonable* medical options.” Usually, we might tell patients about “*reasonable* medical options.” I believe that adding “*most*” conveys that what we believe are a patient’s medically reasonable options may not be the last word on the subject. There may be other options that a patient may want that may be possible; for example, an option may become possible due to the patient’s special appeal. Thus, we should be open to going beyond what is customarily viewed as

medically reasonable to serve as a patient’s advocate. I mentioned an example of this in my introductory article in the fall 2020 issue of *JCE*.¹⁵ A children’s hospital allowed one parent to stay with the child if the child had COVID-19. Learning about this possibility, other parents might make a similar appeal at their child’s hospital. Another example is that some intensive care units allow small pets to visit in response to patients’ special requests.

Step Three: Assess Patients’ Responses

A next step is to ask a patient, “What is most important to you in what I have just said?” and “Did the options I just listed include what you would want, or are there other options you would want in addition?” Asking the second question will make it clear we anticipate that a patient may want options beyond those we have listed. On hearing this, a patient may be more willing to make an additional request.

Following on the discussion regarding the use of the phrase “medically reasonable,” another risk is that it may unduly bias us to subscribing to and deferring to professional guidelines, rather than going beyond professional guidelines when doing so would benefit the patient. As Ross models for us in her article on childhood sports, professional guidelines sometimes may, for various reasons, fall short. Chief among them is that guidelines may be the result of compromise by those who wrote them.¹⁶ They also may be affected by social pressures.

Step Four: Check Whether We Understand

The next intervention is to check whether we accurately understand what a patient has said. We can ask, “It sounds like you are saying [repeat what the patient has said]. Do I have this right?” This is the one part of executing SDM that is ideal, as-is, and is not controversial. Checking on what a patient has said is so universally and unequivocally important that we should consider doing this also and/or more often in every aspect of our daily practice.¹⁷ One risk that still exists is that, after we learn how to do this, we may come to utter these words automatically. Should this happen, it may seem to patients that we don’t really care, and that we check merely because it is what we believe we should do or have been taught to do. The risk that these words become automatic indi-

cates, more generally, the ever-present risk that when we use SDM we will not be sufficiently invested in it. It is easy to use the questions I have recommended, but what matters is the extent to which we are invested in SDM and how effectively we convey that we are invested.

Should we have doubts about how invested we are in SDM and how effectively we convey we are invested in it, and to offset the risk of appearing insincere, we can ask patients to elaborate more fully and deeply about what they have said. For example, we can ask, "You said that you are worried about who will care for your cat after you die. . . . I imagine that you have said this because your cat is as dear to you as a child. Is that right?" This questioning could seem rote, but going this extra mile may go far to offset this impression and risk.

Step Five: Plan for the Next Step

Usually, the last step in SDM is to explore with patients where they will go next. For example, we might ask, "Shall we consider now what we should do as our next step?" Note that asking this question in this way presupposes that there is a next step that patients should consider. It may be, however, that patients do not feel ready to decide anything at that point. We should say this, as well: "It may be that at this time you don't want to decide about this."

Patients may need time because the questions are so important and they may be asking them for the first time. They may need to take a breath and to see what they come to feel. That this may take time is a tenet of motivational interviewing. It presupposes that there are several stages that patients will go through before they can decide what they want to do, or are willing to do. This state-of-the-art approach is now recommended and carried out in most medical contexts, but the clearest example of how this may be done involves patients with problems that involve the use of addictive substances. We shouldn't ask initially, "Are you willing to quit?" We should ask something more like, "Would you be willing to consider with me some of the gains you get from drinking, and some of what you might gain if you didn't?"

BEYOND SDM

There are two ways that we may be able to help patients to a greater extent by going be-

yond what is usually thought of as a part of SDM. The first is for us to question or challenge what patients decide. The second is to share and discuss what they and we are feeling before we discuss the options and decide what to do. In this last section I will discuss both.

Whether to Question or Challenge What Patients Decide

In many cases patients and parents do not choose what is best because they overlook a consideration that is very important to them, either due to their illness or the turmoil that surrounds it. It is possible they may choose an option that isn't what they really want the most. If this is pointed out to them, they may be most grateful, and change their decision.

This may happen for several reasons. Chief among these is that our emotions, especially when they are strong, may hijack our reasoning. We may do what we believe we want and then rationalize by "cherry picking" among many competing rational thoughts, so that our logic supports what we feel we want at that time. Such decisions may be greatly biased, without our knowing that this is the case. Ethically, what should we do when we suspect that this may be the case for patients?

Jodi Halpern, in her book *From Detached Concern to Empathy*, puts forth the case that we should share with patients what they don't seem to see, and our rationale for doing so, when it may help them.¹⁸ Halpern posits, for example, that patients may be in a reactive rather than a proactive state. Their normal capacity to see their choices, as she puts it, may be "ripped out." *Ripped out*. These two words, and the title of her book, say all that needs to be said. If we care about our patients, we may have to do whatever we can to move them closer to being able to truly choose what they really want. It may be that they don't know with certainty what they most want, and we don't want to imply to them that they need to convince us that they are choosing what they most want. They may feel exhausted and overwhelmed by trying to figure this out.

There are numerous illustrative examples. One that Halpern poses involves an older man who had terminal cancer. He lived with his children and grandchildren, whom he loved. He learned of a new experimental treatment for his cancer, but to participate in the research he

would need to live far away from his home for three months. In his desire to continue to live, he chose to participate in the research, although the likelihood of the remission of his cancer was remote. Halpern believes that this is the kind of case where we might most help patients by asking, "Is this what you really most want?"¹⁹ If we do this, a threshold question is how far we should go. Asking this question is probably as far as we should go when we are unprompted.

An example of this question, at its extreme, is whether we should go so far as to challenge a patient's religious beliefs. Charles W. Sauer and Krishelle L. Marc-Aurele consider this question in the case of Jehovah's Witness parents who gave birth to a 23-week-old, very premature infant.²⁰ The parents wanted full life support for the baby, but not blood transfusions. The clinical team obtained a court order to transfuse the child, but he later died. The authors ask whether transfusing the infant immediately at birth might have changed the outcome.²¹

The clinical team could have challenged the parents immediately. If the team knew about it, they could have shared with the parents that there is, within the Jehovah's Witness Society, a subgroup whose views would have permitted the parents to give their baby blood after his birth. As Anna Hoffman notes, "Importantly, not all Jehovah's Witnesses subscribe to the blood transfusion taboo."²² Members of this subgroup interpret biblical passages related to the consumption of blood as condemning the literal act of *eating* blood, as opposed to this being an act that includes transfusion.²³

When we challenge a patient's religious views, to an extent we challenge the patient's culture and identity. It might be most caring to share with patients something they might not know. If the parents of this infant did consent to their child's initially receiving blood, it might have impaired their capacity to continue to bond as intimately with the Jehovah's Witness community. The subgroup of the Jehovah's Witness Society mentioned above, the Associated Jehovah's Witnesses for Reform on Blood, advocates for the right of Jehovah's Witnesses to make informed decisions about their medical care without the threat of discipline from their faith community.²⁴

Should we ever go so far as to question a patient's or parent's religious or cultural beliefs? And, if we determine that we should, how should we do this? It may be that if we go this

far, or believe that we should, we might use some of the same approaches to SDM that I outlined earlier. Using this case as an example of how we might proceed, we might tell the parents initially that there might be another choice they could make that would be within the Jehovah's Witness religion and culture, that might allow them to increase the chance of their child's survival. We could ask the parents if they would want us to share this information with them. Or we could ask them first if they would like to discuss the pros and cons of receiving this information from us.

Share and Discuss Feelings with Patients First

As I said earlier, a second way we may help patients to a greater extent, by going beyond what is usually thought of as SDM, is to share and discuss what they and we are feeling before we discuss the options and decide together what to do. Sometimes our feelings about what we are experiencing are overwhelming. I recall, for example, the reactions of a new mother and the medical staff when her baby was born with ichthyosis, a rare condition in which the child's skin is fishlike. No one present had ever seen this before. All were in shock.

I will now propose ways we can proceed when we should share and discuss strong feelings with our patients before we discuss options and make decisions together about what to do.

When a Patient Experiences Emotional Pain

An example of a patient's emotional pain is when a woman chooses to have a late-term abortion. Chavi Eve Karkowsky is an obstetrician specializing in maternal-fetal medicine who went to work in Israel. The legal requirements for abortion there are different than for most other countries. Women there can have a late-term abortion under many conditions.²⁵

Karkowsky reports her own responses. She says that she was "standing in a dark room in a hospital not far from Tel Aviv, performing an ultrasound on the taut belly of a woman well into her third trimester. She was 35 weeks pregnant, due in about a month." Karkowsky measured the fetus's head, and the numbers she saw on the ultrasound suggested that the head was "too small." She was overcome with a strong urge not to tell the woman what she'd observed. She felt "fearful of where this discussion might

lead,” namely, to a late abortion, but legally, she was “required to.” She writes that “conducting this conversation requires as much surgical skill as operating on a pregnant uterus.”

The experience of women in the United States, Karkowsky reports, can be much worse: “Such women talk about crossing picket lines of protesters who are screaming at them not to do what they have already spent days or weeks weeping about.” *Weeks weeping about.* This is another phrase that is worth repeating. After reading this account, if we are ever in a similar situation, how could we not talk with a woman about what she is feeling before offering to be with her as she decides what to do?

Our Own Emotional Pain

Helen Gharwan, in her article “Physicians, Tears, and the Feeling of Shame,” writes, Mr. W starts talking. He inquires about hospice and talks about not wanting to burden his family. Tears continue rolling down his face. “But I am still young, doc, too young to die.” I look at his sister. She, too, cries silently as she tries to hide her tears from him. . . . After a few moments I stand up and leave the room with my attending. As we talk in the conference room I wipe away tears from the corners of my eyes. My attending notices and says, “You don’t need to feel ashamed about your tears.” I am struck by her words. Although I realize that her intent is to be supportive, I am surprised as to why she felt the need to say what she had just said. I am not ashamed of my tears. But I am surprised that the word “shame” has come up in this situation. How can feeling a fellow human being’s pain and empathizing with it ever be perceived as something to be ashamed of?

Gharwan adds what may be a rationale, and even a compelling rationale, to not leave patients so alone with their feelings. She writes, “did I appreciate the intensity of his sadness only because for a tenth of a second his eyes met mine and because I chose to not let him be alone by looking away in that decisive moment when he realized that his end is near?”²⁶ Gharwan shows the opportunity that a careprovider and patient may have in such instances to acknowledge how they are the same emotionally, and, in a deeper sense, how they share the same situation in life. Both may learn from the au-

thentic engagement of being with each other and that they are not, in this sense, alone.

I could consider how it is possible that patients’ and careproviders’ feelings can build upon each other and become a negative, ever-increasing, hidden vicious cycle. I could consider how such feelings may, whether they are expressed and shared or not, interfere with patients’ making the best proactive decisions for themselves. But I will not. Gharwan’s description of what she felt, and particularly her account of how, for a fraction of a second, she did not look away, makes her point profoundly. She makes the case for taking a moment or more to explore a patient’s feelings and then to possibly share our own before we engage in SDM. When we are not able to do this, as when Gharwan looked away from her patient, it may reduce the human bonding that both parties need at this time, and reduce their felt human dignity as well.

CONCLUSION

The present best, widely accepted ethical standard for us to communicate with patients is to engage in SDM. After I discussed three articles that appear in this issue of JCE, I reviewed the five main steps of SDM and raised two ways that we can possibly go beyond them: (1) to challenge patients when they might be missing key considerations in their analyses, and (2) to share feelings that are so intense that they might interfere with SDM. We might want to do this in many other cases.

I will end this article with the question of whether we should ever cry with our patients.²⁷ There are different views on this.²⁸ I would like to use Gharwan’s experience to consider the question she raises of weeping with a patient. There is a profound aspect of this question that is rarely identified or discussed. In the few seconds that Gharwan describes, it is possible that she and Mr. W were mutually in touch with their shared eventual outcome and, in this sense, their absolute equality. They both faced a shared incapability of escaping death. This was a rare opportunity, perhaps even an honor and gift, to authentically walk with each other to their end. They may have parted, feeling to their core, the meaning and beauty of sharing that moment. This included the tension of Mr. W’s dying, and that they would experience this together only at that time. Yet they both would

die, and they both knew this. There is something to be said for explicitly sharing this.

NOTES

I wish to thank Norman Quist for his profound, insightful suggestions regarding numerous aspects of this article.

1. R. Tallman, "Helping Children Hurt Themselves: Why Pediatricians Ought to Support Adolescent Football Players in Their Athletic Goals," in this issue of *The Journal of Clinical Ethics* 31, no. 4 (Winter 2020): 326-30.

2. L.F. Ross, "The Pediatrician's Moral Obligation to Counsel Directively Against Youth Tackle Football," in this issue of *The Journal of Clinical Ethics* 31, no. 4 (Winter 2020): 331-7.

3. B. Table, J. Thomas, and V.A. Brown, "Psychiatric Advance Directives as an Ethical Communication Tool: An Analysis of Definitions," in this issue of *The Journal of Clinical Ethics* 31, no. 4 (Winter 2020): 351-62.

4. A.H. Pieterse and A. Finset, "Shared Decision Making: Much Studied, Much Still Unknown," *Patient Education and Counseling* 102, no. 11 (November 2019): 1946-8.

5. We can ask such questions as, "Do you ever have difficulty making ends meet at the end of the month?" See, i.e., Center for Effective Practice, "Poverty," November 2011, <https://cep.health/clinical-products/poverty-a-clinical-tool-for-primary-care-providers/>; U.S. Centers for Disease Control and Prevention, "Social Determinants of Health," <http://www.cdc.gov/socialdeterminants/FAQ.html>; AMA, "AMA Health System Sciences Learning Series," <https://edhub.ama-assn.org/health-systems-science>.

6. L.C. Sobell and M.B. Sobell, "Motivational Interviewing Strategies and techniques: Rationales and Examples," 2008, https://www.esrdnetwork.org/sites/default/files/MI_rationale_techniques.pdf.

7. M.A. Hall et al., "Trust in Physicians and Medical Institutions: What Is It, Can It Be Measured, and Does It Matter?" *Milbank Quarterly* 79 (2001): 613-39.

8. A. Semuels, "The White Flight from Football," *Atlantic*, 1 February 2019, <https://www.theatlantic.com/health/archive/2019/02/football-white-flight-racial-divide/581623/>.

9. M. Marom, A. Gilboa, and E. Bodner, "Countertransference Responses of One Music Therapist to Autistic Echolalia," *Nordic Journal of Music Therapy* 29, no. 3 (2020): 222-7, 223.

10. *Ibid.*, 223.

11. *Ibid.*

12. Marom, Gilboa, and Bodner, "Countertransference Responses," see note 9 above, p. 236.

13. *Ibid.*, 236-7, citing K.E. Bruscia, "The Signs of Countertransference," in *The Dynamics of Music Psychotherapy*, ed. K.E. Bruscia (Gilsum, N.H.:

Barcelona, 1998), 71-92, 83.

14. Marom, Gilboa, and Bodner, "Countertransference Responses," see note 9 above, p. 236.

15. B. Weiser, "After the Virus Came, 22 Parents Moved into their Children's Hospital," *New York Times*, 10 June 2020, <https://www.nytimes.com/2020/06/10/nyregion/coronavirus-children-hospital.html>.

16. Ross's example is the only paradigm needed, but there are numerous other examples of approaches that may be best for patients, even though they lie outside the usual medical standards of care. One such example is to surgically place a feeding tube in a patient with dementia and is getting worse. Generally this is contraindicated, but, even if rare, it may be most meaningful and beneficial, to patients and their families.

17. This checking can be helpful in any context. Partners that are warring, for example, may be locked into an ever-increasing negative, vicious cycle. One way to try to break this cycle is for one partner to ask, "Have I got your view right?"

18. J. Halpern, *From Detached Concern to Empathy* (New York, N.Y.: Oxford University Press, 2001).

19. Halpern used this example when she gave a talk to thousands of attendees at an annual meeting of Public Responsibility in Medicine and Research (PRIM&R) on research ethics some years ago.

20. C.W. Sauer and K.L. Marc-Aurele, "Attempting to Honor Beliefs of Jehovah's Witnesses at the Edge of Viability in an Infant Born at 23 Weeks' Gestational Age," *American Journal of Case Reports* 17 (2016): 375-8.

21. *Ibid.*, 378.

22. A. Hoffman, "Jehovah's Witness Parents' Refusal of Blood Transfusions: Ethical Considerations for Psychologists," *Journal of Health Psychology* 21, no. 8 (2016): 1556-65, 1559.

23. *Ibid.*

24. The Associated Jehovah's Witnesses for Refusal on Blood (AJWRB) includes both current and former Jehovah's Witnesses and legal and medical professionals. See Hoffman, "Jehovah's Witness Parents' Refusal," see note 19 above, p. 1559.

25. C.E. Karkowsky, "I Found the Outer Limits of My Pro-choice Beliefs," *Atlantic Monthly*, 7 August 2019, <https://www.theatlantic.com/ideas/archive/2019/08/pro-choice-ob-gyn-confronts-limits-her-beliefs/594151/>.

26. H. Gharwan, "Physicians, Tears, and the Feeling of Shame," *Journal of Palliative Medicine* 17, no. 9 (2014): 1070-1.

27. C. Lam, J.M. Vingerhoets, and L.M. Bylsma, "Tears in Therapy: A Pilot Study About Experiences and Perceptions of Therapist and Client Crying," *European Journal of Psychotherapy and Counselling* 20, no. 2 (2018): 199-219.

28. O. Tishby and H. Wiseman, "Types of Countertransference Dynamics: An Exploration of Their Impact on the Client-Therapist Relationship," *Psychotherapy Research* 24, no. 3 (2014): 360-75.