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## *At the Bedside*

# Seven "Between-the-Lines" Questions All Ethics Consultants Should Continue to Ask

*Edmund G. Howe*

### ABSTRACT

Clinical ethics consultants (CECs) must know key moral principles and have adequate psychosocial skills. This is, though, not enough. They must also have and hone "between-the-lines" skills that will change over time. This article discusses seven of these skills that CECs need before, during, and after consultations. They have in common the unusual primary goal of maximizing CECs' ability to bond with the patients and families with whom they consult. A focus on relationships, rather than on ethical outcomes, may paradoxically enhance the possibility of achieving an ethical outcome.

In this issue of *The Journal of Clinical Ethics* (*JCE*), in "A Pre-Doctoral Clinical Ethics Fellowship for Medical Students," Katherine J. Feder and colleagues describe a fellowship in clinical ethics consultation that they developed for third- and fourth-year medical students.<sup>1</sup> Two of the students have already acquired national healthcare ethics consulting certification (HECC) from the American Society for Bioethics and

Humanities (ASBH). The six months of training is a significant part of students' time in medical school. Hopefully, other medical schools will follow suit.

In "Competencies and Milestones for Bioethics Trainees: Beyond ASBH's Healthcare Ethics Consultant Certification and *Core Competencies*," also published in this issue of *JCE*, Kimberly E. Sawyer and colleagues propose a series of competencies and milestones to track the progress of students in clinical ethics consultation training programs.<sup>2</sup> Such objective measures are now commonly used in medical education. Competencies and milestones help teachers better assess students' learning, and help teachers to determine how much independent clinical responsibility they should allow students to have when they see patients.

There are, however, "between-the-lines" skills that clinical ethics consultants (CECs) must learn and continue to learn as long as they practice. The need to continue to learn exists because these skills are open to CECs' on-the-spot, somewhat subjective judgments, and thus can always be improved. How CECs apply their subjective judgments may most profoundly affect the outcomes of patients and their family members. CECs' responses may change what occurs in the hospital, such as patients' life or death, and may wholly alter what patients and their families experience going forward. Family

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members, for example, may continue to experience deep joy in their relationship with their loved one, rather than feeling lasting bitterness.

Perhaps the greatest skill is to be able to ask the right question at the right time, even when it may be painful to ask. Further, CECs may need to be able to admit in some instances that what they have been doing not only hasn't worked, but most likely won't work in the future. For these reasons I will discuss seven questions that are particularly important for careproviders to ask. I will present these questions in the order in which careproviders are most likely to confront them, provide a real-life example of each, and then explain how, having asked the question, a careprovider might best proceed.

A common thread underlies all of the questions: the goal they share is to enhance bonding between patients and careproviders in every consultation. This priority is, I suspect, uncommon, but it may be more important than any other factor in an ethics consult. Such bonding is always critically important in its own right. This bonding may enhance how the parties involved in a consult experience their lives going forward. Finally, this priority may increase the equality and autonomy of patients and their family members. The primary goal should be, in my view, for CECs, patients, and family members to leave the hospital walking together, hand-in-hand, if possible. This result is modelled in an article published in this issue of *JCE*, by Amy E. Caruso Brown, "The Last Bastion of Paternalism? A Reflection on Proceduralism, Power, and Privilege."<sup>3</sup> Brown describes working as a pediatric oncologist, treating a child, "Mateo." His parents, working closely with her, decided that it was time to allow Mateo to die. Several months later, the parents continued to express their gratitude to Brown. This is an end for which all careproviders should strive.

### QUESTIONS TO ASK BEFORE A CONSULTATION

#### Should We Wholly Ally Ourselves with the Patient and Family?

When they begin a consultation, CECs may offer to wholly be the ally of patients and family members. This means, CECs should explain, that they will do all that they can to further the interests of patients and family members, *as patients and families see them*. Further, CECs

can say that they will do this regardless of their own personal views.

Careproviders, other than CECs, may have other priorities, for example, to limit costs. For example, careproviders are strongly urged to consider costs when they prescribe medications: they may prescribe a drug that is less likely to be effective because it is much less expensive. Patients and family members may be able to question such decisions by appealing to the hospital or even in court. They may not do this, however, without the urging and support of a CEC. By making such an offer to help, CECs offer to be *with* patients and family members as they make an appeal, and even to assist when they pursue additional interventions to which they may be entitled.

Thus, being an ally to patients and families may include going with them to the courts or to the press. It may take courage. This is a virtue that Sawyer and colleagues rightly deem to be required in CECs, and it is this kind of support that Brown provided to "Allison," a patient who opposed her surgeon's recommendation. Allison was 30 weeks pregnant, and her fetus would die unless she had a cesarean section. But the fetus had serious problems and might not have survived. Further, Allison would face serious risks from a c-section. She said she was willing to die if that would give her fetus any chance to survive. Brown did all she could to assist Allison. I will follow this brief summary of Allison's situation with aspects of Brown's analyses, which are key to the questions I will consider below. I will extend Brown's insights to suggest what careproviders might do in similar cases.

#### *Brown's Analysis*

Brown provides many reasons that we might want to take on the same kind of role she did, to be an ally for Allison. Brown acted as she did in large part because she believed it was what she should do, ethically. I will go further: I urge careproviders to support patients' requests even when these requests go against careproviders' values. I will explain why shortly.

Brown states that performing surgery has traditionally been entirely at the discretion of surgeons, although patients and families "might be free to seek a second opinion, depending on social, economic, and educational capital." In saying this, Brown highlights two critical points. The first is that patients may already have the means to appeal a surgeon's decision. For ex-

ample, Allison sought help on social media. Thus, careproviders who support patients may be supporting them in what they already can do for themselves. But it may be less likely that patients will do this without the support of another, such as a careprovider. The support of a careprovider may therefore alter patients' outcomes and increase their equality.

Brown notes, too, that even though patients have some right-to-appeal options, they may not be able to access them, or at least they may have difficulty accessing them. In this case, Allison lacked the financial means to go to another state, where she would have been able to get the c-section she wanted. Patients may not be able to offset the obstacles they face, even with the support of a careprovider. But we may be able to help patients overcome limiting factors in other ways, and this may increase their equality.

Brown states that although surgeons' refusals to do surgery are "treated as objective clinical decisions," their decisions may actually not be completely objective. Rather, their decisions may be "influenced by clinicians' own characteristics, such as the tendency to be more conservative or more aggressive." Brown accurately tags the possibility—and a grave risk for patients and for all of us—that whether or not we have surgery or any other intervention, what we get depends on our clinicians' personal "characteristics," as Brown puts it. When it is possible that certain aspects of an outcome were arbitrary, we may come to be concerned that any given outcome may have been shaped by arbitrariness. When we act wholly as patients' allies, this risk may be greatly reduced. Brown states that although doctors may make decisions for patients that, more often than not, are the best decisions possible, doctors' perspectives may lack nuance. They may be subjective. When careproviders take on the role of being wholly the allies of patients and their families, this may add nuance to their decisions and increase their objectivity.

#### *How to Best Do This*

If we want to let patients and family members know that we will put their interests first, we should say so when we first meet them. This is important because patients and families, like all of us, may be especially influenced by first impressions. In this case, patients and families, after hearing this, may be more open to seeing us in a different, more positive light, and less as members of the staff and possibly as hospital

"enforcers" who will oppose their interests when we must. After saying that we will place their interests first, we should add that we must tell other staff what we are doing, in a timely manner, to give staff enough time to pursue any avenue opposing this that they see as necessary.

By this I mean that, in some instances, patients' and families' interests will not match our own. A colleague of mine described how a 15-year-old boy, in the hospital for an appendectomy, told staff that sometimes his father got drunk at home, and he would cover his dad with a blanket as he slept on the couch. The staff was concerned that this might constitute child abuse, and believed they were required to report it to Child Protective Services (CPS). The staff called hospital security to make sure the father did not remove the boy from the hospital before CPS investigated. CPS did not find abuse or neglect, but the boy and his father may not have seen the staff as their allies after this.

Another example that might evoke this kind of staff response is from Myra Bluebond-Langner's book, *The Private Worlds of Dying Children*. The parents of an older girl would not tell her that she was dying.<sup>4</sup> (This case will be discussed further below, and I will ask whether every careprovider should be expected to be able to address this kind of situation optimally.) When this kind of thing happens, it is the staff's burden to intervene. What is absolutely to be avoided is to say we will be the ally of patients or family members through much or most of a consult, until we feel we can't support what they say they want. Should this happen, they may feel betrayed and abandoned. It is possible to give support, even when we morally oppose what they want to do. This approach contradicts a priority that is commonly espoused, that careproviders, in most if not in all cases, can and should put our own ethical values first. When we will not follow our own views, but will prioritize the views of patients and families, we should tell them that we will do this, in advance. We should say explicitly that it is not our views as careproviders that should count the most, but their views.

Patients and families may still not believe us, but saying this may add to our credibility with them. They may wonder, why else would we say all this unless we mean it? We may do this best, paradoxically, by asking patients and families to *not* trust us, unless and until they have reason enough to choose to trust us. We

might say, "Please don't trust me, unless and until you believe that you should!" We could say this with a smile, connoting that, even as we say it, we know that patients should trust us, and we hope they will.

On the other hand, we could wait to make the same offer later. We could do it, for example, midway through a consult, as this may be when a disagreement first arises. This is illustrated in the following case, which I observed. Family members didn't want the patient to know that he was dying. Staff presumed that they could work this out with the family, but found they couldn't. The family arranged to stay by the patient's bedside through the night to insure that staff wouldn't tell him that he was dying, although the family asserted, unequivocally, that the patient did not want to know. The CEC who was consulted advised the staff to—literally—break through the human barricade the family had created around the patient's bed, to tell him he was dying. The staff followed this advice, and the family was enraged. It might have been better for the CEC to wholly support the family.

It is up to us to take the initiative to offer to be allies to patients and families. Before doing so, we could ask ourselves the kinds of hypothetical questions that forensic psychiatrists and psychologists ask when they must determine whether an alleged offender acted in response to an irresistible impulse. (An irresistible impulse is a defense that is similar to a plea of temporary insanity: that the person was unable to control his or her actions.) One question that is asked in these circumstances is whether the alleged offender would have acted in the same way if police had been "at the offender's elbow." If the alleged offender would have acted in the same way, it is likely that she or he was responding to an irresistible impulse.<sup>5</sup> In the same way, we might ask patients who request a treatment that staff do not consider appropriate whether they would request the same treatment if they had a specialist on their condition and a lawyer at their elbow. If they say their request would be different if those experts were at their side, this may suggest that we should offer to be their ally.

This does not mean that the patients we assist will succeed in having their requests met. But having an ally may soften any negative experiences they have. When the patient's family members wanted to protect him from learning that he would die, for example, the CEC could have spoken on the behalf of the family—had the family wanted the CEC to do that—and the

CEC may have been able to negotiate a resolution short of the staff's forcefully breaking through the family's barricade at the bedside.

When patients or family members feel the support of even just one person, their resentment or embitterment may lessen. Having this support, patients may see that they and the staff are part of the same team, seeking a workable solution. This change may be more possible when a careprovider takes their side. This is illustrated in the following case, from my own experience. A woman in her later years was in a coma in the hospital. The staff thought she was dying or that, at least, she would never wake up. She had not responded to any of the treatments she had received for some time. Staff still did not know what was wrong. Since they had nothing more to offer and since, as they thought at that point, she would never get better, they recommended to her family that they withdraw her life-sustaining treatments and allow her to die. I was the CEC in this case, sitting at the end of a long rectangular table. On my left side were five family members; on my right side, five staff. The patient's five adult children all adamantly opposed the staff's suggestion. She could recover, they protested. The family leader said, "After all, Ma could get well." I said, after a short pause, "Yes, she could." The same family member then reversed herself. She said, for the first time anyone in her family had, "Maybe, though, the staff is right." Her siblings almost instantaneously agreed. The mother's treatment was withdrawn. But she miraculously got well and left the hospital, walking. Even when this rare acceptance of a team's suggestion does not occur, the family (or patient) may gain from knowing that the CEC made an effort to be their ally.

The case of the young woman described in Brown's article who was not able to convince the surgeon to perform a c-section to save her fetus may be an example of this. She had Brown, her CEC, supporting her. She left the hospital profoundly disappointed, but she still had the experience of having Brown by her side. Might this have made a difference later on in her life?

### **Should We Ever Wear Two Hats?**

Ideally, a second question we should consider before we first offer to assist a patient or family is when, if ever, we should be willing to wear two hats.<sup>6</sup> In this context, wearing two hats means that we would, on the one hand, seek to meet a patient's or family's needs fully, while,

on the other hand, we might oppose their interests. An example of how this may occur in a consult is when we or other staff believe that a patient or family seeks to deceive us in some way for secondary gain. Staff may feel compelled to play detective, as it were, while they treat the patient. They may want the CEC to wear two hats too. They may be concerned that the patient or family seeks monetary compensation; for example, they report that the effects of an illness or injury are worse than they are.

Or, as another example, a family mourns that a patient is in a coma or is incompetent. As the patient's surrogates, they state that they know the patient would want to be kept alive. But staff may suspect a hidden agenda, namely that the family wants to continue to receive and benefit from the patient's regular Social Security checks. If we wear two hats and don't tell the patient or family that we are doing this, we deceive the them. My intent is not to explore whether or not doing this is justifiable. My intent is to raise the question of whether we can fully meet a patient's or a family's medical needs while we investigate them or their motives. I believe we can't. Our nonverbal behavior, if not what we say, may betray us. If I am right, CECs who offer to be the ally of patients or family members should not take on such conflicting roles.

It is entirely plausible that patients or family members may glean evidence of our dual loyalties, if we have them. Patients sometimes reveal that when they are with their careprovider, they scrutinize every word and nonverbal gesture, to try to discern if their careprovider is hiding something from them. For example, a careprovider may be hiding information that an underlying cancer is causing the patient's symptoms. In these situations, patients may detect even the most subtle cues and connotations. Given this possibility, if, as we investigate our suspicions about a patient, we distance ourselves from the patient, all of the gains from all else that we have done to assist that patient in the past may be lost.

#### **QUESTIONS TO ASK DURING A CONSULTATION**

##### **Should We Start a Consult with Mediation Approaches?**

Staff may or may not call in a mediator before they request an ethics consultation; if they

do, a mediator may not always be available. If a mediator is not available, we may benefit patients in ways that a mediator could by using mediation approaches at the beginning of the consult. What mediation approaches add to ethics consults may be open to controversy;<sup>7</sup> Autumn Fiester asserts that these approaches add immensely, and she highlights the distinctive goals that mediation approaches may help bring about.<sup>8</sup> Even some careproviders who have not received training in mediation approaches may be able to use them effectively. For example, when all of the stakeholders in a consultation are able to identify their deepest wants, they may be able to come to an agreement on an ethically acceptable outcome. When this occurs, though, it may further different values, as illustrated in the following case.

#### *Different Values*

This is a case I observed. A man in his thirties was dying from cancer. His doctors predicted he had at most six months to live. He was in a coma due to septicemia, an infection in his blood stream, that antibiotics, in his case, had not cured, because he had an abscess in his body that the antibiotics hadn't reached. His careproviders believed that the antibiotics would work if surgery was performed to drain the abscess. The patient's wife said he would not have wanted surgery, but his parents said that he would have wanted it. It appeared that a mediation approach would allow additional outcomes to be considered. Standard ethical analysis would, presumably, prioritize respect for the patient's autonomy, and next prioritize his wife's substituted judgement. This process literally followed state law for that location. Using this ethical analysis, the CEC for the consult believed that the work that would remain to be done after the patient died would be for the patient's parents to forgive his wife.

Using a mediation approach, the CEC attempted to find an area of agreement. It was established that the patient and his wife had a child, who would suffer if his mother and grandparents were at odds. It was reasoned that, if the patient could be asked, he would want his wife and parents to remain close, for the child's sake. Given this reasoning, the wife agreed to surgery, with a do-not-resuscitate (DNR) order. Before the surgery, though, the antibiotics finally worked. The patient woke up, and indicated that his wife was right: he would not have wanted surgery.

He died six months or so later, as expected, but his wife, parents, and child were not estranged.

### *The Needed Skills*

Those who would pursue mediation approaches may need exceptional skills to do so.<sup>9</sup> If they do not have these skills, they may do more harm than good. For example, if a participant in a consultation expresses anger, a CEC may respond defensively.<sup>10</sup> On seeing this, participants in the consult may be less likely to freely share their thoughts and feelings.

Three skills are most important in using a limited mediation approach. The first is to establish and maintain a nonjudgmental setting, which allows participants to openly share what they think. CECs may need to assess beforehand whether or not they have a bias that could preclude accomplishing this. For example, when a CEC learns that a consult will involve a patient who is imminently dying but who has requested life-extending treatment, the CEC might ask him- or herself whether this request seems to be life-prolonging or death-prolonging.

The second skill is to be able to move participants to look deeper within themselves. Discovering deeper personal values may enable participants to find an outcome that is acceptable to all. I recall in this regard, for example, a couple who had come to be much at odds with and angry at one another. The husband lived at home with a terminal illness, and he wanted to die. He had been dying slowly and then suddenly took a severe turn for the worse. His wife called an ambulance that came and saved him. Afterwards, he was enraged about this. He came, though, to realize that there was not only one way that his wife could love him, but two. There was his way, but she had called an ambulance because she loved him.

A third skill is being able to respond optimally when a participant in a consult responds with anger. Here, as Fiester points out, understanding and acknowledging the source of a participant's anger may help to quell its intensity within minutes. Not being judgmental in any way is, above all, the key.<sup>11</sup> In addition to having these skills, we should begin a consult by informing all of the participants what will happen if, after discussion, they can't agree. The participants need to know from the start what the process could be, later, should they not find a way to agree. Sharing this information may impose added pressure on participants to compro-

mise, knowing that there is a risk that the outcome may be worse if they do not. To tell the participants this, in advance, respects them to the greatest degree by increasing their understanding of what may happen next.

### **Should We Refer a Consult to a Colleague with Better Psychosocial Skills?**

Some of us may have better psychosocial skills than others, and these superior skills may make a difference in successfully using mediation approaches. These skills may make a difference in other ethical consultation contexts as well; for example, when they are needed to pursue a highly delicate topic, or when a careprovider lacks the ability to withstand and overcome overwhelming, stressful emotions. This section will address such highly delicate topics, and the next section will consider overcoming overwhelming emotions. To seek out a colleague who is more skilled than ourselves takes humility and courage. Sawyer and colleagues list humility as a virtue that CECs should come to possess.

A first example of this, referred to earlier, is that of the parents who would not tell their older child that she was dying.<sup>12</sup> In such a situation, if a careprovider could persuade the parents to tell their child, the child's outcome might be optimal.<sup>13</sup> On the other hand in this case, a less-skilled careprovider might cause the parents to feel as if they were being judged, and in response they might seek to remove their dying child from the hospital, if they could. If this happened, staff might call for hospital security to block them, causing additional distress.

A second example of the need for better psychosocial skills is when a careprovider informs parents that their newborn has died or is dying, and that they may, over the longer run, fare better if they hold and even bathe the baby, whether deceased or still alive, as soon as they feel able—if they can.<sup>14</sup> No matter how well this is done, the parents may see it as most insensitive. Careproviders may believe they should attempt to inform parents, but the utmost psychosocial skills are needed to do this successfully.<sup>15</sup> Thus, if careproviders feel that a colleague may have more psychosocial skills than they do, it may be preferable to bring in the colleague to carry out this task.

When we attempt to inform such parents, I suggest that we begin by saying how troubled

we feel at the prospect of carrying out the task before us. We can share that we know that, on one the hand, we must give them this information, but that we realize, on the other hand, how incredibly insensitive it may seem.

More generally, all careproviders should seek to anticipate the ambiguous meanings in what they say, that patients may misperceive, and, if possible, address and clarify them as early as possible. Patients can then take in what we mean to say. This is illustrated in a real case that I observed. A patient was chronically hospitalized. She needed daily treatment that could only be given in the hospital. Her loved ones visited her around the clock. A careprovider thought that the patient might not know that she could refuse the treatments she was receiving, and, if she did refuse them, she would die. So the careprovider told her this.

The very next day she refused all treatments, and soon after died. She may have “heard” the careprovider as telling her that he believed she should stop the treatment. She may have believed this because she knew that those visiting her were taking time from their own lives to visit her every day. The hitch was, her loved ones visited her because they wanted to—she was clearly that special and beloved. The careprovider could have told her beforehand what he *didn't* mean. He could have made clear that he told her this only because he wanted to be sure that she knew that she had this option.

### **Should We Refer a Consult to Another When We Feel Emotionally Overwhelmed?**

Another instance in which a CEC may best refer a consult to another is when the case feels emotionally overwhelming. The worst risk in these situations may be to patients; that is, we may not recognize the stress to ourselves, or, if we do, we may choose to “tough it out.” When that is the case, we may unconsciously take out our anger on the patient for causing us pain, and may do this in spite of our best efforts. We should, then, continuously monitor our own stress. If it seems that the stress we feel is too much for us, we should seek help from a colleague, or refer the consult to a colleague. Our professional culture may oppose these choices by the use of shame. When we do ask a colleague for help, our colleague’s warmth and support may far exceed what we expect, because our colleague probably will understand. The relief

that we will most likely feel may be similar to the relief that patients feel when a careprovider says she or he will be the patient’s ally.

This stress is documented wonderfully by Iris Ohel-Shani and Dalit Yassour-Borochowitz in their article published in this issue of *JCE*, “Moral Distress and Feticide: Hearing the Voices of Maternal-Fetal Medicine Physicians.”<sup>16</sup> The authors discuss the stress felt by physicians who perform late-term abortions in Israel, where this is legal. One such physician’s report is illustrative. She states, “I’m sure in the early weeks [the fetuses] feel pain. It’s terrible to stab them. Or they are trying to resist, trying to escape, which is a horrible sight.” She seeks to comfort herself. She says, “Well, maybe I saved a family,” and, “You try to tell yourself things like that too.” The physicians interviewed said that they seek, in their own state of stress, to comfort patients who are having an abortion. In their article, Andréa Becker and Lena R. Hann wrote, “you don’t know what a woman’s level of comfort is. Is she imagining this as a ball of tissue, or is she imagining it as a baby? . . . We usually talk about it like it’s a ball of tissue. We never say baby, and we try not to say fetus. . . .”<sup>17</sup>

In the case that Brown reports, Allison’s surgeon tried to console her by saying, “It sounds like you are worried that you haven’t done everything you could for your child.” Seeking to reassure her, he told her that she had. This approach may have helped patients in other such instances, but in this one, Allison knew that her fetus would die because this surgeon refused to operate. Careproviders who are especially psychosocially skilled might, in these instances, ask a question, rather than make a statement. They might ask a patient like Allison, for example, “What do you feel you need to do to be a good parent to your child?”<sup>18</sup> I would add a question to this: “What do you feel you need to do that you *can* do?”

### **Should We Refer Decision Making to Another Person or Body?**

When ethics consults reach a dead end and reasonable people still reasonably differ, there may be no way to resolve the impasse. The best decision may be to a switch the discussion from what the outcome should be to who should make the decision, under the circumstances. At present, this occurs most commonly when a child is terribly ill and there is no clear reason

to keep the child alive or to let the child die. The decision is then often referred to the child's parents.

An example of a lack of agreement is when evidence of nonpaternity is discovered incidentally, disclosure of the test result will have no medical gain for anyone,<sup>19</sup> and an ethics committee is asked for a recommendation about disclosure. As in other ethically difficult cases, the members of the ethics committee may remain divided, and so may decide to vote to reach a decision.<sup>20</sup> This way to make an ethical decision—by taking a vote or by a ruling of the majority—is a prime example of ethically suboptimal decision making. Voting may seem most desirable, because, at least in the United States, it accords with our beliefs in a democratic process, and that all people should have an equal say. The drawbacks, however, also are apparent. The outcome of the vote may depend on who is present on a given day. Worse, the person or persons who dissent may be those who have the most insight on the matter. In the example of unsought nonpaternity data, the majority may be rule-bound and respond wholly and reflexively by applying the principle of transparency: that a hospital should never keep a secret. There are notable exceptions regarding transparency; a very controversial example is when a transplant hospital will not explain why a transplant is stopped at the last minute. (For example, a family member strongly opposes the donation at the last minute.)

In the case of disclosing the results of an unsought nonpaternity test, disclosure may destroy a family's life together. If a majority of the ethics committee votes to disclose on the basis of transparency, perhaps it is likely that they missed an important aspect of the case. The attraction of a dominant principle such as transparency or of making a decision on the basis of a simple majority may too easily prevail. The risk, as the nonpaternity example illustrates, may occur in cases that are "at the margins." At the margins, there may be a greater number of nuances that should be considered, as Brown suggests. Such difficult cases may best be referred to another decision-making body, rather than be subject to a majority vote when no agreement may be possible.

This does not presuppose that the new decision makers will arrive at the best possible answer. If, though, the new decision-making process is debated as vigorously as the previous

attempt to find the best outcome, a patient or family may be able to experience the eventual decision as acceptable, even should the decision not be one that the involved parties wanted.

Given this, the parties in a consult should know from the start that it is possible for a termination be referred to another body. For example, if there had been an alternative means to resolve Allison's request for a c-section other than the surgeon's own personal moral views, Allison and Brown might have been able to accept the eventual decision better.<sup>21</sup>

### **Should We Ever Contact a Patient or Family after a Consult?**

Individuals most vulnerable to harm are parents whose child has died. Authors Meaghan S. Weaver and colleagues advise careproviders to keep in touch with these families,<sup>22</sup> and this would include parents like Allison. I believe that when careproviders work with parents or patients this intimately, for example as Brown did with Allison, they should offer to stay in touch in some way. If they do not, patients or family members may experience suddenly losing the relationship as an additional, painful loss. The lives of parents who have lost a child, Weaver and colleagues write, have been "irreversibly changed."<sup>23</sup> Their world has become "unrecognizable to them."<sup>24</sup> Bereaved families, they maintain, may feel displaced from their "medical home."<sup>25</sup> They have lost their "human connection" to the "caring medical team."<sup>26</sup> They may have come to regard their child's careproviders as their "medical family."<sup>27</sup> Bereavement research, they add, indicates that these families perceive a greater need for support in the second year following a child's death than in the first year, and that their "grief trajectories" continue for many years.<sup>28</sup> When careproviders neglect "bereavement outreach," they conclude, is to "miss an opportunity to extend their previously developed caring connection."<sup>29</sup>

These conclusions are profound. Weaver and colleagues suggest, first, that careproviders should fully attend to what they say. They might say initially, when first meeting the parents after a child's death, "There are no good words, but please know how very sorry I am." Careproviders should not use words that parents may hear as a cliché. Weaver and colleagues caution, for instance, against routinely saying anything like "I know how you feel." Doing this may re-

sult in parents feeling still more alone, and suffering to an even greater extent.

The authors suggest that if careproviders have treated a child for a long time, they should continue their contact with parents, as long as the parents want. Later, the authors suggest, it might be best to share a story, memory, accomplishment, or experience that they had with the child, or that they remember the parents shared with them.<sup>30</sup> We can apply these principles even after an ethics consultation. In this regard I think of a practice urged and carried out by the ethicist John Fletcher.<sup>31</sup> He was also a clergyman. In his latter role, he would only marry a couple if they agreed beforehand to forgive all of the people toward whom they felt a grudge. I note his practice here to indicate the similarly exceptional commitment he felt to following up with patients even after they left the hospital.

He invited all patients and their families with whom he consulted to come back to the ward a week or two after the consultation to meet with staff and tell them what, for them, had gone wrong—if they felt that way. I can still hear Fletcher's voice when he would call patients or family on the phone. "We need you," he would say. Patients would come in and share what they had felt, even when they felt offended. Fletcher and his staff had, in one case, for example, recommended to a child's parents that they allow their child to die. The child had had several cardiac arrests and thus needed constant heart monitoring, and careproviders needed to be near enough to the child to resuscitate his heart at all times. The parents rejected the staff's recommendation. Subsequently the child's heart got better, and his heart-stopping arrhythmias became much less frequent. His parents shared how the staff's suggestion had displeased them. Their sharing may possibly have been instructional for the staff, and their being able to share this may have increased their bonding with the staff.

I recommend that we inform patients and family members at the beginning of a consult that we would like to contact them afterwards. We could add why, which would be not only for the education of the staff, but to build on and increase positive feelings between patients and staff, feelings that should be prioritized throughout the consult. I would go a different way than Fletcher did. I would tell patients and family members that what matters the most in meeting after a consult is what patients and families would prefer to do, not what the staff might

learn. I would say that the conversation could benefit future patients. I would emphasize to patients and family members that they could change their mind about meeting, at any time. If patients and family members agree to meet, when they arrive I would be sure to sit next to them, and perhaps closest to them, throughout any discussions as a way to convey my absolute emotional support. If they couldn't come or wouldn't come, I would ask if they would be open to have me come to their home with whatever staff they worked with, that I could successfully round up. I would call this an "ethics home visit." Bonding is, I believe, all important.

### CONCLUSION

After an ethical conflict, patients and family members may sometimes feel embittered. This article seeks above all to alter this outcome. My suggestions include that careproviders offer to be the ally of patients and family members, start consults with mediation approaches, and prioritize bonding, in an attempt to thwart possible embitterment, and to allow patients and family members to have a high quality of life going forward. These goals require us to seek the help of others if we lack sufficient psychosocial skills to use mediation approaches, successfully work through delicate issues, or avoid causing harm to patients should we experience overwhelming stress. These actions require exceptional humility and courage. I have discussed the kind of stress that occurs in physicians who perform abortions and have commented specifically on the physicians' efforts, despite their stress, to seek to relieve these patients.

I end this article with an appeal to careproviders to follow up with patients and family members after a consult is completed. If we do not, this may be an additional loss, since, over time, patients and family members may have come to regard careproviders more or less as family, as a result of having spent so many intimate moments together, and these moments may have been as important and meaningful to patients and family members as any in their lives. It is not that they are *like* family. They *are* family.

### BLINDING OF THE CASES

Details of the cases presented have been altered to protect the identity of patients, family members, and careproviders.

### NOTES

I thank Norman Quist for numerous insights he gave me on this article.

1. K.J. Feder, S. Chao, C.J. Vercler, A.G. Shuman, and J. Firm, "A Pre-Doctoral Clinical Ethics Fellowship for Medical Students," in this issue of *JCE* 32, no. 2 (Summer 2021).

2. K.E. Sawyer, N. Dundas, A. Snyder, and D.S. Diekema, "Competencies and Milestones for Bioethics Trainees: Beyond ASBH's Healthcare Ethics Certification and *Core Competencies*," in this issue of *JCE* 32, no. 2 (Summer 2021).

3. A. Caruso Brown, "The Last Bastion of Paternalism? A Reflection on Proceduralism, Power, and Privilege," in this issue of *JCE* 32, no. 2 (Summer 2021).

4. See M. Bluebond-Langner, *The Private Worlds of Dying Children* (Princeton, N.J.: Princeton University Press, 1978). See also A.L. Katz, S.A. Webb, and the Committee on Bioethics, "Informed Consent in Decision-Making in Pediatric Practice," *Pediatrics* 138, no. 2 (August 2016): e20161485, doi: 10.1542/peds.2016-1485, and Committee on Bioethics, "Informed Consent in Decision-Making in Pediatric Practice," *Pediatrics* 138, no. 2 (August 2016): e20161484, doi: 10.1542/peds.2016-1484.

5. See, e.g., D.A. Haycock, *Murderous Minds* (New York, N.Y.: Pegasus Books, 2014), especially pages 80-81, on how, based on brain function, this could occur.

6. G. Niveau and I. Welle, "Forensic Psychiatry, One Subspecialty with Two Ethics? A Systematic Review," *BMC Medical Ethics* 19, no. 2 (10 April 2018): 25, doi: 10.1186/s12910-018-0266-5.

7. A. Fiester, "The Failure of the Consult Model: Why 'Mediation' Should Replace 'Consultation,'" *American Journal of Bioethics* 7, no. 2 (February 2007): 31-2.

8. *Ibid.*

9. A. Fiester, "What Mediators Can Teach Physicians About Managing Difficult Patients," *American Journal of Bioethics* 128, no. 3 (March 2015): 215-6.

10. *Ibid.*, 215.

11. *Ibid.*

12. I would like to thank Norman Quist for alerting me to the need for careproviders to have the likely necessary psychosocial skills if they are to pursue this endeavor of trying to persuade parents to tell their children that they are dying.

13. Bluebond-Langner, *The Private Worlds of Dying Children*, see note 4 above; Katz, Webb, and the Committee on Bioethics, "Informed Consent," see note 4 above.

14. See D. Wolke, N. Baumann, B. Busch, and P. Bartmann, "Very Preterm Birth and Parents' Quality of Life 27 Years Later," *Pediatrics* 140, no. 3 (September 2017): e20171263, doi: 10.1542/peds.2017-1263; C. Kingdon, E. O'Donnell, J. Givens, and M. Turner, "The Role of Healthcare Professionals in Encourag-

ing Parents to See and Hold their Stillborn Baby: A Meta-Synthesis of Qualitative Studies," *PLoS One* 10, no. 7 (2015): e0130059, doi: 10.1371/journal.pone.0130059; A. Lathrop and L. VandeVusse, "Affirming Motherhood: Validation and Invalidation in Women's Perinatal Hospice Narratives," *Birth* 38 (2011): 256-65; V. Daugirdaite, O. van den Akker, and S. Purewal, "Posttraumatic Stress and Posttraumatic Stress Disorder after Termination of Pregnancy and Reproductive Loss: A Systematic Review," *Journal of Pregnancy* 2015 (5 February 2015): 646345, doi: 10.1155/2015/646345.

15. I would like to thank Norman Quist for this insight.

16. I. Ohel-Shani and D. Yassour-Borochowitz, "Moral Distress and Feticide: Hearing the Voices of Maternal-Fetal Medicine Physicians," in this issue of *JCE* 32, no. 2 (Summer 2021).

17. A. Becker and R. Hann, "'It Makes It More Real': Examining Ambiguous Fetal Meanings in Abortion Care," *Social Science & Medicine* 272 (March 2021): 113736, doi: 10.1016/j.socscimed.2021.113736.

18. M.S. Weaver, W.G. Lichtenthal, K. Larson, and L. Wiener, "How I Approach Expressing Condolences and Longitudinal Remembering to a Family after the Death of a Child," *Pediatric Blood & Cancer* 66, no. 2 (February 2019): e27489, doi: 10.1002/pbc.27489; E.G. Howe, "Ethical issues when non-paternity is an incidental finding," *International Journal of Pregnancy & Child Birth* 7, no. 1 (2021): 1-4, DOI: 10.15406/ipcb.2021.07.00218.

19. M. Prero et al., "Disclosure of Misattributed Paternity," *Pediatrics* 143, no. 6 (June 2019): e20183899, doi: 10.1542/peds.2018-3899. See also D.C. Wertz, J.C. Fletcher, and J.J. Mulvihill, "Medical Geneticists Confront Ethical Dilemmas: Cross-cultural Comparisons Among 18 Nations," *American Journal of Human Genetics* 46, no. 6 (June 1990): 1200-13; M. Weaver, "The Double Helix: Applying an Ethic of Care to the Duty to Warn Genetic Relatives of Genetic Information," *Bioethics* 30, no. 3 (March 2016): 181-7.

20. Fiester, "What Mediators Can Teach Physicians," see note 9 above; see, more generally, R.M. Sapolsky, *Behave* (New York, N.Y.: Penguin Books, 2017) for studies on how people may have biases without knowing this.

21. Weaver, Lichtenthal, Larson, and Wiener, "How I Approach Expressing Condolences," see note 18 above.

22. *Ibid.*, 1.

23. *Ibid.*

24. *Ibid.*, 2.

25. *Ibid.*

26. *Ibid.*

27. *Ibid.*, 5.

28. *Ibid.*

29. *Ibid.*

30. *Ibid.*

31. John Fletcher played a primary role in bringing *JCE* about.