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When Family Members Disagree

Edmund G. Howe

Edmund G. Howe, MD, JD, is a Professor of Psychiatry and the Director of Programs in Medical Ethics at the Uniformed Services University of the Health Sciences in Bethesda, Maryland; and is Editor in Chief of *The Journal of Clinical Ethics*. ©2007 by *The Journal of Clinical Ethics*. All rights reserved.

In this issue of *The Journal of Clinical Ethics*, in "How Much Emotion is Enough?" Annie Janvier, a mother and neonatologist, describes the emotional pain she felt when she and her husband were trying to decide whether to sustain their daughter's life. Their baby had been born after less than 25 weeks of gestation. Janvier writes, "Violette started to slowly suck on her pacifier. My husband saw this as a sign: she was improving and there was hope. I answered, 'Even anencephalics can suck: brain stem, brain stem!'"

By saying "brain stem!" Janvier meant that, even though Violette could suck, it did not mean that she would later do at all well; for example, she might never be able to relate meaningfully to others, or to think. That Janvier said this to her husband gives us a hint of the anguish that family members may feel when they must make this kind of decision together. Such anguish can cause permanent rifts in their relationships. (In this discussion, all persons who are emotionally involved in a patient's outcome will be referred to as "family members").

Rifts may occur even when a family member is not a formally designated surrogate decision maker. Craig D. Blinderman provides an example of this in "Jewish Law and End-of-Life Decision Making: A Case Report," in this issue of *JCE*. In this case report, two adult daughters have wholly different views on whether their father would want treatment continued. Only one daughter is the designated decision maker, but she and her sister have markedly different religious beliefs. It is not difficult to imagine how, in situations such as the ones Janvier and Blinderman describe, lifelong rifts may result from conflicts that begin while families make medical decisions. This outcome is exceptionally tragic.

While many unwanted outcomes may be unavoidable, it may be possible to prevent the destruction of love between family members as they make decisions for a patient. It is possible for careproviders to help family members avoid this harm, and I will describe ways that careproviders can help families. (In the following discussion, "careproviders" will include ethics consultants and other careproviders who are able to help family members as they make decisions.)

First, I will suggest that careproviders should make assisting family members a higher priority than it may be now. Second, I will provide specific ways that careproviders can enhance family members' cohesion and decision making. Third, I will suggest another clinical practice that careproviders can initiate: to ask patients routinely, when discussing advance directives, the degree to which patients value family cohesion, and the extent to which patients value cohesion against their own future best interests. Many patients, when asked, will say that they value family cohesion more than anything else.¹

THE IMPORTANCE OF COHESION

The goal of maintaining family cohesion may differ from the goal of respecting patients' autonomy or pursuing patients' best interests. Family cohesion is given greater moral weight in mediation, an alternative to the more prevalent practice of ethics consultation. Nancy Neveloff Dubler states in "Commentary on 'Beyond *Schiavo*': Beyond Theory," in this issue of *JCE*, that her institution has offered mediation for more than 15 years. How different this mediation is, Dubler remarks, from narrow, principled analysis. Mediation is, she continues, more fitting to the enormous depth and intricacy of medical and family situations. Dubler illustrates the greater moral weight that mediation places on family consensus with the case of Mrs. B, a patient with HIV who repeatedly refused to be treated with highly active antiretroviral therapy (HAART). When Mrs. B lost competency, Dubler was willing to entertain that Mrs. B be given HAART despite her previous consistent refusals, because this might have been what Mrs. B would have wanted *for her family*. This case illustrates why careproviders might give family cohesion increased moral weight.

In this case, Mrs. B's daughter thought it was possible that although her mother clearly refused HAART for herself, she might have accepted it later, to meet the needs of her family, to ease her family into her death. Whether family cohesion is what some or most patients want — not to mention what their families want — is an empirical question. Regardless, careproviders can ask patients' families what they think the patient would have wanted, as Dubler does, even when the patient wasn't asked when capacitated.

Dubler's language is revealing, as it shows the extent to which she believes that Mrs. B might have wanted to help her family. Dubler asks Mrs. B's daughter what she thinks her mother might say to her, as it is obvious that the daughter is so loving and caring. As it turns out, even though Mrs. B consistently refused HAART, the medical team might have considered it, at the family's request, because Mrs. B had a fever and HAART might have provided palliative, not curative, care in hospice. This suggests a question for our greater society: should such options be given to families in cases when palliative care *isn't* an option?

Notwithstanding this question, careproviders can ask a patient's family, when they can no longer ask the patient, what the patient valued most. There are many reasons that patients assign primary value to family cohesion, and many of these reasons are implicit in the case report of the father and his two daughters that is provided by Blinderman. Presumably both sisters felt great loss when their father became so ill. The daughter who had surrogate decision-making authority may have experienced it as an exceptional burden; Blinderman suggests that this is often the case. But the other daughter may have felt hurt when her father did not choose her as his surrogate decision maker, or did not choose to assign the responsibility to both of his daughters. This might have set the seed for greater conflict later on when the sisters disagreed about treatment, and the designated sister had exclusive, overriding authority. If there was discord and the sisters couldn't resolve it, their suffering may have been increased because, after losing their father, they may have also lost each other's friendship and emotional support.

Patients may anticipate this and strive to avoid it. They may appoint all siblings surrogate decision makers — or none. In this regard, I think of a patient I knew who was dying from his illness. He told his adult children explicitly and repeatedly that what he wanted most was for them to continue to care for each other and to continue to get together after he died. When he died, his children flew together across the ocean with his ashes to his birthplace, as he had previously asked them. He told his children that spreading his ashes there wasn't what was most important to him — what was most important was that, as a result of doing this together, it might increase the chance that they would remain close. And they have!

Conflict at the end of life can drive family members apart. It is inevitable for family members to have somewhat different preferences. In addition, family members often have past experiences with each other that can exacerbate these conflicts. Another possible source of conflict is that all persons have ambivalent feelings. Family members may have very strong feelings regarding what should be done at the end of a loved one's life. When another person, such as the patient's surrogate, makes the decision, they may irrationally blame this other person for the parts of their ambivalence that weren't fulfilled.

Such ambivalence is illustrated in a short story, "Life Support," by Dorothy Howe Brooks.² In the story, Cynthia and her husband John are divided over what to do when their newborn child has a heart defect and needs cardiac surgery. The baby's only hope is this surgery, but his chances, even with surgery, aren't good. Doctors had whisked the baby away from Cynthia moments after he was born, and her husband is the one to tell Cynthia that their son, although surviving, is just barely alive. Cynthia reaches for John, holds him close and tight, and they cry together.

Three weeks later, when the couple visit their son in the hospital, John tells Cynthia that she *must* agree that the baby have surgery. However, when Cynthia looks at their son, she sees that it is death, not life, that the machines are preserving. Later, Cynthia dreams that while she is breast-feeding the baby, he stops sucking. He looks as if he is only asleep, but she knows that he isn't. She feels calm. She doesn't cry out or call for help, because she feels certain of her baby's needs. It is this certainty that makes her know that this is a dream.

It is easy to imagine how Cynthia's ambivalence, even as it is described only briefly in this fictitious piece, could have eroded her relationship with her husband over time. She may have consciously or unconsciously denied the part of her that opposed the surgery when she agreed to it, feeling pressured by her husband's demand. If their son has a bad surgical result, she may blame her husband.

If careproviders can assist patients' families in recognizing and discussing their ambivalent feelings before end-of-life decisions must be made, it is possible that it could reduce the possibility that the family members will lose their love for each other later. Primarily, careproviders can learn to listen for the feelings that family members haven't expressed. If some family members express their feelings but other family members don't, careproviders can ask how it is that some family members have feelings that seem very different. If the other family members then express their feelings, careproviders can explicitly say that although the feelings expressed may seem wholly different, at their core they may be alike.

For example, in "How Much Emotion Is Enough?" Janvier and her husband disagree about treatment for their baby daughter, but both want what is best for her; similarly, the daughters of the patient who Blinderman describes disagree about what should be done, but both seem to want what is best for their father. If family members agree that their loved one valued family cohesion, careproviders can help them see that they share the same core emotion, and this may help them not to blame each other later.

Careproviders can do this, of course, under limited conditions. The patient cannot have expressed a clear prior preference regarding treatment, and the patient cannot have a clear better interest. The use of these two criteria has a precedent. Parents, like Janvier and her husband, can decide what their children's careproviders should do when there is no compelling ethical reason that they — or anyone else — should decide one way or another. Infants and young children have no prior preference. Thus, what I have been suggesting extends these options from parents and young children and infants to family members who face making decisions in analogous circumstances for incompetent adult patients who have not expressed themselves, and whose preferences and best interests are unknown and are not inferable. Janvier and her husband decided as they did, in part, it appears, to preserve family cohesion. Janvier explains, "I . . . chose to listen to him because I love him, *because we had to be on the same side*, and because I couldn't fight for my daughter's death." (Emphasis added.) Janvier writes, years later, "*We made a good decision because it is the one we made at the time.*" (Emphasis added.)

How might careproviders take this initiative? I offer my experience as a member of an ethics consult team that tried this decades ago. We met with the wife and five family members of a patient who was in a coma. The patient also had untreatable cancer. His coma was due to an infection inside his body that antibiotics couldn't reach. His careproviders believed that surgery could effectively treat the source of this infection, but that even then, due to his cancer, the patient would survive for six months, at the most. The wife said that her husband wouldn't want the surgery, and that she had discussed this with him. The patient's family members, to a person, said that he would want the surgery: "He's a fighter."

The ethics consultants thought the wife had two choices. She could maintain her views, make her decision, and ask her husband's family to forgive her. Or she could decide that what her husband would want

most was that she and his family come up with a decision that they all could live with — together. The wife chose the latter. One reason the consultants thought this might be what the patient would want most was that the patient and his wife had a young child, and this choice might help the wife and child and family stay together later on.

Everyone at the table accepted a compromise decision: the patient would have surgery and a do-not-resuscitate order. The patient recovered from the surgery and died six months later, as expected. More happily, his widow and child remained close to his family.

HELPING FAMILIES STAY CLOSE

In this issue of *JCE*, Arthur L. Caplan and Edward J. Bergman, in their article "Beyond *Schiavo*," assert that ethics consultation, as it is now carried out, is too often ethically flawed. They suggest that, in selected cases, careproviders should seek mediation rather than ethics consultation. There is an additional ethical problem that Caplan and Bergman don't discuss, which is how family members may react psychologically to the process of ethics consultation.

In "Beyond *Schiavo*," Caplan and Bergman assert that ethical reasoning often can't produce a single best answer, and, when this is the case, family members, not careproviders, should make the decisions entirely, because their interests are much more at stake. A similar argument, to give parents this authority in cases involving their children, is even more compelling. Caplan and Bergman fear that all too often such decisions are made, directly or indirectly, by ethics consultants and committees or other careproviders — and this fear is supported by some recent studies.³ For instance, Autumn Fiester states in "Mediation and Moral *Aporia*," in this issue of *JCE*, that recent national survey data indicate that 46 percent of the ethics consult services surveyed respond to requests for consultations with a *single* recommendation, and that nearly half of the surveyed services reach a recommendation via vote.

This is problematic because many times there is no single, self-evident, right resolution. Fiester also states that consult services should not "claim moral authority when there is none," and that the ethical reach of a service should not "exceed its grasp." Given these reasons, Caplan, Bergman, and Fiester argue, patients' family members, not consult services, should make the decisions. This conclusion is supported by the finding that some consult services reach a recommendation by voting. Recommendations achieved by vote may differ, depending on how many and which members of a consult service are present on the day of the vote; or, for that matter, which consult service are asked for a recommendation. Because these variables are open to chance, to some extent their recommendations are arbitrary. Caplan and Bergman and others suggest that careproviders should, instead, refer family members to mediators, who will assist family members in discovering and implementing a decision that is based on their own views. This is preferable, they say, to imposing the ethical insights of others — even inadvertently — on family members.

The flip side of the data Fiester presents indicates that many consult services don't make a single ethical recommendation and don't make decisions by vote. This is consistent with current guidelines for ethics consultation.⁴ The problems attributed to ethics consultation may be much more a problem of how ethics consultation is *practiced*, than how it *should and could work*. Yet ethics consultants who know better may still be vulnerable, even unwittingly, to imposing their ethical views on others.

A recent verbatim account of some ethics consultants' interactions with families described in the literature is illuminating.⁵ One ethics consultant repeatedly gave family members appropriate comfort and reassurance; often, however, just after doing this, the same consultant repeatedly prompted a physician present to elaborate on the negative results that family members could expect if, as they desired, efforts were made to keep their loved one alive. The authors of the study call the physician's repeated description of the negative results the "*dire* scenario." In another case from the same study, family members repeatedly provided a consultant with "poignant details" of the patient's life. The authors of this study speculate that family members repeatedly did this in the hope that they would make the staff members present "understand why their loved one would want to live." The ethics consultant countered this by "reinterpreting the [patient's wishes] or behavior in a way that supported the staff's recommendation to limit care."⁶ This same ethics

consultant followed up, repeatedly, by "reframing" what the consultant believed that the family *should* be experiencing. For example, the consultant, after comforting the family, sympathized with the difficulty they must be having in accepting an interpretation of the patient's wishes that was contrary to their own!⁷ This last bit of behavior particularly illustrates a concern that ethics consultants may, although wholly dedicated to their patients, impose their ethical views without even knowing it.

Another possible negative effect is that family members may see their own values differently after hearing an ethics consultant's views. The family's views may be completely valid, but, after hearing from a consultant, they may start to doubt the validity of their views. This may result in at least three suboptimal responses. (1) The family may overly comply with what the consultant views as best: they may overtly agree with what they are told, even though it isn't what they really feel or believe. (2) The family may become more rigid in their views; they may hold to their mindset more strongly in response to what they are told. This may become a serious problem, because the family members may have otherwise changed their views, over time. (3) Family members may try to "win over" or game the care team; they may choose consciously to appear more compliant, for example, in the hope that by doing this, they may be more pleasing to the care team, and ultimately, get more of what they want.

This would seem to be exemplified by the case example of the family who provided the ethics consultant with poignant details of their loved one's life, to help staff members understand why the patient would have wanted to live. Sadly, the relationship between family and the care team and their interactions became a charade. Is there a way to avoid this? I believe there is. When a careprovider first meets with a patient's family in circumstances like this, the careprovider, when appropriate, can tell the family that he or she has training and experience in medical ethics, and *may* have insights that will be helpful. At the same time, the careprovider should explain that offering these insights could be harmful, because if the careprovider seems to favor one decision, the family might find it more difficult to follow their own beliefs. The careprovider can say that, above all, he or she doesn't want the family to adopt anyone's views but their own, and the careprovider can ask the family what they want, for example:

- Would it be useful for the careprovider to help family members explore their own views and achieve consensus?
- Would ethical insights be useful, if the careprovider has any to share?

Careproviders should assure family members that, whatever their decision, they can later change their minds. Careproviders can also ask family members how they would prefer to make a decision — should all family members agree, or, for example, a majority.

MAXIMIZING A FAMILY'S POTENTIAL

The careprovider should, at some point, ask which family members should be present when a decision is made. I suggest that careproviders can only go one way on this: they must inform family members that ethically, if not also legally, the family must include all equal members of their family, however they may define "family." Careproviders should say that this requirement is not a personal, idiosyncratic view, but is the present ethical and legal consensus.

Careproviders should begin a consult by insuring that all of the family members have the same medical information. Then they can go on to ask the family members what the patient was like, as Dubler and others advise. This may particularly help family members decide what the patient would have wanted. Careproviders can then ask the family if the patient would have most wanted family cohesion. What is most crucial is how family members feel, as their emotions may determine what they will decide, and over time, will carry with them in the future.

ESTABLISHING FEELINGS OF SAFETY

Once careproviders have insured that all family members have the same, adequate information and have asked what the patient was like, what is most important is for family members to feel free to openly express

what they feel and believe. In this issue of *JCE*, in "A Commentary on Caplan and Bergman: Ethics Mediation — Questions for the Future," Robert Arnold and colleagues state this succinctly: "neuro-cognitive data indicate that when people are emotional, the cognitive centers of the brain are less effective." Careproviders should therefore attend first to helping family members feel safe. Most of us feel safe when we believe that we have some control.⁸ Based on this, in these situations careproviders can invite family members to bring in any other persons whose presence would help them feel more at ease — this might even include a lawyer! Families probably will decline this, yet, as in most instances, taking the initiative may, of itself, serve to enhance a sense of trust and greater safety.

Careproviders must also allow families greater control over the amount of time they feel they need to make a decision. This might seem contraindicated, as it may affect the patient's outcome. If the decision is truly the family's to make, however, they should be able to decide that they need more time. Families may decide they need more time as a whole, or that only one member needs more time to be comfortable with a decision. If for some reason time is limited, careproviders should state this, along with any other known or possible limitation, at the outset. This is what Dubler did when she informed Mrs. B's daughter that Dubler did not know whether the care team would agree to provide HAART in hospice. Careproviders can also tell family members that they will probably need some time to absorb what is happening, and then time to emotionally adjust. Since most family members will need time to absorb and adjust, careproviders should be prepared to repeat themselves.⁹ Family members also may need time to retreat into themselves, and the time needed for this retreat may differ for different family members.¹⁰ Many families may need additional time to be able to achieve consensus, and careproviders should tell them this at the outset, as well.¹¹

VALIDATING VIEWS

Validation involves helping family members to feel heard and understood. Careproviders can ask family members to agree to ask other family members what they are feeling, because if they can understand what other family members are feeling, they will be better able to achieve consensus.¹² How might validation work in actual practice? Here is one example from my experience.

I was involved in a consultation at which all of the members of the patient's family sat at one side of the table and all of the members of the care team sat at the other. I sat at one end. All members of the care team believed that continuing all-out care to the patient was futile. The family members all thought all-out care should be continued. One family member, acting as a leader, said it was possible that the patient could recover. I said, "You're right. She could. She could get well at any time, even though all of the doctors say it is most unlikely." The careproviders tried to muzzle their rage at me. But the family leader replied, "Well, maybe the doctors are right. Perhaps we should let Mama die with dignity, since she most likely will die soon, anyway." At this, the family changed their minds, and the many medications Mama was being given were stopped. (Perhaps I should end the story here, but I must relay what happened next . . . Mama got well and went home!)

ADVANCE DIRECTIVES

Many patients, when asked, will say that what they most want is for their family members to remain close. In the case that Dubler describes, Mrs. B hadn't discussed with her careproviders what she most wanted in regard to her family. If Mrs. B's careproviders had discussed this with her when she was competent, this might have helped resolve her daughter's later uncertainty. Given this, careproviders might ask all patients, when they discuss advance directives, what they want for their families, and specifically if family cohesion is important to them. Patients who say that they value family cohesion highly could proceed in any of the following ways.

Patients could make all of their family members surrogate decision makers, and could allow their family's decision to prevail only when all can agree. This legally is plausible; in Maryland, for example, in some contexts when there is more than one equal surrogate and they remain divided, the decision may be referred to an ethics committee.

Or patients can try to enhance family cohesion by giving none of their family members decision-making authority. This way all of their family members will remain disempowered — but equal. This approach may have a subtle advantage, because some people who know that they may be named as a surrogate, even against their best intentions, unconsciously begin to distance themselves from the patient. This may occur automatically and outside their awareness, much like anticipatory grief. When patients learn that this can happen, they may want to avoid possible distancing.

Finally, here is the option that I favor most: patients can get family members together to discuss it, and choose together how to proceed. This will give them experience should they later have to make treatment decisions for the patient.

CONCLUSION

The focus here has been on a tragedy that is often overlooked. Siblings and other family members all too often lose their love for each other when a loved one is severely ill, and they must make a decision, but they disagree over what should be done.

My primary intent has been to enhance careproviders' ability to help family members maintain their close relationships should they need to make decisions involving a loved one. In this regard, I think of an image that Janvier writes presents: "I remembered, vividly, entering a parent's room and witnessing a mother pumping [breast milk] after her baby's death: she was crying almost at the same rate as the pump, squeezing her milk to throw it away, pumping for a dead baby. I thought this was one of the saddest images I had seen."

We can only hope that, whenever this recurs, even if there have been disagreements on what should be done, mothers in this situation, squeezing milk but having no baby, will still have their husband by their side.

MASKING OF THE CASE

Details in cases throughout this article have been changed to protect the identities of patients and family members.

NOTES

1. Patients may, in general, be more concerned about their family members' welfare than about what happens to themselves. J.T. Berger, "Patients' Interests in their Family Members' Well-Being: An Overlooked, Fundamental Consideration within Substituted Judgments," *The Journal of Clinical Ethics* 16, no. 1 (Spring 2005): 3-10. Patients are particularly concerned about adding to their families' burdens. P.A. Singer et al., "Reconceptualizing Advance Care Planning from the Patient Perspective," *Archives of Internal Medicine* 158 (1998): 879-84. See generally M. Meeker and M. Jezewski, "Family Decision Making at End of Life," *Palliative and Supportive Care* 3 (2005): 131-42; K.H. Abbott, J.G. Sago, and C.M. Breen, "Families looking back: One Year after Discussion of Withdrawal or Withholding of Life-Sustaining Support," *Critical Care Medicine* 29, no. 1 (2001): 197-201; J.M. Breslin, "Autonomy and the Role of the Family in Making Decisions at the End of Life," *The Journal of Clinical Ethics* 16, no. 1 (Spring 2005): 11-9; and E.K. Vig et al., "How Surrogates Navigate End-of-Life Decision-Making," *Journal of the American Geriatric Society* 54 (2006): 1688-93.

Family members who make decisions for a patient as a group make decisions more readily than do individual surrogates. M.H. Limerick, "The Process Used by Surrogate Decision Makers to Withhold and Withdraw Life-Sustaining Measures in an Intensive Care Environment," *Oncology Nursing Forum* 34, no. 2 (2007): 331-9, p. 337.

When careproviders encourage family members to reach a consensus decision that all can accept, they may benefit the patient as well as the family, as family "dysfunction can unduly prolong patients' care," according to S.F. Buchanan et al., "A Mediation/Medical Advisory Panel Model for Resolving Disputes

about End-of-Life Care," *The Journal of Clinical Ethics* 13, no. 3 (Fall 2002): 188-202, p. 200. See finally D.W. Brock, "What Is the Moral Basis of the Authority of Family Members to Act as Surrogates for Incompetent Patients?" *The Journal of Clinical Ethics* 3, no. 2 (Summer 1992): 121-3; C. Levine and C. Zuckerman, "The Trouble with Families: Toward an Ethic of Accommodation," *Annals of Internal Medicine* 130, no. 2 (19 January 1999): 148-52.

2. D.H. Brooks, "Life Support," in *If I Had My Life to Live Over I Would Pick More Daisies* (Watsonville, Calif.: Papier-Mache, 1992).

3. See also A. Fiester, "The Failure of the Consult Model: Why Mediation Should Replace Consultation," *American Journal of Bioethics* 7, no. 2 (February 2007): 31-2, and E. Fox, S. Myers, and R.A. Pearlman, "Ethics Consultation in United States Hospitals: A National Survey," *American Journal of Bioethics* 7, no. 2 (2007): 13-25. In "The Failure of the Consult Model," Fiester states, "If at best an ethics committees recommendation is its best guess, this is not a good enough rationale to dictate the course for a patient," p. 32.

4. Family members participate in 7 to 12 percent of decisions in the intensive care unit. Limerick, see note 1 above, p. 331. Family members are consulted in 65 to 90 percent of ICU cases in which patients die. Limerick, see note 1 above, p. 332.

5. L.T. Watkins et al., "The Role of the Bioethicist in Family Meetings about End of Life Care," *Social Science & Medicine* (2007), online, 7 of 15.

6. Ibid.

7. Ibid.

8. Careproviders may even choose to turf medical decisions to family members when this may help family members determine what they want. The failure of the treatments to achieve an appreciable effect may help family members to make a decision. Limerick relates, for example, that one family member said, "They'll ask us if we've got to raise the oxygen again. I said, "That's enough." ' ' Limerick, see note 1 above, p. 336.

9. Ibid., p. 335.

10. Ibid.

11. E.F. Hiltunen et al., "Family Decision Making for End-of-Life Treatment: The SUPPORT Nurse Narratives," *The Journal of Clinical Ethics* 10, no. 2 (Summer 1999): 126-34, p. 129.

12. Vig et al., see note 1 above.