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## *At the Bedside*

# Mediation Approaches at the Beginning or End of Life

*Edmund G. Howe*

### ABSTRACT

The approaches used in mediation may help ethics consultants, especially in difficult cases. In this piece, I primarily discuss these techniques. I also discuss how clinicians may be of the most help to parents of infants with severe genetic conditions, to research participants, and to patients who may be at risk for Alzheimer's disease and their surrogate decision makers.

In this issue of *The Journal of Clinical Ethics*, Autumn Fiester and Edward J. Bergman guest edit a special section on the use of mediation in clinical ethics consultation. In "Contentious Conversations: Using Mediation Techniques in Difficult Ethics Consultations," Fiester offers some guidelines based on an assumption that strong emotions are likely to skew our thinking.<sup>1</sup> She describes approaches that refute "strike while the iron is hot," urging instead to strike while the iron has cooled. It is important for clinicians to have the best possible skills when they face conflicts, as articles in this issue of *JCE* illustrate. In their article, "Intensive Care, Intense Conflict: A

Balanced Approach," Erin Talati Paquette and Irini N. Kolaitis provide a heart-wrenching example: a woman places her body over her grandchild to block clinicians who seek to reconfirm that the child is brain dead.<sup>2</sup> And in "The 'Commitment Model' for Clinical Ethics Consultations: Society's Involvement in the Solution of Individual Cases," Véronique Fournier, Marta Spranzi, Nicolas Foureur, and Laurence Brunet describe how a hospital staff in France responded when an infant was born with Prader-Willi syndrome (PWS).<sup>3</sup> PWS is a genetic disorder so impairing that the infants parents, legally, could have decided to let him die.

In "Stakeholders' Perspectives on Preclinical Testing for Alzheimer's Disease," Jalayne J. Arias, Jeffrey Cummings, Alexander Rae Grant, and Paul J. Ford ask how we should best conduct research on diagnosing Alzheimer's disease (AD) when there are currently no proven treatments.<sup>4</sup> This question poses new ethical problems now that we now know that AD begins "early on." Margot M. Eves and Bryn S. Esplin discuss, in " 'She Just Doesn't Know Him Like We Do': Illuminating Complexities in Surrogate Decision Making," how ethics consultants might best help to resolve irreconcilable conflict.<sup>5</sup> Like mediators, they seek to the find the deepest values on which conflicting parties can agree.

In this introduction, I will discuss mediation more generally and how its techniques may be applied. For the most part I will use examples taken from the articles in this issue of the journal. I will

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also suggest two radical departures from present practice that ethics consultants and other clinicians may want to consider.

### **Core Mediation Approaches**

Fiester's article may be analogous to an article that Leston Havens, a psychiatrist, wrote for fellow psychiatrists a decade ago. In "The Best Kept Secret: How to Form an Effective Alliance," Havens asserts that the most important thing that psychotherapists can do, by far, is establish a therapeutic alliance with patients.<sup>6</sup> Havens reports how to do this: a clinician must first "find" the patient—that is, "identify and acknowledge [the patient's] affective state, human predicament, and hopes or lack of hopes for the future"—and bring this back to the clinical encounter, communicating to the patient the understanding the clinician has acquired. Like Havens, Fiester recognizes that even the slightest "slip" by a clinician or ethics consultant can shift an interaction so it goes irreversibly awry. When this happens, a patient may look the same on the outside, but what goes on inside the patient may have totally changed. On this point, Jolion McGreevy, in "In the Ethos of the Safety Net: An Expanded Role for Clinical Ethics Mediation," gives the example of a patient's daughter who agrees to the staff's treatment plan because she feels afraid that her uninsured father might be abandoned if she disagrees.<sup>7</sup>

Havens notes it may be difficult to avoid making a slip. For example, when a patient has paranoia, a clinician must first recognize that there is a way (if not many ways) in which the paranoia could be reasonable. (In her article, Fiester echoes the need for clinicians to make this kind of underlying assumption.) But even when a clinician sees this and communicates it to a patient, a clinician still may fail. For example, a clinician may inadvertently connote that a patient is somehow at fault. Havens gives an example. A clinician may say to paranoid patient, "You must feel persecuted," which seems a very empathic thing to say, but may not seem that way to a patient. Havens says it might instead "invite a fresh collision" with a patient, who may protest: "I don't *feel* that way. I *am* persecuted." Havens advises that a clinician could say, "You must have experienced persecution" as "the safer route."<sup>8</sup> Fiester conveys the same need for fine-tuning our responses to patients and their families, which I will now describe.

### **Stay Neutral**

Fiester states that remaining morally neutral is "essential" for clinicians. It is, she says, "a strategic imperative." Should a clinician show bias, it may,

in a moment, undo patients' trust. Then, instead of trusting, patients—and families—may ask themselves how they might best "game" the clinician to bring about the best result, causing them to carry on a charade. When a clinician violates moral neutrality, even if the clinician agrees with the patient, it may erode the patient's trust, as the patient may infer that, the next time, a clinician who is not morally neutral may not side with the patient.

The two assets most critical to effective mediation are, it would seem, maintaining neutrality and feeling and conveying sufficient genuine passion to achieve a resolution. This passion may be necessary to move conflicting parties so that they will want to go this same route. Let us consider each of these assets. First, is this degree of neutrality even possible?

Norman Quist asked whether mediators can "set aside all personal biases—developed through attitudes and values—in their decision making and be truly impartial."<sup>9</sup> He elaborated: "In a clinical setting, how do you, can you, as in the therapeutic setting, invite and leave open the possibility for the reevaluation of all values, with the unconditional acceptance and holding environment that is special to the therapeutic alliance? . . . It does not seem to me that you can—or that most can, anyway."<sup>10</sup>

The answer to these questions is crucial to understanding why mediation approaches, like mediation, may be exceptionally successful. All clinicians may use the approaches I outline here, yet only a subset, as Quist suggested, may have the personal qualities "special to the therapeutic alliance" that can combine absolute neutrality with sufficient empathy toward all of the differing parties to bring about the desired resolution. This is the missing puzzle piece that is absent from most accounts, that verbal and nonverbal communication can be taught and increase patients' perception of clinical empathy.<sup>11</sup> Successful mediators may have an exceptional capacity for empathy and emotional bonding, whether it be acquired or innate.

### **Validate Feelings, Even of Anger**

Fiester recommends that even when a patient or family member responds in a way that we don't understand, we should presuppose that there is some reasonable explanation that we should try to learn. Once we think we know the reason, we should seek to affirm what we have inferred. Fiester recommends that we allow—and even encourage—a patient or family member to express more fully what she or he feels, even when this is anger. Validation of another's feelings may have an effect that is close to miraculous. It may move the other to change his or her point

of view, even if this view had been fixed. Sometimes the person's view can change immediately.<sup>12</sup>

Here is a specific example from a case on which I was consulting. The consult was requested by a medical team in response to an elderly woman who was gravely ill and in a coma. Despite the many medicines she was taking and the many tubes that were in her, she wasn't getting any better. Her family and the medical team were, as Fiester might describe it, at loggerheads. The medical team told the family, "We should stop treatments now because they are futile." The patient's daughter, a leader in her family, said, "No. She still could survive," and it was clear that she had the approval of the whole family. At this point, I said abruptly to the family, "You're right. Your mother could get better." The clinicians who asked me to do the consult were probably shocked. In retrospect, I should have told them I would do this—validate some aspect of the family's view, although that might go against what the team had wanted. It's important to validate a family's view prior to beginning a consultation. In this instance, the family's response relieved the clinicians' stress. The daughter responded as abruptly: "Maybe the doctors are right. Maybe we should stop mother's treatments. At least then she can die with dignity." The staff stopped the patient's meds. (She then miraculously recovered and left the hospital, walking.)

This kind of response to validation isn't uncommon. Havens reports this, for instance, in regard to the patient who said that he didn't *feel* persecuted, he *was* persecuted: "Clinicians' fears of fostering paranoid delusions by such confirmations will be relieved by observing the opposite result."<sup>13</sup>

Most physicians have experienced instances in which a patient recovers when everyone believes the patient will die.<sup>14</sup> These cases—and their opposite, in which a patient dies when everyone thinks she or he will live—add to the uncertainty that patients, family, and clinicians constantly encounter. Clinicians can ask patients and family how they feel about such uncertainty.<sup>15</sup> Quist goes further, proposing that facing such uncertainty with others "may be a possibility for greater openness," allowing more robust sharing and increased unity. He says that those who share similar concerns experience a "uniting thread." In mediation, such a uniting thread can help bring dissenting parties closer to each other.<sup>16</sup>

### **Give Others the Benefit of the Doubt**

What should ethics consultants do when they sense a person may be using his or her anger for personal gain? The person may do this, for instance, to intimidate others. Fiester refers to this gently—as

she does with all she recommends. She notes that "legally untenable or morally unsupportable resolutions" may seem, or be, "fashioned by the dissolute." When an ethics consultant suspects that one of the parties in a consult may be "doing wrong," Fiester calls this "The Lure of Sinister Motives": but when a consultant suspects wrongdoing, patients and families may feel the consultant is judging them, which may sabotage the success of the consultation. It may then be best to leave such detecting to others. Trying to be a consultant and a "detective" at the same time may undermine consulting efforts. Patients and families may perceive the consultant's distrust and lose their trust in return.

### **Acknowledge that a Policy May Be Questionable**

Sometimes clinicians may feel pressured to impose a policy they believe is wrong. They may feel like Havens's patient: "We don't *feel* pressured. We *are* pressured!" In this regard I recall a practice that some psychiatric wards once required. Psychiatrists had to ask suicidal patients to sign an "antisuicide" contract, stating they wouldn't end their life. Some psychiatrists and some patients objected. Some patients refused to sign. Some weren't sure they could sign a contract honestly because they felt too suicidal. Other patients found it degrading, as they saw it as implying that their psychiatrist was allied with the hospital, rather than being allied with them. In addition to sapping patients' trust, the contracts weren't effective. What could psychiatrists have done instead? How might they have retained patients' trust? One way would have been to acknowledge from the outset what they saw as flaws in policies that required patients to sign a contract. The most important place for psychiatrists is to be with patients, they could have said, bearing with patients, to the extent possible, the unbearable pain of not knowing whether they might take their own life.

Fiester calls this "The Peril of Ground Rules." The rationale for not setting ground rules is like that of not asking suicidal patients to sign a contract. Ethics consultants may want to set ground rules to keep things from "getting out of hand," but such rules may instead stop others from engaging in constructive dialogue. Such dialogue is the means by which we can seek to bring about win-win outcomes from seemingly irreconcilable disputes.

Edward J. Bergman, in his article, "Identifying Sources of Clinical Conflict: A Tool for Practice and Training in Bioethics Mediation," suggests what may be a "higher" ethical road: to bring in a third party to set any ground rules.<sup>17</sup> Asking a third party to set the rules may help "deconstruct" what is happen-

ing, and reveal why the rule that is the source of the conflict exists. Even when doing this doesn't resolve the conflict, it may promote greater understanding of the institution and/or its motives and thus be beneficial, even when the need to comply with a ground rule doesn't change.

### **Be Genuine**

Fiester warns of the dangers of seeking to form an easy alliance by using what she calls "parrotting." For example, medical students are sometimes taught to repeat the last part of what a patient says, to attempt to create greater rapport. It may strengthen the patient/clinician relationship, but some people may experience it as condescending. Medical students may also be taught to lean forward, model their posture after that of the patient, and even to raise their eyebrows. All these "techniques," if disingenuous, may have a negative effect. Another technique, not noticing a patient's strong emotion, may also be a mistake, as it may suggest the clinician doesn't care enough to note the patient's emotions and comment. Such perfunctory responses may be harmful. Suppose a patient is angry and the clinician says softly, "You sound angry." It may seem condescending. Clinicians should pay attention to what they feel and avoid saying anything that is not genuine.

In "Does Perspective-Taking Increase Patient Satisfaction in Medical Encounters?" and several other reports, Benjamin Blatt and colleagues report that patients' "satisfaction" with medical interactions increased significantly when clinicians tried to imagine what patients were experiencing.<sup>18</sup> A quick and easy way for clinicians to consider a patient's perspective is to imagine what he or she is feeling, and write it down in about 10 lines, an exercise may benefit clinicians, as well.<sup>19</sup>

It is broadly acknowledged that it is crucial for patients to trust their clinicians, as patients listen more carefully to clinicians when they trust them. What is the best way to establish patients' trust? Havens says there are several ways to establish a therapeutic alliance when clinicians and patients face challenges in their relationship.

The first approach is for clinicians to affirm an aspect of their relationship with the patient. For example, clinicians might affirm a paranoid person's "right to be angry" or a grandiose person's "right to be proud." Clinicians can also share with the patient an aspect of the patient that they respect. For instance, clinicians might tell a paranoid patient that the patient's suspicions may reflect a "heightened sense of justice" or their "disappointment in others." Clinicians might tell a grandiose person that

he or she has "great ideals."<sup>20</sup> Havens urges clinicians to make such responses before a conflict occurs, and Fiester says likewise.

But even with practice, few of us may have the exceptional social skills required. As Joshua B. Kayser states, in "Mediation Training for the Physician: Expanding the Communication Toolkit to Manage Conflict," some of the best physician communicators may lack the skills necessary to navigate "high-stakes conversations."<sup>21</sup> Tomer T. Levin and Patricia A. Parker provide an exceptional example of these skills in their article, "Preventing and De-escalating Ethical Conflict: A Communication-Training Mediation Model."<sup>22</sup> Levin reports asking a patient for "permission to sit." How much more respectful can a clinician be? How much more could one do to try to "level the playing field?"

If we lack exceptional social skills, we can keep a sharper eye out for indications that we may not be succeeding in an interaction. We can look, as Fiester recommends, for signs, such as the other person's looking down, nodding the head "no," crossing arms, or tapping a foot. All suggest "resistance." If we notice this, we can ask immediately what we may have not gotten right.

Havens says that when we truly discern where a patient "lives," the pain we experience may be substantial. For example, when one of our patients feels helpless, we may feel this way too. Should this occur, our brain may try to defend us from feeling that pain without our realizing it. We may feel only a less painful emotion, like boredom or indifference, instead. If this occurs, we should notice it, especially when the feelings are accompanied by derogatory thoughts, such as contempt. We can question such feelings, and then try to change them. We may best try to do this by recalling a time when we felt something like the patient may be feeling. We may then, Havens says, ask the patient or family member if we have gotten it right.

Quist urges clinicians to share their thoughts with patients more than they do now. He discusses an article by Jerome Groopman, in which Groopman relates how he told a patient, Maxine, a 28-year-old teacher, that she was dying.<sup>23</sup> Quist notes that while Groopman allowed readers to "access to his reflections. . . . It seems ironic that these insights [were] not shared with Maxine." Quist suggests Groopman, too, was uncertain, and "hopes for a cure." What if, Quist asks, Groopman shared with Maxine his hopes and fears while allowing her to "do the same with him"? Quist hopes that such mutual sharing could further the existing, implicitly mutual, underlying relationship between clinician and patient.

## CLINICAL CONTEXTS IN WHICH MEDIATION TECHNIQUES MAY BE EFFECTIVE

### Prader-Willi Syndrome

Prader-Willi syndrome (PWS) is a genetic disorder that occurs in about one of every 10,000 to 30,000 births.<sup>24</sup> It is marked by mild-to-moderate intellectual impairment, anger and moodiness, and compulsive eating. It is sufficiently impairing that some experts recommend that clinicians offer to test for PWS prenatally (as for other severe disabilities), so that a woman whose fetus is affected can decide whether to continue her pregnancy.<sup>25</sup>

In this issue of *JCE*, Fournier and colleagues discuss the case of an infant with PWS. Initially, his parents say that they want to withdraw the baby's feeding tube so that he will die: "Our little boy will probably become fat, stupid, and compulsive, due to the Prader-Willi. He will live a life in complete opposition to our own values. We'll have to fight with him constantly to contain his eating urges. We are not sure that we'll be able to love him enough. And how could he be happy if his own parents don't love him enough?"

Their question warrants discussion: Can children be happy if they don't have parents who love them enough? I ask as a springboard to discuss how mediation techniques may be useful in this and similar situations. I will not discuss whether parents should be permitted to allow their child to die. I will discuss how clinicians may help parents come to love their child more, if this is what they say they want but can't find a way to accomplish. Having loving parents may add immensely—and even be essential—for these children to have an optimal quality of life. Having such parents may be much more important than anything else.

Conversely, some parents may have fears and self-doubts from knowing how important they are to their child. Clinicians could help to reduce their fears by, for example, sharing Donald Winnecott's insight that being just good parents is good enough. It is important also that once parents decide what to do, the medical team assures them that they have made a loving choice.<sup>26</sup>

### Happy or Healthy?

Finding an answer to this question is crucial in helping parents to feel increased love for their child. But before discussing this further, it may be useful to have more information about what raising a child with PWS may be like. I will give the example of Piet. This description was provided by others.<sup>27</sup> When Piet was 18, it became increasingly difficult

for his professional caregivers to move him because he had gained weight. This may have been due to having a new girlfriend who expressed her love for him, in part, by giving him food. Piet said he had never been happier, because he was in love with his new girlfriend. His caregivers believed that they had to "forbid" Piet to see his new girlfriend. They had to do this enable Piet to live a longer life—to preserve his health.

Infants with PWS may pose greater difficulties for their parents, their caregivers, and themselves as they grow up. Most infants with genetic syndromes will do better as they age, and this is true of persons with PWS. But they may continue to crave food, and, as they grow up, they become stronger, and, when denied food, they may become angry. When a child becomes so much bigger and stronger, parents have greater difficulties.

This is best illustrated by a parent's description of what she and her husband now experience with their adult child with severe autism. He doesn't speak. When he was younger and would "explode," his mother said, she and her husband could calm him by holding him. Now that he is grown, the best they can do is try to keep him safe, if they can, and other than that, just "try to get out of his way." (I must add that this woman and her husband, and parents like them, notwithstanding their struggles, usually are wholly committed to their child. For example, they may say that when their child smiles, this makes all they do more than worthwhile.)

People with PWS may eat compulsively. Their parents often describe their appetite as voracious. Some parents keep all the food in their house literally locked up. Others eat in secret so that their child doesn't see them eating and want to eat more. Parents who do this are painstakingly and painfully trying to decide how to balance their child's health with his or her happiness. This is the dilemma that Piet experienced after he fell in love.

### Helping Parents Feel Greater Love for their Child—If that's What They Want

To meet a child's needs optimally, parents need to feel as committed as possible to their child, but, as I've said, this commitment need not usually be absolute. Good parenting should be enough. Yet, in rare cases, parents may need to feel more even more committed. Some parents, for example, since their child can walk and climb, take turns staying up through the night to try to prevent the child from harming him- or herself. Others struggle with getting their child even the most basic medical care. For example, some have to find a dentist who will

come to their car to sedate the child, so the child can receive dental care. Clinicians who specialize in treating these children say there is no one way to raise them that is effective. Rather, parents must tailor their approach to their child's needs. They must, to the degree that they can, try to give their child a "say" in whatever way they can, even if this is to do no more than allow the child to choose the color of the jam the child will eat.<sup>28</sup>

To be sufficiently committed to be flexible to this degree, parents have to feel great love for their child. Yet, as was the case for the parents of the infant with PWS whom Fournier and colleagues describe, parents may not feel this love, at least initially. What can clinicians do when parents—like the ones that Fournier and colleagues describe—don't love their child, but want to—or want to feel more love than they currently do? It may not be possible for them to change how they feel, even if they want to do this. The first approach clinicians may use is well known and direct: they can refer parents to the resources most likely to help, including internet sites, literature, support groups, and particularly other parents. Many parents say their experience with their child is by far the most meaningful aspect of their lives.

If clinicians want to explore the possibility of helping parents, clinicians should take the initiative to ask the parents whether they want to connect with other parents who have a rewarding experience with their child, as well as with other parents who lacked a rewarding experience—so the parents can see "both sides." Before asking about this, clinicians should ask parents whether it is okay to discuss this. Clinicians should ask parents whether they have any interest in pursuing this before proceeding.

Parents are likely to appreciate it when clinicians ask first, even if the parents decline the offer. Some parents with a child who has an impairment may even be offended if clinicians don't make this offer. For example, after one woman learned that her fetus was impaired, several of her clinicians recommended that she have an abortion. When she said she wouldn't, none of her clinicians—whom she continued to see throughout her pregnancy—ever asked her again about any concerns she might have for her unborn child. She still resents this, although she loves her child a great deal.

Clinicians may acquire exceptional new skills to help parents and their child. An example is a pediatrician who has developed an extraordinarily successful approach to telling teenage girls that, although they are female in all significant respects, genetically they are male. (These adolescents have androgen insensitivity syndrome, or AIS, which

causes their body to not be responsive to testosterone. Although they will grow up as women, they will never be able to have children.) This pediatrician tells the girls that they are like building blocks that have the wrong genetic label on them, and shows them a film of a woman who is playing with her child who is adopted, to convey to them that they are girls and they can be very happy parents.

Fournier and colleagues describe the approach the medical staff took when the baby was born with PWS—which may have had a similar effect on the baby's parents as the pediatrician's approach had on the girls with AIS. Taking the time to decide what to do may have conveyed to the baby's parents how much the staff valued the child's life. Knowing this, the parents may have been moved to love their child more. Most notably, the staff did not tell the parents what the staff thought the parents should feel.

The importance of the staff's not trying to impose their views on the parents throughout their deliberations may have been most critical in enabling the parents to acquire the love for their child that they later had. This echoes Fiester's claim that clinicians who do mediation must remain neutral.

Clinicians may take this even further. When parents say they don't love their child, clinicians can assure them that many parents feel this way, and while some parents' feelings change, other parents' feelings don't. The goal in saying this is to convey unequivocally to parents that if they don't feel love, they should not feel judged or any shame. Reassuring and validating parents' feelings should, to the greatest extent possible, increase the likelihood that parents may come to love their child—if it is possible for them to change in this way. This is what occurred with the parents of the baby with PWS, as Fournier and colleagues report.

To be effective, clinicians must genuinely feel nonjudgmental toward parents. Clinicians must not disrespect parents because they don't feel sufficient love for their child. Clinicians may too readily assume that they lack such bias, but this may not be the case. Consider, for example, philosopher Jean-Jacques Rousseau, who fathered several children and sent each to a foundling home, where they likely died in infancy.<sup>29</sup> Do we feel 100 percent okay about Rousseau's choice? Or do we feel something else?

Why might reassuring parents help enable them to feel greater love for their child? It could be because this validates what the parents feel, as well as what is beyond their control. Further, we all are prone to responding reflexively by feeling angry and defensive when another tells us that what we feel is morally wrong. This common human proclivity is

what can make teaching ethics difficult. We hope to convey new insights, but in doing so we risk evoking reflexive resentment in the students we seek to teach! The implication of the above considerations is that if parents feel shamed, they may feel defensive or angry. If that happens, they will be less likely to feel increased love for their child. Alternatively, parents may respond by feeling shame and self-loathing. The end effect may be that they will be less able to feel love for their child.

We may find ourselves morally judging parents (and others) in many contexts. Some parents will not visit their child who is in the hospital. If clinicians feel contempt for these parents, the parents will most likely be able to sense that. In actuality, when parents and loved ones don't visit, there are many possible reasons. They may feel that, when they visit, the pain may be more than they can bear.

Conflicts with clinicians may be another reason that visiting a child is painful—and, when that is the case, the harm is iatrogenic! Clinicians who haven't experienced feelings like these may have difficulty imagining how they can be possible. People's sensitivity to emotional pain may vary greatly. One patient I know, for example, saw an animated movie in which a bear standing in a river caught a fish. He said this scene ruined the movie for him when he saw the fish struggling as the bear caught and ate "him or her." This patient's pain for the fish remained after the movie ended. I, mistakenly, have regarded such emotions as trivial. One patient, for example, found and saved a wild bird that was injured. The bird then died. The patient felt bereft. I, in essence, shrugged off the patient's feelings. I thought, this bird wasn't human, and it could only be expected that it would die. Logical, yes. Sound for this patient, no.

Once so affected, many people may be unable to easily shake off such fretful concerns. One patient's joy in life was destroyed when she lost the friendship of a close friend. Before her friend died, the patient said something that the friend had taken the wrong way. I suggested that her friend's severing all contact may have indicated that her friend had a problem, not her. Only after hearing this was the patient able to overcome her guilt and grief.

There is, however, a much stronger reason that clinicians shouldn't judge parents as unloving when they don't visit their child because they find it too painful. This is because parents may not have control over the feelings they have, and/or their feelings may be too strong to overcome. Fournier and colleagues raise the question of which approach clinicians might best use in these situations. The au-

thors say the approach they used might be preferable, but preferable only—or particularly—in a culture like France's, which places less value than we do in the United States on the autonomy of individuals. This raises the question of whether it is ethical that life-or-death decisions regarding infants with a condition like PWS should ever—even in part—vary according to a country's culture.

In response to this specific question (and in general), mediation could be considered an alternative approach to ethics consultation. Mediation gives absolute priority to not imposing, in some way or other, one's own ethical view. It seeks, rather, to explore more deeply where all of the parties involved already "are." Mediators, by not communicating an ethical perspective, may respect parents' feelings to the greatest extent possible—whatever they might be. Parents then should experience less pressure to feel one way or the other. Since they may feel less pressured and more supported, it might be more likely that they would be able to feel increased love for their child. The "Commitment Model" that Fournier and colleagues describe may have worked in this way for the parents of the baby with PWS. These parents may have been influenced by the staff's taking as much time as they did. On the other hand, the infant's parents may have felt greater love over time, with no connection to the staff's actions.

Finally, we might ask whether medical staff should take a position that goes against that of the greater society. Surely, clinicians should have the "right" (as Havens might frame it) to follow their conscience, as the medical staff did in this case. Yet what should staff initially say to parents when the staff may not do what the infant's parents require? Should the staff tell parents early on, for instance, that while the parents can legally choose to let their child die, the staff, en masse, may oppose that, and refuse to carry out the parents' instructions? Respecting parents would suggest so, but it might have the opposite effect from enhancing the parents' love for the infant, for the reasons outlined above. Would this be another argument for mediation in such cases?

#### CONDUCTING RESEARCH ON AD

As noted above, Arias and colleagues write about the ethics of preclinical testing for AD. We know now that AD begins early.<sup>30</sup> Changes occur undetected within the brain 15 to 20 years before patients experience symptoms. Our best chance of finding a cure, then, most authorities currently agree, is to find treatments that will prevent these silent changes from taking place much earlier: starting treatment

before the disease processes establish a foothold, as it were, and then can't be stopped. But there is a problem with doing research earlier: research participants may learn that they are at higher risk for having AD, or of having AD earlier than others, and that awareness may darken their future. It could be that only a small number of research participants would experience this darkening.

Arias and colleagues note that there are "no published research studies regarding the psychological impact of disclosing preclinical biomarker status for asymptomatic individuals." Still, even if those who would be harmed by presymptomatic testing would be few, their future counts. Given this, the question could be raised: How should we weigh the desperate need of millions of persons throughout the world to have a treatment for AD against the possible harms to these few? Researchers could take a number of different approaches that would reduce these harms. I will consider two.

One approach would be to test research participants for biomarkers that would indicate which participants would be at higher risk of having AD, or of having AD earlier, and give only those research participants promising experimental treatments. Participants who are found to be at lower risk would receive only a placebo drug. This approach would allow participants who are at lower risk to avoid any unknown side-effects of an experimental treatment, and only participants who are at higher risk for AD would risk unknown side-effects.

This approach makes sense, as participants who are at higher risk of having AD, or earlier AD, would stand to benefit more from receiving promising treatments, and those at lower risk for AD would not risk having unknown harmful side-effects. Researchers would not be able to tell which participants were at a higher risk because they would not know whether a participant was receiving a promising new drug or a placebo. (This can be achieved by having an outside, third party assign participants to the various arms of a trial.) There is, though, possible additional risk for those who are at a higher risk of having AD or earlier AD. Participants who receive an experimental drug may be able to discern from its side-effects that they are the ones who are receiving the drug, and thus that they are at higher risk for AD or earlier AD. With this knowledge, some of the higher risk participants may feel despair.<sup>31</sup>

Another approach, recently proposed, involves determining which potential research participants might be at higher risk of being harmed emotionally by the foreknowledge that they are at higher risk.<sup>32</sup> In this approach, researchers would try to determine

which potential research participants had previously experienced greater emotional problems.<sup>33</sup> But this approach is also ethically problematic. For instance, attempts to predict which research participants might be harmed would result in false positives. Those predicted to be at higher risk because they have had greater past emotional problems might feel stigmatized. (Havens might observe, "No, they would not *feel* stigmatized, they *would be* stigmatized!")

It is noteworthy that researchers have suggested that the emotional risk for persons who are more vulnerable might be minimized in two ways. First, potential research participants could bring a companion with them to provide critical emotional support. Second, should potential research participants lack a companion because they lack the interpersonal skills to forge and maintain relationships, researchers could help the participants acquire the interpersonal skills needed to maintain close interpersonal relationships, and so acquire companions.<sup>34</sup>

I would go beyond this and suggest that, in all present AD research, it is ideal for participants to bring a companion with them, for several reasons. Foremost among these is that AD is one of the most devastating diseases a person can have. For example, a man who expects he will have AD says he is searching for the right time to commit suicide—before he loses the capacity to kill himself, but not so early that he will miss too much of what he now finds meaningful in his life. By entering research protocols, he is trying to find out more about his risk for AD, and, if possible, when AD is most likely to occur. But he has run into a problem: studies may exclude those who are suicidal. Thus, he lies.

Having the support of another person as one considers entering a protocol and learning that one has or will have AD may decrease potential participants' angst greatly. Further, participants' companions may be the loved ones who later may take care of the participants. Here lies another possible rub: some potential participants may decide that they do not want to participate in research, as they may not want to know whether they are at higher risk for AD. But their companions may want to know more about the risk and what they can expect. Potential participants and companions may disagree on whether the participants should enroll in the protocol.

This is a situation in which mediation may be a great help. This "neutral endeavor" may most enable such "couples" to decide on what they want, together. This may not only result in the best decision. When they are able to make this decision together, they also may fare better in their lives together later on.

### HOW BEST TO RESPOND TO OLDER PATIENTS WHO COMPLAIN OF WORSENING MEMORY

As considered above, finding out that one is at a higher risk of having AD may darken one's future. In research endeavors, it may be that this risk is well worth taking, as the outcomes may benefit millions, profoundly. In clinical care, however, this isn't necessarily the case. Clinicians respond to patients' idiosyncratic vulnerabilities and needs without having to consider the incredibly high-stakes trade-off of research results. Rather, when older patients come in to see their clinician and mention that their memory is worse, a clinician can inform patients of the risks of doing even the most basic memory testing—before beginning testing. A clinician can tell patients that while increased memory problems may be a first manifestation of early AD, or even a precursor, if testing indicates that either of these is the case, it could darken the patients' future. A clinician can also inform patients that losing some memory may be no more than "normal" aging. The clinician could then ask patients what they want to do.

With this information, some patients may not want to be tested, at least at that time. They may choose to wait because they know that they can successfully use the emotional defense of denial. They may believe—and quite probably rightly—that even if they do have early AD, they can live for a while longer "outside the darkness" and enjoy life, believing their worse memory may be a part of normal aging. At least for a time AD can continue to be "out of sight, out of mind." I asked one patient who was older whether she would want to do preliminary testing for AD after I explained the pros and cons of testing and not testing her memory. She said, "No, I do not want to be tested! I still can speak four languages and even if I have AD, I wouldn't want to know. I love my life now and testing could destroy this!" Years later, she does not have AD, and she hasn't spent any time worrying about it.

It makes a great deal of sense for patients who are deciding whether or not to be tested for AD to have a companion with them, for the same reasons as patients who are deciding whether or not they will participate in AD research. In the same way, a patient's companion may want the patient to be tested for AD, so that, if there is a finding of early AD, the patient can be treated early. The medications available for AD now may slow its progression, but for only a few years. A patient who chooses not to be tested may lose the benefit of those few years. If the patient and the companion can decide what to do together, they may fare better later. Me-

diation may enhance this result. This approach, more than any other, may help patients and companions if and when they disagree regarding clinical testing.

### USING MEDIATION TO ACHIEVE A WIN-WIN IN ETHICS CONSULTATION

In this issue of *JCE*, in their article, " 'She Just Doesn't Know Him Like We Do': Illuminating Complexities in Surrogate Decision Making," Margot M. Eves and Bryn S. Esplin discuss a dispute that occurred between surrogate decision makers.<sup>35</sup> The authors suggest seeking a resolution between the surrogates' two "irreconcilable perspectives" by "uncovering the reasons that underlie [this] disagreement." Prior to having serious lung and kidney problems, the patient was a "larger than life" race car technician. He had recently designated his new fiancée as his proxy decision maker. She thought that what he would want most would be to stay alive; his family, that he wouldn't. His fiancée's relationship with his family and clinicians disintegrated. The staff requested an ethics consult. The authors challenge two presumptions we commonly make. Each challenge may make our work more difficult, but, at the same time, would increase our options, and in some cases benefit our patients to a profoundly greater extent.

The first presumption they challenge is that patients have unambiguous values and preferences. What this means, in the most extreme instances, is that patients may have wants that contradict each other. This does occur. I recall, for example, a patient who told me he didn't want more treatments to keep him alive. Just hours later, I saw him again to reconfirm that this was what he wanted. But he then said just the opposite, that he wanted all treatments possible to sustain his life. We have to be open to this possibility. We can't assume that patients have only one "right" preference, although the Procrustean solution that there can be only one preference may make our ethics consultations easier. What then? We might seek, in these situations in which patients seem to have contradictory preferences, to make additional inferences regarding their wants, based on what else the patients have done or said, as Eves and Esplin suggest. A patient who previously was highly devoted to her or his family, for example, might want, we could infer, more than anything else, for family members to continue to get along after the patient dies.

The ethical and clinical implications of making such an inference and acting on it could be staggering. We would abandon giving surrogate decision

makers priority, as the law may require. Instead we would work with family members to see whether they could come to a compromise on which they could all agree. That is the outcome sought in mediation. Ethics consultants who pursue this outcome would violate the moral principle that buttresses our conventional approach: respecting the patient's autonomy more than anything else, by giving the surrogate decision maker at the "top of the list" the final say, and giving those who disagree only the choice of whether to forgive that decision maker.

In the case of the race car technician, the one to choose would be his fiancée. Ethics consultants who urge or accept a "compromise approach" could open up a potentially harmful and unjustifiable slippery slope. It could undermine our present way of seeking to respect patients' autonomy to the greatest degree: to find and follow the views of the person whom we believe can best speak for the patient.

Still, notwithstanding this risk, Eves and Esplin's insight that patients may have contradictory preferences offers us an essentially new option: to possibly seek compromise, based on our best inference, when such uncertainty exists. Ethically this outcome may be preferable to what we often do now: select one view as right and judge any other views as having to be wrong. A second presumption these authors challenge is that patients say the same thing to everyone. The authors believe that we—as our patients—may say different things to different people regarding our wants, for several reasons. We may, for example, alter what we say because we care about a person, and thus want to protect him or her.

The race car technician may, they suggest, have told his new fiancée that he wanted more than anything else to continue to live, to convey to her how much she had meant and continued to mean to him. Eves and Esplin say that patients may be willing to "sacrifice" stating their true preference honestly, in order to "attend to the emotional needs" of a person they love. Such a "new awareness" could have drawbacks; for example, ethics consultants (and others) could speculate endlessly regarding patients' motives. Ethics consultants (and others) could project their own values and views onto patients, without any awareness that they are doing this.

Still, it may be ethically preferable to seek to infer patients' underlying motives, rather than presume that what they tell various loved ones is the same, and represents what they most want, and so their every statement should be given equal, identical moral weight. Eves and Esplin note that, notwithstanding the above concerns, ethics consultants should always take into account the additional con-

siderations they raise in their article. Optimal practice may thus require clinicians to add this consideration to the questions they ask and to the options they consider.

## CONCLUSION

I have discussed Fiester's guidelines regarding mediation and how to apply them. I have suggested how to use mediation techniques to help parents of children with severe genetic conditions like PWS to make decisions about their child when they disagree with clinicians. I have discussed how clinicians' maintaining absolute neutrality and validating what parents do may help parents who want to feel greater love for their child.

I noted how mediation techniques might prove useful when patients and their companions have different views in the research setting or in the clinical setting, and how clinicians might use mediation techniques to reach win-win solutions when surrogate decision makers and clinicians disagree. The pre-eminent presupposition underlying mediation is that when feelings and reason conflict, feelings may well prevail. Thus, if clinicians can help the parties in conflict stay "cool," they may be able to arrive at a conclusion with which they can all agree.

There is much, much more to be found in these exchanges. For example, Fournier and colleagues describe—displaying most admirable courage—how their staff may have been influenced not only by the usual factors, but by the attractiveness of the infant with PWS, who was very cute.<sup>36</sup> Appearance may, too, affect our feelings, as Fiester points out. But what if the infant hadn't been so cute? This question underlines what may be the greatest lesson from mediation: the importance of remaining neutral.

## ACKNOWLEDGMENT

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## NOTES

1. A. Fiester, "Contentious Conversations: Using Mediation Techniques in Difficult Ethics Consultations," in this issue of *JCE*, 26, no. 4 (Winter 2015).
2. E.T. Paquette and I.N. Kolaitis, "Intensive Care, Intense Conflict: A Balanced Approach," in this issue of *JCE*, 26, no. 4 (Winter 2015).
3. V. Fournier, M. Spranzi, N. Foureur, and L. Brunet, "The 'Commitment Model' for Clinical Ethics Consultations: Society's Involvement in the Solution of Individual Cases," in this issue of *JCE*, 26, no. 4 (Winter 2015). In the Fall 2015 issue of *JCE*, Jennifer Kett discussed not *wheth-*

er clinicians should ask parents to decide whether or not to let their child die, but *when*. As Fournier and colleagues say in this issue of *JCE*, all of the clinicians involved in decision making were “ready to acknowledge the principle that the final decision belonged to parents.” J.C. Kett, “Prenatal Consultation for Extremely Preterm Neonates: Ethical Pitfalls and Proposed Solutions,” *The Journal of Clinical Ethics* 26, no. 3 (Fall 2015): 241-9.

4. J.J. Arias, J. Cummings, A.R. Grant, and P.J. Ford, “Stakeholders’ Perspectives on Preclinical Testing for Alzheimer’s Disease,” in this issue of *JCE*, 26, no. 4 (Winter 2015).

5. M.M. Eves and B.S. Esplin, “‘She Just Doesn’t Know Him Like We Do’: Illuminating Complexities in Surrogate Decision Making,” in this issue of *JCE*, 26, no. 4 (Winter 2015).

6. L. Havens, “The Best Kept Secret: How to Form an Effective Alliance,” *Harvard Review of Psychiatry* 12, no. 1 (January-February 2005): 56-62.

7. J. McGreevy, “In the Ethos of the Safety Net: an Expanded Role for Clinical Mediation,” in this issue of *JCE*, 26, no. 4 (Winter 2015).

8. Havens, “The Best Kept Secret,” see note 6 above.

9. N. Quist, “Hope, Uncertainty, and Lacking Mechanisms,” *The Journal of Clinical Ethics* 18, no. 4 (Winter 2007): 35-61.

10. Personal correspondence with Norman Quist, November 2015.

11. H. Reiss and G. Kraft-Todd, “E.M.P.A.T.H.Y.: A Tool to Enhance Nonverbal Communication Between Clinicians and Their Patients,” *Academic Medicine* 89 (2014): 1108-12.

12. This may be difficult for readers to believe. This kind of abrupt change occurs commonly, however, in psychotherapy. It is known as an “Aha!”

13. Emphasis added. Havens, “The Best Kept Secret,” see note 6 above, p. 58.

14. M.P. Kirschen and J.K. Walter, “Ethical issues in Neuroprognostication after Severe Pediatric Brain Injury,” *Seminars in Pediatric Neurology* 22 (2015): 187-95, 191.

15. *Ibid.*

16. Quist, “Hope, Uncertainty, and Lacking Mechanisms,” see note 9 above.

17. E.J. Bergman, “Identifying Sources of Clinical Conflict: A Tool for Practice and Training in Bioethics Mediation,” in this issue of *JCE*, 26, no. 4 (Winter 2015).

18. B. Blatt et al., “Does Perspective-Taking Increase Patient Satisfaction in Medical Encounters?” *Academic Medicine* 85, no. 9 (September 2010): 1445-52.

19. C. Yan, S. Noble, and R. Berggren, “The 6-Word and 55-Word Story: A Self-Reflection Process for Healthcare Professionals in 30 Minutes or Less,” paper presented at the 17th Annual Meeting of the American Society For Bioethics and Humanities, Houston, Tex., 24 October 2015.

20. Havens, “The Best Kept Secret,” see note 6 above, p. 9.

21. J.B. Kayser, “Mediation Training for the Physician: Expanding the Communication Toolkit to Manage Conflict,” in this issue of *JCE*, 26, no. 4 (Winter 2015).

22. T.T. Levin and P.A. Parker, “Preventing and De-escalating Ethical Conflict: A Communication-Training

Mediation Model,” in this issue of *JCE*, 26, no. 4 (Winter 2015).

23. N. Quist, “The Paradox of Questions and Answers: Possibilities for a Doctor-Patient Relationship,” *The Journal of Clinical Ethics* 14, no. 12 (Spring-Summer 2003): 79-87.

24. “Prader Willi Syndrome,” U.S. National Library of Medicine, Genetics Home Reference, <http://ghr.nlm.nih.gov/condition/prader-willi-syndrome>.

25. D. Kotzot, “Prenatal Testing for Uniparental Disomy: Indications and Clinical Relevance Ultrasound,” *Obstetrics and Gynecology* 31, no. 1 (January 2008): 100-5.

26. M.P. Kirschen and J.K. Walter, “Ethical issues in Neuroprognostication after Severe Pediatric brain Injury,” *Seminars in Pediatric Neurology* 22 (2015): 187-95, 191.

27. R.H. van Hooren et al., “Ethics of Prevention; An Interactive Computer-Tailored Program,” *Scandinavian Journal of Public Health* 35 (2007): 503-9, 504-5.

28. R.H. van Hooren et al., “Values in the Care for Young Persons with Prader-Willi Syndrome: Creating a Meaningful Life Together,” *Child: Care, Health and Development* 31, no. 3 (May 2005): 309-19, 313.

29. Rousseau arranged for all his infant children to be consigned to a foundling home, and a biographer notes, “he must have known that most of the babies consigned there were dead within a year.” J. Miller, *Examined Lives* (New York: Farrar, Straus and Giroux, 2011), 233.

30. N. Zagorski, “NIH-Led Partnership Launches Open Data Portal to Speed Alzheimer’s Drug Development,” *Psychiatric News* 50, no. 9 (1 May 2015): 15.

31. This concern has been raised in regard to autosomal dominant AD, which is a fully penetrant, early onset familial form of AD that typically occurs in the mid-30s to late mid-50s. The number of individuals who decide to undergo predictive, pre-symptomatic testing for this fully penetrant early form of AD is low—in one study, less than 10 percent. M. Hooper et al., “The Impact of the Availability of Prevention Studies on the Desire to Undergo Predictive Testing in Persons at Risk for Autosomal Dominant Alzheimer’s Disease,” *Contemporary Clinical Trials* 36, no. 1 (2013): 256-62, 257.

32. L.B. van der Meer et al., “Do Attachment Style and Emotional Regulation Strategies Indicate Distress in Predictive Testing?” *Journal of Genetic Counseling* 24 (2015): 862-71.

33. “Baseline psychological functioning is a better predictor of post-test response than the actual test result itself.” J.S. Roberts, K.D. Christensen, and R.C. Green, “Alzheimer’s Disease as a Model for Genetic Risk Disclosure: Implications for Personal Genomics,” *Clinical Genetics* 80 (2011): 407-14, 411.

34. van der Meer et al., “Do Attachment Style and Emotional Regulation Strategies Indicate Distress in Predictive Testing?” see note 32 above.

35. Eves and Esplin, “‘She Just Doesn’t Know Him Like We Do,’” see note 5 above.

36. For an example of this, see a picture of a child with PWS in N.P. Mann and G.E. Butler, “Prader-Willi Syndrome: Clinical Features and Management,” *Pediatrics and Child Health* 19, no. 10 (2009): 473-8, 475.