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At the Bedside

When Family Members Disagree

Edmund G. Howe

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

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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 de-

scribes 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 Accomodation," *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 Dai-*

sies (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.

Features

Beyond *Schiavo*

Arthur L. Caplan and Edward J. Bergman

In the aftermath of the *Schiavo* case, commentators continue to focus on the rights and wrongs that characterized this tragic high-profile saga from its inception.[1] Far less attention has been devoted to the lack of effective mechanisms by which differences between patients, surrogates, families, and healthcare providers can be addressed with dignity, a modicum of privacy, and the hope of consensual resolution.

Over the past 20 years, bioethicists and dispute-resolution professionals have begun to explore the use of bioethics mediation as a means of processing the especially painful class of disputes in which families disagree with one another, or with doctors, about the care of those who cannot communicate.[2] One salient characteristic of these controversies is the fact that each participant, whatever his or her role, invariably lays claim to the same concern — the best interests of the patient. While the patient's interest can be a stand-in for participants' fears and anxieties — a spouse's dread of being alone or a physician's discomfort with losing a patient — their positions are rarely a by-product of malice or ill will. None of these "stakeholders"[3] may be conversant with the language of bioethics, but they may, nonetheless, be unwitting advocates of sound bioethical principles.

For example, a wife pleading for adherence to her husband's long-stated preference for death over respirator-dependent life is also an advocate for the principle of patient autonomy.[4] A son who asks that his father be afforded every means available to medical science for the cure of his disease evidences a commitment to the principle of beneficence,[5] or the duty of a physician to help the patient. A physician who states that a pati-

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ent's condition is futile and concludes that heroic interventions will engender needless suffering is an advocate for non-maleficence[6] or the duty to do no harm. Finally, family members who argue that, for religious, cultural, or personal reasons, they cannot abide death absent every attempt to preserve life, embody the bioethical principal that healthcare decisions must be made in the context of the individual's total life and value system so that family concerns, religious beliefs, and cultural norms (among other factors) must be given weight so long as the patient is not, in consequence, allowed to suffer unreasonably.[7]

What these examples reveal is the frequency with which end-of-life-disputes are not ethical controversies susceptible of definitive answers reached through ethical reasoning. Abstract principles articulated as dispositive by designated "experts" fail to capture, and arguably to respect, the unique and complex nature of each such individual decision-making process.[8] These are profoundly human conflicts in which each of the participants can be seen as a proponent of a particular balancing of ethical principles in the context of relationships, personal history, and competing value systems. Some commentators, emphasizing the role of narrative in clinical ethics, posit that patients themselves are the true ethicists whose moral choices unfold as the product of life stories that embody the meaning and ethics of ordinary life reflected in the sufferers' individual experience.[9]

Hospital ethics committees perform ethics consultations for individual cases in addition to their role in the formulation of institutional policies.[10] Many observers agree that, whether by virtue of insufficient training and experience, procedures focused on producing a single, ethical imperative rather than a range of acceptable options, or reducing clinical ethics to decision by majority, or, worse, decision making driven by fear of legal liability, ethics committees have not always fulfilled the needs of acutely distressed individuals for assistance in end-of-life decision making.[11]

A secondary concern is that some ethics committees, whatever their shortcomings, receive only a minuscule number of consultation referrals in relation to the number of events that might benefit from outside intervention.[12] Disputes in this realm encompass strained relationships, personality differences, cultural considerations, communication and information issues, and the need for a forum that can help empower those persons on the disadvantaged side of a dramatic imbalance of power.

Unless a participant is incompetent, ill-informed of the medical or contextual facts,[13] or possessed of motives that prove inconsistent with his or her claimed commitment to the patient's best interests, one stated treatment preference is often not more, or less, ethical than another.[14] While such conflicts are often subjected to traditional ethical analysis, the mediation process is well-suited to fleshing out the existence of disparate elements that may be driving a dispute.[15]

A number of commentators have characterized the ideal physician-patient relationship as patterned on a negotiation model.[16] If such is the case, it appears logical that mediation, a form of assisted negotiation, be utilized when the unassisted physician-patient negotiation has gone awry. Genuine differences frequently exist between rational individuals in possession of the same facts and devoid of ulterior motives. Ideological battles waged in the media, as in the *Schiavo* case, foster public perception of family members as saints and sinners, seeking judicial validation of their asserted monopolies over decision making or simply righteousness. What actually occurred in *Schiavo,* and occurs in similar cases, is a failure of the patient's most significant others to reach consensus on a course of action. In such cases the court must determine, not which preference is ethically or even legally correct, but which individual is legally empowered to make a decision in the absence of agreement, and, in some instances (dependent upon the statutory and case law of the jurisdiction), whether man-

dated criteria have been applied by the decision maker.[17]

In the majority of cases, a responsible agreement that does not violate the right of a patient to choose (either in an express writing or by clear evidence of intent as defined by the law of the jurisdiction) and does not impose unnecessary suffering on the patient will be viewed as benign by both legal and bioethical criteria. Parenthetically, such agreements are unlikely to be attacked by third parties unless a legitimately interested party has been excluded from the process. What may be needed and useful in many situations is a form of bioethics mediation to resolve disputes or to prevent them from emerging.

Mediation of end-of-life-disputes is not a simple task. Talent, skill,[18] and training[19] are required of the bioethics mediator. Models for the effective use of neutrals in clinical settings are only in their infancy. Resources must be dedicated to the development of this specialized field — to professional training, scholarship, credentialing, criteria for success, and public awareness.

The unique aspects of bioethics mediation place special demands on the mediator. Neutrality and the perception of neutrality are jeopardized by the frequent status, to date, of bioethics mediators as employees of hospitals where cases are being considered.[20] Alternative provider options should be developed and studied. When the mediator is connected to the hospital, an exploration of steps to diminish the threat to neutrality should be undertaken. When the mediator is independent of the hospital, questions nonetheless persist regarding the plausibility of neutrality when the mediator is charged with enforcing legal and ethical norms as constraints on the parties' self-determination.[21]

Patients and families are at the extreme end of a power imbalance in disputes with healthcare professionals who are versed in a vast and complex scientific literature. Lay participants are further handicapped by the psychological and physical debilitation associated with the illness or injury from which they suffer. Parties to a bioethics mediation are rarely represented by legal counsel. Hence, the mediator plays a significant role as communicator and translator of otherwise opaque information in the service of leveling the playing field.

But the mediator is not the patient's personal representative. The beneficial aspects of the mediator's possession of subject matter expertise in various aspects of medicine, beyond an understanding of legal and bioethical norms, seem evident. How and where this education is to be provided and what constitutes a reasonable, measurable standard of expertise has yet to be determined.

Confidentiality, a signature element of the mediation process in most non-bioethical healthcare contexts,[22] is subject to inherent limitations in bioethics mediation because the patient's chart must remain accessible to subsequent healthcare providers who are not parties to the mediation.[23] State laws differ with respect to the privileged nature of mediation communications and when these may be discoverable.[24] To what extent, if any, should the mediation be charted? Will this have a chilling effect on candor within the process? If so, can these effects be minimized?

While all of these obstacles to the application of classical mediation paradigms in the healthcare arena are daunting, capitulation to such challenges denies stakeholders in the dispute a previously nonexistent forum in which they are given a voice, access to comprehensible explanations, an outlet for catharsis, and an arena in which to express dissent. Bioethics mediation confers similar benefits upon members of the healthcare team who may or may not have decision-making power in the event of nonagreement.

Since it is triggered by crisis, bioethics mediation inevitably demands an outcome. If mediation is unsuccessful, decisions will be made by those empowered to act, with or without unanimity amongst the stakeholders. If the less-empowered stakeholders disagree, they can appeal to the hospital administration or petition a court of law for intervention in ac-

cordance with the substantive and procedural requirements of the jurisdiction. While much commercial mediation is also conducted in the shadow of the law,[25] so that failure to reach a consensual resolution also leads to a litigated rather than negotiated outcome, many disputes outside the healthcare sphere can remain in suspense for years until the pressure for resolution becomes acute. The implications of this distinction for the conduct of bioethics mediation have not been fully explored. Commentators in the realm of international relations have postulated that crisis negotiations in a diplomatic context possess unique dynamics.[26] Experience may demonstrate that special crises are applicable in end-of-life disputes.

Technological advances in medicine will inevitably continue at a remarkable rate. Our ability to sustain life at various suboptimal levels will surely increase commensurately, rendering end-of-life disputes even more commonplace than at present. While a diversity of views on such delicate topics is inevitable, and reflects the complexity of life itself, participants in this most personal and definitive act of decision making must be afforded an appropriate forum in which to engage such profound issues with clarity and respect.

The politicization of the Schiavo family's painful and acrimonious struggle over the fate of their wife and child[27] clearly manifests society's failure to invest in processes that facilitate constructive dialogue for reconciliation of divergent, emotionally charged perspectives on life-and-death issues. This failure carries potentially damaging consequences for an increasing number of families. We believe the time has come for bioethicists and individuals associated with hospital ethics committees to invest in the development of bioethics mediation. We owe that to the vast number of people who now, or inevitably will, face awesome confrontations with mortality in hospital settings. Bioethics mediation carries the promise of a significant contribution to a pressing issue in American healthcare in a manner that complements existing skills and infrastructure while greatly expanding the opportunity for consensual resolution of a significant class of disputes.

NOTES

1. A.L. Caplan, J.J. McCartney, and D.A. Sisti, ed., *The Case of Terri Schiavo: Ethics at the End of Life* (New York: Prometheus Books, 2006).

2. N.N. Dubler, "Mediation & Managed Care," *Journal of the American Geriatrics Society* 46, no. 359 (1998) (proposing a bioethics mediation model in the managed-care context); see also R.J. Wagener, "Introducing Medication to Hospital Ethics," *California Law* (December 1992): 69 (noting the formation of a center specializing in bioethics mediation); see also M.B. West and J.M. Gibson, "Facilitating Medical Ethics Case Review, What Ethics Committees Can Learn from Mediation and Facilitation Techniques," in *Bioethics: An Introduction to the History, Methods, and Practice*, ed. N. Jecker, A.R. Jonsen, and R.A. Pearlman (Sudbury, Mass.: Jones & Bartlett, 1999), 293-99; see also Y. Craig, "Patient Decision-making: Medical Ethics and Mediation," *Journal of Medical Ethics* 22 (1996): 164-7; see also J.M. Gibson, "Mediation for Ethics Committees: A Promising Process," *Generations* 18, no. 4 (1994): 58-60.

3. B. Gray, *Collaboration: Finding Common Ground for Multiparty Problems* (San Francisco, Calif.: Jossey-Bass, 1989), 5, 14-5, 62-6, 168-9, 261-64.

4. T.L. Beachamp and J.F. Childress, *Principles of Biomedical Ethics,* 5th ed. (New York: Oxford University Press, 2001).

5. Beauchamp and Childress, see note 4 above.

6. Beauchamp and Childress, see note 4 above.

7. A.R. Jonsen, M. Siegler, and W.J. Winslade, "Introduction," in *Clinical Ethics,* 5th ed. (New York: McGraw Hill, 2002), 2-11.

8. K.D. Clouser and B. Gert, "A Critique of Principlism," in Jecker, Jonsen, and Pearlman, *Bioethics: An Introduction to the History,*

Methods, and Practice, see note 2 above, pp. 147-57.

9. See, e.g., R. Charon and M. Montello, ed., S*tories Matter: The Role of Narrative in Medical Ethics* (New York: Routledge, 2002).

10. D.E. Hoffman, "Mediating Life and Death Decisions," *Arizona Law Review* 36 (1994): 821, 822-3, 842-8 (explaining how ethics committees arose to provide a multi-disciplinary approach to assist families with difficult cases); see also J. McIver, "Mediation for Ethics Committees: A Promising Process," *Generations* 94 (1994): 58.

11. See E. Fox and R.A. Pearlman, "Ethics Consultation in United States Hospitals: A National Survey," *American Journal of Bioethics* 7, no. 2 (2007): 13-25; Hoffman, "Mediating Life & Death Decisions, see note 10 above (naming structural, process, and substantive concerns associated with ethics committees); A. Fiester, "The Failure of the Consult Model: Why 'Mediation' Should Replace 'Consultation'," *American Journal of Bioethics* 7, no. 2 (2007): 31-2.

12. Fox and Pearlman, see note 11 above.

13. See e.g. D. Franklin, "Come Again? Good Medicine Requires Clarity," *New York Times,* 24 January 2006 (discussing problems of providing enough information to obtain patients' informed consent, particularly for those with low levels of literacy).

14. Hoffman, "Mediating Life & Death Decisions," see note 10 above (stating some ethics committees appear uncomfortable with trying to determine one ethical answer, believing a range of options are acceptable); Society for Health and Human Values — Society for Bioethics Consultation Task Force on Standards for Bioethics Consultation, *Core Competencies for Health Care Ethics Consultation* (Glenview, Ill.: American Society for Bioethics and Humanities, 1998), 7 (discussing the ethicist's role in helping families choose between more than one morally acceptable option).

15. See e.g. C.W. Moore, *The Mediation Process; Practical Strategies for Resolving Conflict,* chaps. 9 and 10 (San Francisco, Calif.: Jossey- Bass, 1996), 213-43; D. Golann, *Mediating Legal Disputes: Effective Strategies for Lawyers and Mediators,* chap. 2 (Boston: Little Brown, 1996), 39-59; Hoffman, "Mediating Life & Death Decisions," see note 10 above (noting this has led some to "refer to mediation as a more feminine approach to conflict resolution").

16. A. Lazare, *On Apology* (New York: Oxford University Press, 2004), 204; A. Lazare, *The Interview as a Clinical Negotiation,* in *The Medical Interview: Clinical Care, Education and Research,* ed. M. Lipkin, Jr., et al. (New York: Springer-Verlag, 1995), 60-2; see also J. Groopman, "Introduction," in *How Doctors Think* (New York: Houghton Mifflin, 2007), 1-26 (arguing that effective medical diagnosis is dependent on the artful employment of negotiation skills, e.g. "open-ended questioning" and "active listening"); see also P.W. Chen, *Final Exam,* chap. 8 (New York: Alfred A. Knopf, 2007), 166-8 (discussing important patient interview techniques).

17. See generally, J. Menikoff, *Law and Bioethics: An Introduction*, chaps. 10 and 11 (Washington, D.C.: Georgetown University Press, 2001), 241-355.

18. *Core Competencies for Health Care Ethics Consultation,* see note 14 above (asserting that ethicists need ethical assessment, processing, and interpersonal skills); see generally, N. Dubler and C. Liebman, *Bioethics Mediation* (New York: United Hospital Fund, 2004).

19. Dubler and Liebman, *Bioethics Mediation,* see note 18 above, pp. 16–21 (highlighting the areas in which an ethicist must be knowledgeable).

20. See generally L.J. Marcus et al., *Renegotiating Health Care* (San Francisco, Calif.: Josey-Bass, 1995), 327-8 (providing examples of neutrality issues associated with informal mediation by an employee of an institution); K. Gibson, "Mediation in the Medical Field: Is Neutral Intervention Possible?" *Hastings Center Report* 29, no. 5 (1999): 6-13; *Core Competencies for Health Care Ethics Consultation*, see note 14 above, p. 7 (discussing the impor-

tance and difficulty of maintaining constituent neutrality).

21. D. Perlman, "Mediation and Ethics Consultation: Towards a New Understanding of Impartiality," 2001, *http://www.abanet.org/dispute/essay/perlman.doc* (arguing that ethicists should not remain neutral in regards to moral norms, but only in regards to the parties); Hoffman, "Mediating Life and Death Decisions," see note 10 above, p. 821.

22. Gibson, "Mediation in the Medical Field," see note 20 above, p. 6 (explaining a working assumption for many mediators is that the mediation must remain confidential).

23. See e.g., Dubler and Liebman, *Bioethics Mediation,* note 18 above, pp. 26-7.

24. The discoverability of a patient's chart note containing references to a mediation process requires an analysis of each state's mediation statutes and court rules and the state's case law interpreting those sources.

25. See generally, E.J. Bergman and J.G. Bickerman, *Court-Annexed Mediation: Critical Perspectives on Selected State and Federal Programs* (Bethesda, Md.: Pike & Fischer, 1998).

26. See e.g. B. Starkey, M.A. Boyer, and J. Wilkenfield, *Negotiating a Complex World* (Lanham, Md.: Rowman & Littlefield, 1999), 83-5.

27. T.A. Shannon, "The Legacy of the Schiavo Case," in *The Case of Terri Schiavo: Ethics at the End of Life,* ed. Caplan, McCartney, and Sisti, see note 1 above, pp. 260-3.

Commentary on "Beyond *Schiavo*": Beyond Theory

Nancy Neveloff Dubler

Art Caplan and Edward Bergman have written an article that I applaud.[1] I present a complementary perspective — not speculation and theory but experience. My colleagues and I have been mediating disputes for over 15 years in complex "bioethics" cases in a major academic medical center.[2] Mediation works. It is not a panacea — neutrality and confidentiality are concerns (more theoretical than actual) — but the mediation literature provides teachable skills for parsing cases that are medically, ethically, emotionally, and contextually complex.

A call for bioethics consultation is a cry for help. Clinical care always includes options, even if only the timing of providing or withdrawing care. Bioethics consultation is never requested if the patient is doing well, thriving, and awaiting discharge to embark on a ski trip. A request for consultation is a call to address the complex care choices for patients whose medical and social situations are tenuous. Patients with compromised capacity who are demanding to be discharged to home, families who are demanding "do everything" even though death seems immainent, patients who are uninsured and whose medical needs are compelling.

Consider the following case.

Mrs. B, a 52-year-old Latin-American patient who had been a high school teacher, was brought to the medical center by her daughter, who found her at home because she seemed confused and disoriented. At the time of admission, Mrs. B was minimally communicative and not clearly decisionally capable. She was HIV positive and had a T-cell count of 4 and a viral load of over 400,000.

Mrs. B had been known to the HIV clinic in the hospital for years and had repeatedly refused HAART (highly active antiretroviral therapy). During her current admission to the hospital, Mrs. B had accepted all suggested treatments, but consistently refused HAART. Indeed, about six months before her admission, she had heard an alterna-

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tive medicine provider on the radio and had sought her out for treatment. The provider, who was also a physician, urged Mrs. B to start HAART, and she refused.

AIDS dementia, documented on Mrs. B's imaging scans, was extensive, and, according to the AIDS specialists, almost certainly long-standing and now irreversible, even with aggressive treatment with HAART. All testing to discover the cause of a persistent fever had been negative, and the neurologist's consultation note stated that the fever was likely the result of neurological deterioration. About six weeks into Mrs. B's hospitalization, her daughter insisted that Mrs. B be given HAART. The daughter insisted that her mother had never realized how sick she was when she had refused it in the past. The team was resistant. A clinical ethics consultation (CEC) was requested by the team.

The clinical ethics consultant went to meet Mrs. B, who was not arousable, and, in her room, encountered Mrs. B's daughter — Sylvia. The consultant had previously met with the medical team and the liaison psychiatrist who had seen the patient over the six weeks of her admission. (It is the protocol for this ethics consultation service to meet with the team first.)

The consultant invited Sylvia to meet with the care team in the conference room. In the conference room, the consultant introduced herself to Sylvia as follows: "I am the clinical ethics consultant at the hospital. I am often asked to become involved in a case when there appears to be some disagreement among the patient, the team, and the family about the plan of care. My task is to search for a consensus that is possible for all . . . that is, I try and mediate a solution.

"As part of this process, I am committed to making space for everyone to be heard. If we agree, or if we do not, I will place a note in your mom's chart and record what seems most important to everyone — their positions and their arguments. I do work for the hospital, but I do try and remain neutral and to act as a facilitator in any case. If that seems all right with you, *tell me about your mom.*"[2]

Sylvia — a powerful, attractive, articulate lawyer — described her mom as a strong, independent, successful, loving and caring woman, who had never revealed her illness. Sylvia found a note while helping her mother move and had kept her own counsel about her mom's illness. Sylvia loved her mom deeply and could barely conceive of a world without her. She said that she knew that Mom did not want HAART, but, she argued, if Mom really knew now that she was dying, perhaps, just not to leave us, she might agree to it. "She loved us so much, and if she knew that we needed to give her HAART in order to bear her death, she would agree."

One of the physicians asked Sylvia, "Do you really want to start your mom on HAART when she has so consistently refused it?"

The mediator saw the anguish on Sylvia's face, and requested a moment to summarize what she had heard: "This is a strong and loving woman who did not share her AIDS diagnosis with her family, and who, as far as we can tell, repeatedly told the hospital staff that she would accept all other interventions, but refused HAART. She never told anyone why, and never gave any coherent reason."

The consultant continued, talking to Sylvia, "We are not asking you whether to start HAART; the team feels that your mom has rejected this option and is not comfortable with going ahead. So, we don't want you to feel that if you say, 'Don't begin HAART,' that you have in some way harmed your mom and facilitated her death. But, maybe if she knew she were dying, as a symbol of her love for you, maybe she might agree. We can't know that. What do you think your mother might say to you, her daughter, who is so loving and caring?"

Sylvia responded, "I think she would say no." She then asked, "Why did you invite me to this meeting if you had already made up your mind?" The consultant replied, "We invited you because you, too, are our responsibility. We want you to be able to go on when your mom dies, and we think that she is dying now. If it were so important to you to start HAART, even though the experts say it is highly unlikely to bring about any change, the team might consider it . . . as a way of helping you. The team feels that your mom is beyond suffering, and that starting her on HAART would not harm her or cause her pain. If your mom were to appear to suffer in any way from the medications, it would be stopped immediately. The medication would do your mom no harm, and may support you. The medical team seems uncomfortable with this, but would consider it if it were crucially important to you and your siblings."

The attending physician said, "It might be possible to start Mrs. B on HAART and move her to hospice so she could be in her own home. Some hospice programs permit interventions for possible palliation — the fever may give us this option; perhaps this might be possible."

Sylvia agreed to meet with the hospice physician and to speak with her siblings before she would give her answer. Their decision was to bring Mom home on hospice without starting HAART.

How different this mediation is from a narrow, principled analysis that would state:

The patient, when presumed to be capable, refused HAART and that disposes of the need for discussion and closes off all options.

Caplan and Bergman agree. Unfortunately, much of what passes for bioethics consultation is still an exercise in brittle, principled analysis. Mediation provides space for a broader discussion that is more fitting to the enormous depth, intricacy, and intimacy of medical and family situations. Was Mrs. B, given the degree of dementia, really decisionally capable over the last years as she refused HAART? Would she have agreed to HAART if she knew that the alternative was death, or that acceptance of the treatment would help her loved ones come to terms with her death? What could be done, now, to ease her family into her death?

What might a mediator point out from this much-edited chart note?

- Explanation of the mediation process, the limitations of confidentiality, and the fact that the mediator is a hospital employee [issues noted by Caplan and Bergman] were all presented at the outset.
- Options were constructed and explored during the discussion.
- The mediator used reality testing — "What do you think your mother might say to you. . . ." — to help relieve the daughter of the burden of giving up her position about starting HAART.
- Ethical principles — prior autonomous statements — were not ignored, but were not immediately dispositive.
- Attempts were made to bring the persona of the patient to the discussion at hand.
- The daughter's feelings and fears were elicited and validated.
- Risks were taken by the staff to support this family;
- The attempt was made to have the team shoulder the terrible burden of this decision without disempowering the family.

In fact, it was a classic bioethics mediation with a family member who initially took the position that she "wanted everything" done for her mother.

Finally, a word about the chart note: a bioethics chart note tells a story. It tells the reader, and reinforces for the participants, what happened, how it happened, who the players are — patient, family, providers — what their interests were, and how the options for care were ethically developed and supported.

The bioethics chart note has a plot, and perhaps a subplot. It has intertwining characters, some of whom have interacted before and have a history together, and some of whom are new to the setting and the issues. How the players perceive the situation and their threatened rights or interests will determine, to some part, how they play out their roles. The note documents who participated, what the dynamic of the interactions were, what issues emerged, how an ethical analysis would look, and what recommendations emerged from the process.

The author of the chart note is also a character in the unfolding narrative; she, too, has a role and interests. Her interest is largely in reaching a consensus that encompasses, to the degree possible, all of the clashing, colliding, and conforming values and interests of the other parties. She is the mediator of all of the past and collected history in the context of the present clashes of perspectives, needs, wants, and desires. It is through her eyes, and in her voice, that the chart notes take form. That voice should reflect the reality, as far as it can be determined, of the meetings and interaction. When it is the voice of the "bioethics consultant," that, too, must be clear.

The bioethics consultant is also an employee of the hospital and must be aware, at all times, that her voice is one among a chorus. So if the outcome of the consultation might cause concern to the administration or to the office of legal counsel, the chart note detailing what happened should be sent to them — after it has been placed in the chart. Institutions need to trust and respect this voice, but, under certain circumstances, might disagree with the outcome and intervene accordingly.

At Montefiore Medical Center we have conducted more than 1,000 consultations since the early 1990s in which mediation has set the tone and provided the skills. Mediation skills can be taught; we have trained medical professionals nationwide to use these skills: to listen for and acknowledge interests and feelings, frame, reframe, summarize, stroke, explore options, and search for consensus.

Finally, not all cases can be mediated. Before or after *Schiavo,* situations involving family members who despise each other must be decided by persons other than themselves. Mediation is collaborative and explorative. It is not for all situations.

MASKING OF THE CASE

The case presented in this commentary has been changed to protect the identity of the patient and the patient's family members.

NOTES

1. A.L. Caplan and E.J. Bergman, "Beyond *Schiavo,*" in this issue of *JCE.*

2. N.N. Dubler and C.B. Liebman, *Bioethics Mediation: A Guide to Shaping Shared Solutions* (New York: United Hospital Fund, 2004).

3. "Tell me about Mama" is a program at Montefiore Medical Center that instructs residents to sit down and ask about the patient before they ask any permissions for interventions on the patient.

A Commentary on Caplan and Bergman: Ethics Mediation — Questions for the Future

Robert Arnold, Mark Aulisio, Ann Begler, and Deborah Seltzer

Ethics consultation is now widely accepted in hospitals as a way to resolve ethical disputes between families, patients, and various healthcare providers. Exactly how consultation should be done, however, is not standardized. In 1998, the Society for Health and Human Values — Society for Bioethics Consultation Task Force on Standards for Ethics Consultation argued that ethics facilitation is the most appropriate approach for healthcare consultation.[1] Contrasting this model to an authoritarian model in which the consultant serves as a "moral expert" and makes a recommendation, and a pure facilitative model in which the consultant merely wants to forge consensus, the task force stated,

> We believe an ethics facilitation[2] approach is most appropriate for health care ethics consultation in contemporary soci-

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> ety. . . . The ethics facilitation approach is informed by the context in which ethics consultation is done and involves two core features: identifying and analyzing the nature of the value uncertainty and facilitating the building of consensus. . . .[3]
>
> In contrast to an authoritarian approach, ethics facilitation emphasizes an inclusive consensus-building process. It respects the rights of individuals to live by their own moral values by not misplacing moral decision-making authority or acceding to the personal moral views of the consultant. In contrast to a pure facilitation approach, ethics facilitation recognizes that societal values, law, and institutional policy, often as discussed in the bioethics literature, have implications for a morally acceptable consensus. The ethics facilitation approach is fundamentally consistent with the rights of individuals to live by their own moral values and the fact of pluralism. It, therefore, responds to the need for ethics consultation as it emerges in our society.[4]

According to this view, the role of those performing ethics consultation is to help the parties articulate the contours of the conflict, clarify misunderstandings and questions, point out unrecognized implications of participants' views, recognize all parties' emotional and moral distress, and negotiate a compromise that satisfies all participants and is within societal and institutional standards.

Arthur Caplan and Edward Bergman come to a similar conclusion in their article, "Beyond Schiavo," although they use the term "mediation" rather than "facilitation."[5] First, they point out that "ethics" conflicts in the hospital do not typically consist of irresolvable conflicts of ethical principles, but instead are the result of misunderstandings, hurt feelings, and a disinclination to creatively discuss how everyone's values can be promoted. Second, they suggest that what helps the parties come to decisions that reflect their values is less a matter of sophisticated ethical analysis and more about bringing parties together, getting them to talk, and getting them to listen to each other in an attempt to find common ground. This is entirely consistent with our experience in which ethics consultations involve issues such as:

- A family who believes that their loved one cannot get better and is suffering and doctors who believe that the patient can get better.
- A patient who needs a high-risk, life-saving surgery, about which the surgeon is ambivalent. While the patient refuses the surgery, his competency is in question. An ethics consultation is requested when the surgeon and psychiatrist come to different decisions about the patient's capacity to consent to surgery. In investigating the situation, it becomes clear that, regardless of the patient's capacity, the patient's surrogate also does not want the surgery.
- A doctor who believes that further intensive care is "futile" and wants to stop treatment and thinks that the family does not "get it." In a meeting, the family agrees that the patient is likely to die, but wants to wait until his son comes home from the Army later in the week to forgo treatment (although they are willing to sign a do-not-resuscitate order for the patient, and to forgo resuscitation should the patient arrest).

There is little with which to disagree in the article by Caplan and Bergman. They point out many of the advantages of mediation. They also raise some unresolved theoretical questions — such as what it means for the consultant to be neutral — that proponents of mediation need to flesh out. We hope to expand on their article in three ways. First, we want to point out that there are a number of models of mediation that consultants need to choose among. Second, we want to point out the educational implications of accepting the mediation model. Third, we call for more research on the relationship between mediation and consultation.

MODELS OF MEDIATION

The difference in how one looks at conflict influences the mediation framework that one adopts. In their analysis, Caplan and Bergman describe the conversation between parties in an ethics consultation as being about conflicting principles or values. Caplan and Bergman translate principles and values into an interest-based model of mediation. In this approach, described by Roger Fisher, William Ury, and Bruce Patton in their seminal work, *Getting to Yes: Negotiating Agreement Without Giving In,* one abandons the more traditional framework of positional bargaining and focuses, instead, on the identification of participants' mutually defined interests.[6]

Other models of mediation focus more on the relationship between conflicting parties. In the transformative model of mediation,[7] the assumption is that it is the absence of empowerment and recognition that prevents the parties from reaching a deeper understanding that is essential to resolving conflict. A primary purpose of transformative mediation, therefore, is to change the relationship between disputants to a more beneficial and positive one. Another model of mediation, narrative mediation, assumes that underlying conflicts are misunderstandings caused when each person holds on to his or her story as the truth. Narrative mediation helps the participants let go of old, entrenched stories, and, through collaborative work, supports the disputants to form a new, mutually created story that becomes their story.[8]

Whether these relationship-focused views of mediation are ethically or empirically preferable to an interest-based model needs to be elucidated. However, these models of mediation are consistent with data on the importance of dealing with emotion both in making decisions and in healthcare communication. For example, neuro-cognitive data indicate that when people are emotional, the cognitive centers of the brain are less effective. Data suggests that emotion-handling and empathy are as important in predicting conflict, dissatisfaction, and even instigating lawsuits.[9] Recent work also emphasizes the importance of healthcare providers' emotions; reporting, for example, that doctors experience loss, sadness, and hopelessness as their patients become more ill; and that physicians who are close to their patients prognosticate less well than "neutral second opinions."[10]

Ethics consultants thus need to be as comfortable handling participants' emotional reactions as they are understanding and elucidating an individual's moral view. In addition, consultants, like relationship counselors, can help participants be more cognizant of and respond more empathically to other parties' emotional needs and concerns. In this way, consultants may not only solve the existing problem, they also help the other parties to learn to negotiate more successfully in the future.

TRAINING CONSULTANTS

The degree to which those who perform clinical ethics consultations have the skills to serve as mediators is unknown. We are worried, however, that most ethics committees underemphasize this aspect of their training. One expects that everyone doing ethics consultation has some familiarity with basic notions of autonomy, non-maleficence, beneficence, and justice. We wonder how many of those involved in ethics consultation have spent time reading a major work on mediation or conflict resolution. Do they know about the major types of mediation or how mediation is structured? This literature and the lessons it teaches are important for those performing ethics consultations.

Mediation, like ethical analysis, is a skill. Individuals engaged in consultation need to be observed and receive feedback on their ability to mediate conflicts as well as their knowledge and ability to manipulate ethical principles. Individuals engaged in ethics consultation can learn a great deal from how healthcare practitioners learn communication skills. In teaching physicians communication

skills, we do not merely have students read books about how to communicate; instead, we have them practice communication with standardized patients, receive feedback on how they did, and then practice again. Those doing ethics consultation should, similarly, practice running meetings with standardized healthcare providers, patients, and families.

Ethics consultants must also think about educating other healthcare providers about the assumptions underlying their work. If the healthcare team does not understand that a consultant's role is to serve as a neutral mediator who helps all parties come to consensus, then the team may expect the consultant to convince a family to take the actions the healthcare team wants. Then, if this doesn't occur, the healthcare team may perceive the consultant as "being unhelpful" and request consults less often.

RESEARCH AT THE MEDIATION/CONSULTATION INTERFACE

Finally, more scholarly work is needed in the field. First, with rare exceptions, there is little scholarly work at the interface of ethics consultation and mediation.[11] We need to reach out and work much more closely with our colleagues in business and the law. We need to understand more about the psychology of conflict and its resolution, about different models of mediation and their strengths and weaknesses, and the growing literature on ethical issues faced by mediators. (There is also, of course, the theoretical matter of defining what counts as a "good" outcome for clinical ethics consultation.)

Conversely, mediators may learn more about their field from working with those involved in ethics consultation on healthcare. Caplan and Bergman point out how healthcare mediation is like negotiation in a diplomatic crisis. If mediators spend more time practicing in healthcare, it may lead to advances in both the science and the art of mediation.

There also is a tremendous need for empirical work. Other than one recent article, we know of no studies of what those who do "bioethics mediation" actually do.[12] Of particular importance here would be knowledge of how bioethics mediators take into account key contextual features such as societal values that give rise to the rights of individuals, institutional mission and policy, and other key normative issues such as conceptual clarification of the notions like "surrogate" or "best interest" and the like.[13] We need to both better describe the different ways mediation is done and to start to analyze how various methods of mediation may influence the outcomes of patients, family members, and healthcare providers.

We appreciate that Caplan and Bergman point out the importance of "mediation" for ethics consultation. We think there is a growing consensus on this. What needs to be done now is to better characterize what mediation means for ethics consultation. This includes how those involved in ethics consultation might draw on mediation models and techniques and how such models and techniques might be taught to those who are engaged in ethics consultation in clinical settings. We look forward to better understanding and operationalizing the role of mediation in ethics consultation.

NOTES

1. Society for Health and Human Values — Society for Bioethics Consultation Task Force on Standards for Bioethics Consultation, *Core Competencies for Health Care Ethics Consultation* (Glenview, Ill.: American Society for Bioethics and Humanities, 1998), 6. Robert M. Arnold, MD and Stuart J. Youngner, MD served as co-directors of the Task Force; Mark P. Aulisio, PhD served as executive director.

2. While the conflict resolution literature may treat the terms differently, for the purpose of the present commentary, *ethics facilitation* and *ethics mediation* are synonymous.

3. *Core Competencies,* see note 1 above, p. 7.

4. Ibid.

5. A. Caplan and E. Bergman, "Beyond *Schiavo,*" in this issue of *JCE.*

6. R. Fisher, W. Ury, and B. Patton, *Getting to Yes: Negotiating Agreement Without Giving In,* 2nd ed. (New York: Houghton Mifflin, 1991).

7. B. Bush and J.P. Folger, *The Promise of Mediation: Responding to Conflict Through Empowerment and Recognition* (San Francisco, Calif.: Jossey-Bass, 1994).

8. J. Winslade and G. Monk, *Narrative Mediation: A New Approach to Conflict Resolution* (San Francisco, Calif.: Jossey-Bass, 2000).

9. W.G. Anderson et al., "What Concerns Me: Expressions of Emotion by Advanced Oncology Patients During Outpatient Visits," *European Journal of Cancer Supplements* (in press).

10. W. Evans et al., "Communication at Times of Transitions: How to Help Patients Cope with Loss and Re-Define Hope," *Cancer Journal* 12, no. 5 (2006): 417-24.

11. N.N. Dubler, *Bioethics Mediations: A Guide to Shaping Shared Solutions* (New York: United Hospital Fund, 2004).

12. L.T. Watkins, G. Sacajiu, and A. Karasz, "The role of the bioethicist in family meetings about end of life care," *Social Science & Medicine* (11 September 2007): (epub ahead of print).

13. *Core Competencies,* see note 1 above, pp. 6-8.

Mediation and Moral *Aporia*

Autumn Fiester

As Art Caplan and Edward Bergman rightly point out, many clinical ethics conflicts involve genuine ethical ambivalence: there is more than one applicable moral principle, those relevant moral principles often conflict, and there is more than one ethically justified option as a legitimate outcome of the conflict.[1] Although some conflicts are really less about moral disagreement than miscommunication, many conflicts involve a clash between disparate moral considerations, values, or principles, and the morally correct decision or action in these situations is truly in dispute. The *Schiavo* case is a perfect example.

The philosophical term for this state of moral ambiguity is *aporia.* The term *aporia* comes from the Greek, meaning a "state of perplexity." In an *aporetic* situation, there will not be an immediate or automatic consensus among all of the parties involved about the morally appropriate course of action. In such cases, various stakeholders will appeal to the principles supporting their own preferred outcomes. The only way to avoid "winners" and "losers" in these conflicts is to employ a process that doesn't "take sides," but instead tries to navigate a solution that all parties can share. Bioethics mediation provides such a process. Typically in these conflicts involving competing principles, the hospital's ethics consult service (ECS) will be called in, but the prospect for a shared agreement and a "win-win" resolution between the parties depends on the type of process utilized by that ECS. Many — if not most — consult services are verdict-based: they are working towards a concrete recommendation as the outcome of their deliberations and effort. In fact, the data from a national survey of ECSs report that 65 percent of ECSs always provide a recommendation, and a *single* best course of action is recommended 46 percent of the time.[2] The data don't speak to this question directly, but what is implied by these statistics is that the outcome of the consultation privileges one stakeholder — and the principles she or he prioritizes as most salient in the case — over another stakeholder and his or her preferred principles.

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Without a privileging of one set of values over another (and, correspondingly, siding with one set of stakeholders over another), it wouldn't make any sense for an ECS to provide a "recommendation," because there would be no conflict, no one advocating an alternative. "Recommendations" are only provided in a context in which choices among competing alternatives need to be made.

But models of ethics consultation that "take sides" in such aporetic disputes are of questionable moral legitimacy because all of the stakeholders are appealing to valid moral principles. If there are legitimate moral claims on both sides, then making a recommendation amounts to the judgment of some body of decision makers that has weighed the arguments and decided which are most compelling. But what gives us confidence that this judgment is the ethically correct one? To be the arbiter between these competing principles, the ECS must have superior ethical knowledge and expertise to any of the actual stakeholders in the dispute. But what would lead us to believe that members of an ECS possesses such supreme moral expertise? It certainly isn't their training. The same national survey found, for example, that only one consultant in 20 had any formal ethics training and only 50 percent had any apprentice-based training.[3] In *aporetic* cases, it is unclear what level of training would be adequate to adjudicate between valid moral considerations, but these levels are surely insufficient. Once the moral expertise to make such choices is in question, there can be little basis for moral confidence about the verdicts or judgments made in those ethics consultations. The fact that nearly half of all ECSs *vote* at all and 20 percent of ECSs vote *half* of the time[4] exacerbates the concern about confidence in such decisions, because voting indicates the very uncertainty at issue: in these cases, an ECS may not have consensus among its own members (or else why would a vote be taken).

Mediation provides a better method of conflict resolution in these *aporetic* cases than verdict-based processes, because it works towards consensus about *outcome,* even where consensus about principles or values is not possible. Mediation facilitates the creation of a shared solution between parties without taking a stand on which moral principles or claims ought to trump the others in the disputed case. Because it is not verdict-based, it does not claim moral authority when there is none — its "ethical" reach does not exceed its grasp, as in so many traditional consults. And because it includes the voices of all of those affected by the outcome, it legitimizes the moral claims of all of the participants, thereby leveling the moral "playing field" in an arena with clear power and status differentials.

Bioethics mediation is often criticized for taking the "ethics" out of ethics consultation, raising the concern that a neutrally negotiated outcome represents a potential "anything goes," including an outcome that may be ethically suspect. But this criticism — at least in *aporetic* cases like *Schiavo* — is unwarranted: mediation actually provides a built-in ethical safeguard in the face of moral uncertainty, because it refuses to prioritize one set of values or principles over another in the absence of true moral knowledge and/or an authentic moral consensus about what the "right" answer actually is.

NOTES

1. A. Caplan and E. Bergman, "Beyond *Schiavo,*" in this issue of *JCE.*

2. E. Fox and D. Pearlman, "Ethics Consultation in United States Hospitals: A National Survey," *American Journal of Bioethics* 7, no. 2 (2007): 13.

3. Ibid.

4. Ibid.

Hope, Uncertainty, and Lacking Mechanisms

Norman Quist

Something is not working in ethics consultation: in certain situations, relationships within families and with careproviders and surrogates have become so emotionally charged and destabilized that attention is dominated by conflict and misunderstanding, foreshadowing a loss of dignity and hope. In a compelling, urgent article in this issue of *JCE,* informed by events in the *Schiavo* case, with examples from the literature on theory, practice, and outcomes, Caplan and Bergman address this situation: redirecting our attention to what they see as "a lack of effective mechanisms" for dealing with a "painful class of disputes in which families disagree with one another, or with doctors, about the care of those who cannot communicate."[1] It is no small matter that many of these cases are situated in the immediate, intense environment of end-of-life decision making.

How might we understand these encounters, and their limits? What can we hope? Following the tack of Caplan and Bergman, I will extend the discussion of the complex relationships between patients, families, surrogates, and physicians, and "hope for consensual resolution," offering a somewhat different account of what is lacking. While Caplan and Bergman foreground an apparent irreconcilability of appeals to competing biomedical principles as what is lacking, I will suggest that a "salient characteristic" among participants, what Caplan and Bergman identify as a common concern for the patient's best interests, may be far less stable and more complex, and thereby less directive, than first imagined. When Caplan and Bergman sketch their expectations for mediation and for mediators, they are right in noting that abstract principles "articulated as dispositive by designated 'experts' fail to capture, and arguably respect, the unique and complex nature of each such individual decision-making process," and that "patients and families are at the extreme end of a power imbalance." It is less clear that their descriptions — or their hope for mediation — capture this enormous challenge.

SITUATING THE PROJECT AND THE PARTICIPANTS

"There is nothing that we can really think of except what happens to us." — Robert Frost

Might there be two ways to interpret Caplan and Bergman's project? On one reading, the focus is limited to an "especially painful class of disputes," caring for those who are not competent to communicate their

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wishes. If these cases are the most difficult, it must be because the patient is unable to participate and because relationships within families and with careproviders are the most divided or fractured. On this reading, the "lack of effective mechanisms" affects a small class of families in disputes where nothing works (and the fear is nothing will work); these families cannot hope, and careproviders and ethics consultants cannot hope with them, for a consensual resolution.

Here, it is less clear how the participants may understand a patient's best interests, perhaps even as different from their own interests, and here appeals to competing bioethical principles are less likely meaningful. Here, I imagine that individual defense mechanisms and habits of thought are least accessible to introspection or self-reflection as participants struggle to keep the external world consistent with their inner world.[2] Here, those participating in bioethics consultation may find it especially difficult, if not impossible, to think about the problem in an appropriate way, in this intense context.[3] There is abundant evidence to suggest that most people are able and willing to alter their attitudes to bring them in line with how they have behaved.[4] When cases become the most difficult, the most emotionally charged, it seems that a resolution of differences is always just beyond reach — and will likely be imposed after an appeal by one party to a legal authority and through court-enforceable directives. How well are the special needs of these families understood?

Here, it may require an imaginative leap to understand and respond to what it means when each participant "invariably lays claim to the same concern — the best interests of the patient," especially when "there is nothing that we can really think of except what happens to us." In these cases, in this practical context, it seems inevitable that some participants will suffer a loss of dignity, privacy, and hope. After all, this is a very hard conversation: a conversation about hopes and fears, understanding defenses and denial, and one's own inner conflicts. It is a conversation to open new ways of thinking; ultimately, it is about how people change: Have I understood myself and others accurately? These challenges are not limited to the most difficult cases or the most defensive participants; they are at the center of this encounter for all participants. What is it about mediation "mechanisms" that might make them more effective?

On a broader reading, taking as a key Caplan and Bergman's review of the extensive literature on what counts in ethics consultation and their comprehensive review of competing approaches and principles, their identification of a lack of effective mechanisms seems also to include a potentially larger class of cases in which the environment for consultation is less contentious than in the most difficult cases, and in which there may be a possibility for greater openness, a more robust unity among participants, but in which participants are deeply concerned or troubled and are divided and uncertain about what is best. It is in these cases, in which, despite varied interests, we find a uniting thread: all "stakeholders" voice the same concern — the best interests of the patient — although each participant may appeal, sometimes unwittingly, to a different abstract bioethical principle: patient autonomy; beneficence; non-malfeasance; or the patient's total life and value system. In these instances the facts of the case seem to resonate in an entirely different way.

If I am right in this two-tier reading, the lack that Caplan and Bergman identify may apply to more than an "especially painful class of disputes"; it may signal a lack at the foundation of ethics consultation itself. Before elaborating on the consequences of this alternative reading, and developing a discussion of what families desire, what they lack, and what difference this makes — for all families — I will comment briefly on defining relationships, stakeholders, and public concern.

STAKEHOLDERS AND PUBLIC CONCERN

The authors' opening reference to the ongoing discussions of rights and wrongs in the dramatic, and painfully public, *Schiavo* case reminds us that there may be no bright line

for deciding who the stakeholders are in relationships, once cases become public. As in *Schiavo,* differences and disagreements can easily move beyond intimate and relational differences between patients, surrogates, families, and careproviders, to become inseparable from more public and social concerns, when vigorous discussions of "rights" and "wrongs" are not enough and more radical measures are played out, all in the name of the "patient's best interest." It seems that any consideration of a more "effective mechanism" to address differences and disagreements in end-of-life decision making must also account for substantial challenges to who counts in "relationships"; how family members are inextricably linked to others; the effect and role of social concern, which can be played out through legal and legislative interventions; and the incorporation of organizational issues in the delivery of healthcare and decision making. Just as the mechanism of the traditional physician-patient relationship has changed, more or less significantly depending upon the setting, so too has the definition of those who may be seen as "stakeholders."

When Caplan and Bergman write near the end of their article, "the politicization of the Schiavo family's painful and acrimonious struggle over the fate of their wife and child clearly manifests society's failure to invest in processes that facilitate constructive dialogue for the reconciliation of divergent, emotionally charged perspectives on life-and-death issues," it seems reasonable that the assumption is that more effective mechanisms may help to resolve or mitigate differences between participants, so that fewer participants will "go public." But as previously private boundaries become porous or nonexistent, when the private is now displayed or posted publicly, when the intention is attention, the personal becomes public. Here differences become politicized. It remains to be seen if mediation will provide participants "an outlet for catharsis and an arena in which to express dissent," and if this will be enough, especially when power and knowledge can easily overwhelm those who live this for the first time. Is this what it means to have a voice? Having a voice is different than being heard and feeling understood, and still different yet from believing that what you say can and may influence an outcome: that's power.

THE CASE FOR MEDIATION

Having walked us through a critique of current methodologies and practices in decision making and dispute resolution at the end of life, Caplan and Bergman propose, "the time has come for bioethicists and individuals associated with hospital ethics committees to invest in the development of bioethics mediation." They challenge us to examine how mediation mirrors and facilitates the goals of ethics consultation, and whether it can fulfill the "promise of a significant contribution to a pressing issue in American healthcare. . . ."[6] Caplan and Bergman's project reinforces the importance of asking of any mechanism or process, *How is this working now?*

A quick review of the literature reveals that mediators are conducting ongoing empirical assessments and evaluations of best practices. Looking to family mediation practices as an example, there is a vigorous discussion about the choice and significance of mediation styles and how they affect outcomes; on understanding and defining the role, participation, and influence of the mediator; and what counts as a good outcome. The mediator is part of a process and has a role to play: what it means to be a mediator. Most strikingly, a prominent concern in these discussions is whether mediators "can set aside all personal biases — developed through attitudes and values — in their decision making and be truly impartial."[5] Here it is reasonable to wonder how these various attitudes and values affect the hope of consensual resolution. When it comes to engaging participants and mediating disputes in "this most personal and definitive act of decision making," following the concerns of those who have studied this engagement, it "seems exceedingly unlikely that a mediator will be able to monitor internal and automatic cognitive processing of information without

their personal attitudes affecting their judgment and behavior."[6]

An assessment of the prospects for mediation will also require a thorough analysis of how knowledge and power function to create and define an environment, the practices and rules in which mediation can and does occur. In bioethics mediation (as currently in ethics consultation), it appears that neither patients nor family members have the prerogative to choose a structure or mechanism of mediation; participants are "asked" to manage within the structure of the mediation process, most often within the healthcare organization. Although the process of mediation may be transparent, it cannot be assumed that it is open, and, because the knowledge base of the stakeholders and their social capital are probably imbalanced, the process continues to be potentially coercive, even though mediators would eschew "philosophical" grandstanding. As Foucault notes, "Power is relations; power is not a thing, it is a relationship between two individuals, a relationship which is such that one can direct the behavior of another."[8]

The interpersonal structure that may frame and define relationships between patients and their families, within families, and even with a surrogate, is likely very different than the structure of the temporary relationships in consultation or mediation that include careproviders and mediators: between consultation and mediation the boundaries change in what is concealed and what is revealed, but how do they change? In both consultation and mediation, careproviders and members of ethics committees who participate in the decision-making process arrive with their own needs, desires, defenses, and expectations. Despite the prospect of superior tools in mediation (or the clarity of the structure of the process), it seems that some of the key questions that challenge mediation theory and practice have a family resemblance to the very questions and processes that led Caplan and Bergman to suggest "a lack of effective mechanisms" for addressing differences and disagreements in ethics consultation.

More importantly, in discussing mechanisms and processes, we have bracketed a discussion of time: are the participants in mediation open to taking the time necessary "to capture, and arguably to respect, the unique and complex nature of each individual decision-making process"? Does the process allow for it? Practically: what are the limits of reimbursement? What structure, what environment enables each of these diverse individuals to feel safe to disclose or expose their fears, hopes, and hesitations, where there is sufficient trust among otherwise unknown others to risk misunderstanding without feeling alienated or shamed? What standpoint will create a space where participants might work safely to understand what they really want or need, so that they are freer to act for the patient's best interests? Is there time for this?

THE HOPE OF CONSENSUAL RESOLUTION

"The fact remains that getting people right is not what living is all about anyway. It's getting them wrong that is living, getting them wrong and wrong and wrong and then, on careful reconsideration, getting it wrong again. That's how we know we're alive: we're wrong. Maybe the best thing would be to forget being right or wrong about people and just go along for the ride. But if you can do that — well, lucky you." — Philip Roth

"The very foundation of interhuman discourse is misunderstanding." — Jacques Lacan

"Just because people ask for something doesn't mean that's what they want you to give them." — Jacques Lacan

For Caplan and Bergman, the primary goal of dispute resolution at the end of life is "the hope of consensual resolution." And although it is unlikely that they sought to emphasize the magnitude and openness of hope in achieving consensual resolution, instead approaching the mediated outcome pragmatically, recognizing both the complexity of life

and death and meaning, might there also be a sense in which true consensual resolution, in which each participant understands what is lacking for him- herself, is always in the distance, always uncertain, and sometimes out of reach?

If we may fairly infer, in this tableau, that the participants are each situated believing that their expectations for end-of-life decision making and outcomes — their concern for the patient's best interests — are somehow privileged, what can we imagine, and what do they imagine, might count as "consensual resolution"? Since consensual agreement here is an agreement between multiple stakeholders that pertains to a course of action or commitment to an outcome, how might we account for the differences that remain personal, or when consensus is achieved through quiet resignation? After all, most of us have been in decision-making positions in which we reprioritize our first expressions of interests and expectations for reasons other than a change of understanding; in which our first hope is to get what we want, or what we think that we want, but, on finding resistance to getting what we want or think we want, we alter our expectations. We may "agree" to accept or to take something different, sometimes something less — and these decisions sometimes haunt us.

Death is the profound human conflict. Death is urgent and intense: it imposes a time limit on discussion. Choices that family members or surrogates make for or on behalf of another are powerful, in ways that may not immediately be understood; they may be life-altering choices for those who must make them. Many of these choices will be woven into the fabric or narrative of individual lives: they will be revisited and rebalanced, to celebrate, reflect, suffer, or deny. Here life philosophies and meaning-making matter. Can it come as a surprise that families (and careproviders) experience a range of conflicting emotions?

Again, power and knowledge, and all our defense mechanisms, may be at work here. How often, and for whom, is "consensual resolution" pragmatic agreement and not resolution? How stable are consensual resolutions? What should participants expect? Do lingering differences, as contentious as they may be, signal a failure of process or a fact of life?

For two very different reasons, following Roth and Lacan, we cannot avoid getting people wrong or misunderstanding them — and they get themselves wrong, what they want and lack; it is the nature of human discourse or the bent of living — we all get it wrong. For Roth, it is getting people wrong that is living: "getting them wrong and wrong and wrong and then, on careful reconsideration, getting it wrong again. . . . That's how we know we're alive: we're wrong." In the hope of achieving consensual resolution, because we can't "just go along for the ride", there must be a space for "getting it wrong."

NOTES

The quotes in the text are from R. Frost, *The Notebooks of Robert Frost* (Cambridge, Mass.: Belknap Press, 2007); P. Roth, *American Pastoral* (New York: Random House, 1997); B. Fink, *A Clinical Introduction to Lancanian Psychoanalysis* (Cambridge, Mass.: Harvard University Press, 1997), quoting J. Lacan, *Seminar II* and J. Lacan, *Seminar XIII.*

1. A.L. Caplan and E.J. Bergman, "Beyond *Schiavo,*" in this issue of *JCE.*

2. B. Wexler, *Brain and Culture* (Cambridge, Mass.: MIT Press, 2006), 28.

3. Ibid., 167.

4. G. Chin, "Cognitive Homeostasis," *Science* 318, no. 5851 (2 November 2007): 717.

5. Society for Health and Human Values – Society for Bioethics Consultation Task Force on Standards for Bioethics Consultation, *Core Competencies for Health Care Ethics Consultation* (Glenview, Ill.: American Society for Bioethics and Humanities, 1998).

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7. S. Cobb and J. Rifkin, "Practice and Paradox: Deconstructing Neutrality in Mediation," *Law and Social Inquiry* 16, (1991): 35-62.

8. M. Foucault, *The Politics of Truth* (Los Angeles: Semiotext[e], 2007), 134, 148.

How Much Emotion Is Enough?

Annie Janvier

Most big decisions in life are not purely rational, yet the cold legal concept of informed consent is. A patient should understand the nature of an intervention and what is likely to occur with or without it, should know about any possible alternatives and what they are, and should have the opportunity to ask questions.

When life-and-death decisions arise, emotions play a larger role as one's world starts to crumble. Physicians may typify decisions as irrational or rational, and may describe decisions with phrases such as "in denial," "too anxious to understand," or "taking time to digest the news," et cetera.

I am a neonatologist and am also a PhD student in bioethics. In 2005, for my second pregnancy, I delivered at 24 weeks and five days at the hospital where I work. My husband is also a neonatologist and is Chief of Neonatology at the same hospital; he is the master of evidence-based medicine and knows about every article published in neonatology.

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What about *our* informed consent?

I presented to the delivery room at 23 weeks and three days, dilated at four centimeters and with bulging membranes. For those who are not in the field, this is not good news. In 1994, the Canadian Pediatric Society (CPS) and Society of Obstetricians and Gynecologists of Canada (SOGC) published "Management of the Woman with Threatened Birth of an Infant of Extremely Low Gestational Age."[1] At 23 to 24 weeks, prognosis was deemed so poor that life-saving interventions were considered optional. The AAP holds similar views,[2] as does the Nuffield Council on Bioethics.[3] Because of my background in bioethics, I was the one who wrote up the information sheet that our hospital gives to parents in these situations, to help them in making decisions. I know that sheet by heart.

My baby was in the "optional" category and we had to make the decision. Because I have an over-active imagination, I had already walked myself through this possible course of events in my mind, many times over.

Physicians like patients who are able to give consent, who can understand, and who can weigh two decisions, ask questions, and choose the best option for them. But when the

alternatives are an uncertain life with an uncertain chance of handicap versus a certainty of death, the equation is difficult to solve: when your baby is dead, she is certainly dead; when she is handicapped, she is 100 percent handicapped. Is a rational, thoughtful decision really possible for any parent at such a time?

When a parent's decision "to do everything, at any cost" does not appear to be in the child's best interest, often comments are made that this has been caused by a problem in communication:

"If the physician had used non-medical terms. . . ."

"If the physician had stayed longer. . . ."

"The translator and the religious representative were not good. . . ."

"An ethicist, a philosopher, or a psychologist could have helped. . . ."

Even though these comments are true on occasion, sometimes death is not what parents have in mind for their child at a particular moment. Fear and love, emotions and desperation, are not rational.

In the delivery room, I said what I had decided many years ago: "Nothing before 24 weeks, and then we will think about it. At 24, maybe 24 and three. . . ."

The team was generally happy with our decision; it might have been different if I had told them to "do everything no matter what" at 23 weeks, or "do nothing no matter what" at 24 weeks. My baby had only good prognosis factors, she was a girl, I had prenatal steroids for more than 48 hours, she had a good weight, my husband and I have a good socioeconomic background.

When emotions are discussed in the informed-consent process, they are often thought to negatively influence competence. In an interesting article, "Is Mr. Spock Mentally Competent?", Louis C. Charland asks if the flight officer from *Star Trek,* who is part Vulcan and therefore unable to experience emotion, could make a truly informed decision.[4] In Charland's view, even if he is a "perfect cognizer," Mr. Spock does not represent an ideal of competence.

In delivery, I was a Mrs. Spock, a rational queen, and a great patient in terms of consent. My husband knew more of the medical literature, but he was the emotional one. My membranes ruptured before 24 weeks: in this situation, 50 percent of women deliver in 24 hours, 75 percent deliver in 48 hours, and the remaining 25 percent in an indefinite period . . . this is what I was thinking while my baby was moving, while I received my intramuscular medication, while the urine bag was changed, while my rectum was dis-impacted.

Even when one is maximally well informed, such decisions should not, in my mind, be approached only rationally — and cannot be. Most of the important decisions we make in life are not made in a cold-blooded, rational fashion: which partner to choose, whether to have children, where to work, and so on. We all have experiences, not only in medicine but also in our daily lives, in which unwanted information may not be heard, and this is not always "denial" or "wishful thinking." When we advise our best friend not to marry an *inconsiderate jerk* that she *knows has cheated on her many times,* and she *knows will do it again* . . . she may be intelligent, she understands what probably will happen, but she decides otherwise. Then again, my own decision to enter into a relationship with my partner was also irrational!

Our daughter Violette was born at 24 weeks and five days. The nurses and the physician told me "Congratulations," and I was livid. Would they congratulate a father who had dropped his baby on the floor? Why did they congratulate me for having a sloppy uterus? The guilt experienced with a premature delivery is paralyzing: "What if . . . ?" and "What could I have done?" become obsessive questions.

Violette had a rocky course. She became severely infected at one month of age, stopped passing urine, became comatose, and her blood pressure was not responsive to the maximal therapy. . . . My husband is an expert in blood pressure for neonates and ventilator management . . . so we knew the stats were not on our side.

On 14 June, after discussion with the treating team, we decided to withhold therapy, extubate Violette, and let her die. The statistics were no longer statistics, and the uncertainty would become certain. I just saw myself listening, saying yes, and felt like it was not happening, similar to the descriptions of women who were raped and were "not there." This decision was made by Mrs. Spock and her husband before visiting the unit to say goodbye.

My breasts hurt and I had to pump. I remembered, vividly, entering a parent's room and witnessing a mother pumping 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. Now it was me, pumping because of the pain. I tried to cry but I couldn't. It seemed the decision was the best one possible.

While we visited before the extubation, 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!" He could not let go even if she was bloated, marbled, and pale!

I was angry that a knowledgable physician could interpret these details in such an irrational manner, after our baby's death was planned. I chose to listen to him because, if she was really in irreversible septic shock, she would not improve and he would change his mind, but I also knew that a period of prolonged low blood pressure is not good for future brain function. I also 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. Violette continued to improve, redeteriorated, improved again, and left the hospital four months after her birth.

Consent in serious decisions requires not only cognition, but also emotion. Uncertainty and emotions are what drives us, what tears us apart, what stimulates us, what makes us cry and sweat and laugh, but they can also kill. I suffered from hypoplastic emotion syndrome, and maybe wish I had felt more.

Some of our friends think my husband and I made a good decision because we are knowledgable; they think if only all parents were as well informed, they would all make good decisions. Others think we made a good decision because our daughter is alive and we are happy. None of these are true. Because the outcome was good does not mean the decision was made well. Retrospective analyses of consent when the outcome is known are simplistic: if there is a "miracle," a dubious decision becomes good and the doctors are heroes. On the other hand, when a patient does badly, many caregivers "knew it from the start." We "went too far," and the physician can be blamed for the lack of informed consent.

A woman who dies despite mastectomy, irradiation, and chemotherapy, experimental therapies and bone marrow transplant did not necessarily make a bad decision. We can never predict with certainty who will do well and who won't, and this does not imply you cannot adjust and "do well" if your child is not "normal." It is not rare to hear caregivers say "had we known this would happen, we would not make this decision again."

Violette is now two years old, and she has no serious disabilities. She still breathes fast and is myopic, and it is too early to know how she will do at school. She is a beautiful tiny little flower who is slowly growing (much too slowly!), surrounded by her scarred and thankful parents. We made a good decision because it is the one we made at the time. I made the decision fully informed, rationally, but with no emotion.

Emotion saved her life.

NOTES

1. "Management of the Woman with Threatened Birth of an Infant of Extremely Low Gestational Age," *Canadian Medical Association Journal* 151, no. 5 (1994): 547-51.

2. H. MacDonald, "Perinatal Care at the

Threshold of Viability," *Pediatrics* 110, no. 5 (November 2002): 1024-7.

3. *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues* (London: Nuffield Council on Bioethics, 2006) *http://www.nuffieldbioethics.org/fileLibrary/pdf/CCD_web_version_8_November.pdf,* accessed 10 October 2007.

4. L.C. Charland, "Is Mr. Spock Mentally Competent? Competence to Consent and Emotion," *Philosophy, Psychiatry, & Psychology* 5, no. 1 (March 1998): 67-81.

Real Life Informs Consent

Felicia Cohn

My husband gripped the drawing of a human heart in his hand, trying to make sense of what the physician was saying. Our daughter, Amanda, had been born with a heart defect and the pediatric cardiologist had been talking with us for what felt like forever. The phrases "incompatible with life," "surgically repairable," "the next 24 hours are crucial," hung heavily in the air. She was our first baby and had been whisked off to the neonatal intensive care unit moments after birth. When she did not return after the 30 minutes promised by the nurse, we knew something was wrong. The new daddy gazed at me without comprehension, wanting to understand what was happening and to make it right. The healthcare professional in me tried to explain, but the new mommy could only cry, choking on the words I wanted to get out. We had decisions to make — the life and death kind that no one should have to make — but all of my experience with similar situations did not prepare me for the emotion involved with being at the center of decision making myself.

By the time Amanda was born, I had been doing ethics consultations for more than a decade, had done research on end-of-life care, and regularly taught medical students and residents about informed consent. I was used to emotional situations, practiced at teasing out the factors relevant to making difficult decisions. I had the elements of informed consent well-rehearsed: capacity, voluntariness, disclosure, understanding, recommendations, consent, and authorization.[1] I regularly break them down for my students, role playing each one so that they can practice, preparing them to help their patients. The students fret over how much to disclose and how to get the signature on the form. They are concerned about legal protections and how much time they have to spend "consenting" a patient. These, however, turn out not to be the most important concerns.

My doctors did a good job. They recognized my capacity for decision making, despite the haze of sleep-deprivation from being in labor all night and the effect of postpartum hormones. My obstetrician, the cardi-

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ologist, the surgeon, and the ICU nurse spent time describing Amanda's condition, her medical and surgical options, the benefits and downsides of each, the option of doing nothing, and their recommendations. My obstetrician knew me well enough to know what kind of support I needed and how directive he should be. To the credit of all, I didn't even see an informed-consent form until just before the surgery, after much dialogue. The process truly had been conducted over time, an ongoing conversation over the hours available until urgency bordered on emergency. Yet even with the abundance of explanation and patience demonstrated by my healthcare professionals, none of it made sense.

As Annie Janvier notes in her article, "How Much Emotion Is Enough?" "Most big decisions in life are not purely rational, yet the cold legal concept of informed consent is."[2] Emotion is an undervalued part of the informed-consent process. It, probably more than educational level, belief system, or socioeconomic status, affects our ability to understand the effect of the decisions we must make under difficult circumstances. While my students worry about the concrete elements of informed consent, it is this less tangible lesson I now try to impart.

I was fortunate in Amanda's situation, if there can be a silver lining to such a tragic situation — years of evidence indicated the best treatment plan, and a surgical fix was possible. The disclosure was easy, not even too time-consuming, as was getting me to sign the form. But the decision making remained hard. I was being asked to make decisions while preoccupied with trying to make sense of a situation I did not want to comprehend. The "what ifs" were overwhelming. "What if the medicines don't sustain her until her first procedure?" "What if the procedure doesn't work?" "What if the surgery doesn't work?" "Is this the best place for this surgery?" "How will she live after the surgery?" And the unspeakable, "What if she dies?" The questions swirled in my head, but I was helpless to ask any of them. Every time I opened my mouth the tears welled up again. My questions went unasked, much less answered. Heart over head, all I could do was nod "yes," asking the doctors to save Amanda's life. In the end I did not care about any other implication of my decision. My decision was not rational, although it appeared so as it coincided with the physicians' proposed treatment. My understanding was assumed rather than established.

For years I have been frustrated by patients or patients' families asking that we "do everything" even in the most dire of circumstances. For the first time I truly came to understand the power of emotion in the decision-making process. While I had long taught my students that patients/families retain decision-making authority even if the decisions they make do not appear to be rational, it was rationality that I regularly sought in consults. The patient/family must demonstrate that they understand the consequences of the decisions they have made. I seek clear explanations for these decisions, believing that if the patient/family can explain it, they must understand it. We must "check" for understanding by asking the patient to explain the course of action selected in his/her own terms or through the questions the patient asks.

Yet the patient overwhelmed by emotion may not be able to do so. I could no sooner have translated my daughter's surgical plan into my own words than I could have performed the surgery myself. My husband, clearly the more coherent of the two of us at the time, struggled with the medical situation the doctors had explained. He is an intelligent, well-educated person, but lacked the background to understand the med-speak, and the willingness to accept the circumstances.

Consenting to the treatment proposed meant Amanda might live. To new parents nothing else mattered. I could not distance myself from the situation, as I do in clinical consults, to assess the facts. I cannot help but wonder if I would have been able to allow my baby to die, even if that would have been the more medically appropriate decision. The families of my patients may be similarly ham-

strung, or guided, by emotion. Sometimes treatment, even if it is unlikely to be beneficial, is desired, despite the burdens, the likely futility, the expense. Other times refusing treatment, even when it is likely to prolong life and improve its quality, may perpetuate misery that cannot be explained logically, or at all. How we feel and what we want may govern the decision making of even those who should know better.

Our story has a happy ending: Amanda is now three, a healthy, active, and sweet little girl who wears her scar like a badge of honor. We are thankful for all that the physicians did, for the guidance they gave, for their efforts to help us understand. The book and drawings they gave us to describe Amanda's condition sit on a shelf in her bedroom, awaiting the day we need to more fully explain the scar on her chest to her. Now we understand and recognize that we made the best decision. Yet, as I look back on what happened, I am struck by the limits of informed consent. I knew my baby was fatally ill, but did not truly understand what that meant. I knew the surgery could save her life, but could not have explained how. I knew I wanted her to live, to come home, to grow up, and in light of that, all of the downsides to the treatment plan were invisible.

From experience, I have learned that the greatest constraints on informed consent lie in the requirements for capacity and understanding. These two elements are intimately tied together as the ability to understand essentially defines capacity. Illness impairs capacity in inconceivable ways. Yet the pursuit of rational decision making may blind physicians to what is really important about making hard decisions. And this, as Janvier implies, may mean that when rationality yields an undesirable answer, more effort to incorporate emotion is needed.

Of course this makes the physician's job even more difficult. There is no tool for measuring the appropriateness of an emotionally charged decision and emotional decisions often give rise to concerns about capacity, particularly when they are contrary to a physician's recommendations. However, we must recognize that sometimes the best decisions are neither rational nor even understandable to anyone other than the decision maker.

I still teach my students to ensure that their patients are able to make decisions and to understand the decisions they make. I share stories about lawsuits due primarily to assumptions about capacity, misunderstanding, or insufficient understanding. I emphasize the need for an ongoing conversation, for the disclosure of information appropriate to the particular patient rather than to the "reasonable" patient.

But now I also teach them that our most important decisions are often irrational (the very decision to have a child, for example) and that illness inherently compromises decision-making capacity. Our desires may trump even the most logical of plans. I teach my students to understand that their patients may not always understand and often do not behave rationally. Informed consent must be measured by empathy as well as rationality. This is both the burden and beauty of the human art of medicine. The practice of medicine allows for emotion in ways that law and policy cannot. Emotion may or may not save a patient's life, but it does give medicine a soul.

NOTES

1. T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics,* 4th ed. (New York: Oxford University Press, 1994), 142-81.

2. A. Janvier, "How Much Emotion Is Enough?" in this issue of *JCE.*

What Parents Face with Their Child's Life-Threatening Illness: Comment on "How Much Emotion Is Enough?" and "Real Life Informs Consent"

Edward J. Krill

It has been 30 years since Charlie died. I think of him all the time. His deep, piercing eyes in the photo taken by our dear neighbor, Jill, look at me every day. The stocking cap that he wore in that portrait is on my closet shelf above the shirts I wear every day. Occasionally my wife, Cecy, and I say something to each other about Charlie, how old he would be, what he might be doing. In silence, he still lives with us.

This may seem unusual, but I remember that living with his illness was harder than recovering from his death. A child's potentially terminal illness, such as Charlie's leukemia, puts your life on hold. Your emotions and motivation are frozen. He was diagnosed at two and died a few days after his fifth birthday party. Everyday events, seeing him play in the yard, come with the realization that this beautiful child, this wonderful little person, may be taken from you. It becomes impossible to enjoy almost anything with him, because the more loving, talented, happy he is, the greater the dread that this wonderful boy may soon die.

When he died, we were freed from the unbearable stress and uncertainty of test results, possible exposures to other children and their illness, and constant adjustments in our lives out of fear and concern that we would do something wrong. You find yourself yearning for a resolution, one way or the other, as weak as that may seem. When he died, after a mercifully brief illness, simply put, we were relieved. We also experienced a sense of futility, loss after an enormous effort, but at least that was over. What was left was to rebuild our emotional lives, but that seemed easier than the daily roller coaster of hope, worry, adjustment, and dread.

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And now, he's a sad memory, a long ago loss, a chapter in our lives that we will never get over and are not trying to block out. What we were given with Charlie was an insight into the important things of life, priorities, things that really matter. We grew from that experience, a good thing perhaps, but it was awful at the time.

Those who provide care to children with terminal illness may gain some insight into this situation from what we went through. Coping with an illness of this type, with the percentages, with the in and out of remission, is at times beyond what you think you can handle, and escape seems a very attractive option. Helping such parents begins with a recognition that they are suffering, and they are doing much of that suffering alone.

After the initial acute stages of Charlie's illness, changes with my job forced us to consider whether we wanted to be closer to our families. We lived in Washington, D.C. I am from Milwaukee and Cecy is from Green Bay. Mothers, fathers, sisters, brothers, and a multitude of relatives lived in those two cities. While our oncologist at Georgetown, Catherine, was so incredibly caring that we named our daughter after her, we agreed that if I could find a job closer to Wisconsin in a location with excellent cancer treatment, we would consider moving. I was told by a colleague that the University of Wisconsin was interviewing for an attorney for its Health Sciences Programs, the hospital, medical school, and such. I got that job, in Madison.

I knew that the clinical care at the university would be up to standard, but it was better than that. As at Georgetown, we bonded with one oncologist, Dorothy. This consistency, seeing her every visit, was extremely reassuring, especially to Cecy. They were friends. Dorothy came to our home, went ice skating with Cecy. We felt complete trust and caring. Maybe this approach would be impossible in most clinical settings, but within this mammoth medical center, we found excellent care for our son and deep concern for what we were going through.

The interesting part was that this move brought us close to family and out of the somewhat impersonal social rituals of Washington, what we had hoped for, but something unexpected happened. We found ourselves in a close-knit Midwestern neighborhood of well educated, mostly university affiliated neighbors who immediately introduced themselves and their children. Many of the moms were mostly at home, the kids played outside on the sidewalks, and since we had to ask about that dread disease chicken pox, they all came to know of Charlie's illness. The lesson is, tell parents not to hide this kind of an illness from anybody.

As wonderful as it was to have family close by, the daily support from our neighbors was a surprise and a Godsend. They were terrific, and we were blessed to have them nearby. Family visits were loaded with emotional baggage. They too were facing the possible loss of a dear child, a member of their family, and could project that impact onto themselves. Family members carry an emotional burden when visiting, new neighbors do not. It was frequently easier to spend time with a neighbor who knew than with your own brother. With family, the raw nerves were right on the edge. With neighbors, there was no agenda, no need to leave with a sense that you have helped Ed and Cecy deal with this tragedy, no need to try to make them feel better.

The neighbor experience is a reason why caregivers, acquaintances, and complete strangers who know the score are wonderful companions for parents with seriously ill children. They are not dealing with their own emotions, and thus have no emotional needs. In short, they can remain open to the stressed-out parents, compared with family who may be pretty stressed-out themselves. They have "emotional reserve."

This explains the well-recognized phenomenon that spouses frequently cannot help each other very much emotionally during the course of this kind of illness. The best that a spouse can hope to do to be helpful is consistency with the tasks and routines of daily liv-

ing. Men and women form relationships to share experiences, bond emotionally, and travel through life with companionship. When a spouse is down, the partner is there to provide support. When a partner is worried, the spouse is there to help sort it out. When a partner is broken by a major setback, the spouse is there to help put that behind and move on with career, life, and goals. When both parents are dealing with the possible death of their child, they have no emotional reserve available to support their spouse. I don't know of any solution, except that caregivers may simply assure spouses that it's normal for a child's possibly terminal illness to create this distance.

One way for caregivers to help spouses is to try to find a way to speak with both of them. After his initial hospitalization, when both of us slept at Georgetown Hospital, Cecy took Charlie for most of his testing and treatments. I went to work. Since I have a background in healthcare and absolute confidence in Cecy, I completely trusted and relied upon the information that she brought back from every visit. I did have some contact with the caregivers at Georgetown and in Madison, but that was infrequent.

But I can see that in other cases, allowing one parent to escape the burden of anticipating testing and treatments, and then actually being with their child during treatments such as spinal infusions, could lead to resentment. So try to make arrangements for both parents to come in, or to meet with the father, like me, who is at work and perhaps not facing the reality of what the disease is doing to his child or his wife.

Communicating with family other than the child's parents, even when a sister, for example, is playing an important role in the care of the child, has considerable risks. The sister may relay information to the mother in a more positive light than is warranted, and may exaggerate the positive, trying to boost the spirits of a sister. Thankfully, we had none of this. We had help, companionship, understanding, and prayers from our families, but no involvement or advice with the treatment decisions that we had to make and no predictions or suggestions regarding the outcome.

Another way that caregivers can help these parents is to avoid giving them options and choices that are complex, uncertain, and, especially, clinically unrealistic. If there are options, state them, but never do that without a recommendation. Many parents in this situation will research the course of the disease and available treatments. With the internet, caregivers can be confident that well-educated parents will have looked at everything from the *Ladies Home Journal* to the Mayo Clinic website to NLM's MedLine. Be willing to discuss this literature (be conversant with it for starters) and after looking over the field of options, share your conclusions. Tell parents what you think would be best for their child in terms of treating the illness, side-effects, likelihood of success, and possible complications. Don't burden parents with your indecision or lack of self-confidence.

Parents wish for a cure, but should not be encouraged to hope for the improbable. Becoming hopeful only to be disappointed adds to the emotional roller coaster. Caregivers lose credibility by painting too rosy a picture, and it's hard to recover from a parent saying: "We didn't expect this." Luckily, at Georgetown and Wisconsin, we were given straight answers, clear recommendations, and pretty much knew what we were facing. A clear prediction that the third loss of remission would mean that treatment had failed was better than not knowing what it meant.

We had very few decisions to make regarding Charlie's treatment. Back in the late 1970s the St. Jude protocols were the only approach anyone was taking. We were consistently presented with the rationale for changes in chemo, the need for radiation, and the changing odds for probable success. We knew and were prepared for the situation when Charlie came out of remission and went from a cold to complete respiratory failure in a matter of

hours. Cecy and I had no great difficulty accepting the fact that heroic efforts to get him through that illness had only a slight chance of success and that, even if that happened, his chances for any real time of normal living were very poor. So we let him go, and have never regretted that decision. We were ready to make it because Dorothy had patiently told us what to expect.

Parents in this situation will blame themselves when the outcome is poor. Parents who have lost a child go back, relive what they did, looking for a cause, finding fault in their care for the child prior to and during illness. With leukemia, not noticing that a neighbor child playing with your son has a runny nose is an event that can be relived over and over. Reassuring parents that nothing they did led to contracting the disease, a loss of remission, or a final illness must be done over and over. This message does not sink in the first time.

Recovery from the death of a child is usually outside the purview of the healthcare provider. The close bond that forms during treatment with frequent visits, intense communication, and shared emotional experiences ends abruptly with the death of the patient. Parents are expected to seek support and grieve without the professionals. In most cases this is probably acceptable; certainly there is no payment for an oncologist's meeting with parents months after their child's treatment has ended. A brief phone call after several weeks and then after a few months could mean a lot to a parent who has been struggling. Grieving parents are sometimes reluctant to seek professional help. This call could be, in part, to determine whether that seems needed, and parents would understand the concern of someone who treated their child and may welcome that suggestion.

I hope that this personal recount of my experiences will provide some insight into the feelings and needs of parents as they try to cope with the possibly terminal illness of their child, and what a caregiver can do to make that burden easier to bear.

NOTES

This article is a commentary on A. Janvier, "How Much Emotion Is Enough?" in this issue of *JCE;* and F. Cohn, "Real Life Infoms Consent," in this issue of *JCE.*

Reflections on Love, Fear, and Specializing in the Impossible

David M. Browning, Elaine C. Meyer, Dara Brodsky, and Robert D. Truog

What families need help with in many end-of-life situations is not a buffing up of their decisional capacities, but compassionate attention to how the events unfolding before them can be made meaningful or bearable.
— Larry Churchill and David Schenck

Being ethical in such situations has less to do with making a single decision than with initiating a process — often a very slow process — of a person or persons coming to feel that how they acted was as good as it could have been, given the inherent impossibility of the situation.
— Arthur Frank

What we need is more people who specialize in the impossible.
— Theodore Roethke

In the article "How Much Emotion Is Enough?" by Annie Janvier, we are offered a rare and compelling glimpse into the journey of baby Violette and her parents, as told through the voice of her mother.[1] Born on the cusp of viability at 24 weeks and five days, Violette's parents, both neonatologists, knew all too well the worrisome survival statistics associated with such extreme prematurity, the precarious course that lay ahead, and the range

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of developmental challenges their tiny infant could face. Violette's mother lays bare the experience of parenting a baby whose life hovered at the edge of life and death, suspended in uncertainty. The author's reflections enable us to better understand the limitations of our highly cognitive, linear ways of thinking about decision making in these situations.

A panoply of emotions — anxiety, fear, love, uncertainty, hope — emerged for Violette's parents, uniquely shaping their decision-making process. At one juncture, Violette's parents decide that withdrawal of life-sustaining treatment is in her best interest. The numbers were undeniable; it seemed the correct choice. But then, Violette starts to suck slowly on her pacifier, a sign, for her father, that constitutes hope; the landscape of decision making is transformed.[2] Violette's father, a "master of evidence-based medicine," finds himself responding to evidence of a different kind, and cannot bring himself to go forward with the plan to withdraw life support. As her mother says succinctly, emotions saved Violette's life.

To structure our commentary, we offer reflections drawn from our experience for the past five years unpacking just these kinds of ethically charged circumstances in our role as faculty facilitators for the Program to Enhance Relational and Communication Skills. PERCS is an initiative of the Institute for Professionalism and Ethical Practice at Children's Hospital Boston and Harvard Medical School. In day-long workshops, an interdisciplinary group of practitioners from a range of experience levels comes together to learn — in a safe and respectful setting — about how best to engage in high-stakes conversations with patients and families.[3] Our pedagogy, based on a relational approach to learning, aims to integrate patient and family perspectives, professionalism, and the everyday ethics of clinical practice.[4]

How might a physician, nurse, social worker, or chaplain be helpful to Violette and her parents under such terrible circumstances? What might we say or not say, do or not do? How might we acknowledge and invite the thoughts and feelings of Violette's parents into our team conversations, family meetings, and efforts to help them go forward? How can we create a calm and respectful holding environment that communicates to families our appreciation of their struggles and our willingness to help shoulder the moral burdens they are facing?[5] As we attend medically to Violette's tiny body struggling for survival, how can we best attune ourselves to her mother and father, poised on their own cusp of viability, striving to find competence as parents?

Violette's mother invites us to accompany her as her world "starts to crumble." By listening to her unique story, we are invited to reflect on a number of rather unquestioned and well-accepted practices in the neonatal intensive care setting. Consider, for example, the common practice of congratulating parents on the birth of their premature and vulnerable babies. For some parents, this acknowledgment is greatly appreciated, but for others, like Violette's mother, such well-intentioned words can fall flat, triggering shame and anger.

Or, consider the practice of providing a substantial amount of medical information to parents (often in a review of systems format) on a daily basis to keep them fully informed about the health status of their infant. Although this is familiar and self-organizing for practitioners, parents can be overwhelmed in this process, and left wondering how all the data really applies to *our* child and *our* predicament.[6] Some parents, some of the time, want all the details; other parents, some of the time, are looking for something else.

The ideal of rational decision making is well embedded in our Cartesian medical culture. Janvier, a parent and neonatologist, alerts us to the dangers of privileging rationality at the expense of the rest of human experience. She reminds us of the critical role played by emotion in parenting and, by inference, the equally critical role of emotion in being a good clinician. If emotion is undervalued and underdeveloped in healthcare settings, and this

hinders optimal care, what should we be doing about it?

From a research perspective, we know something about what matters to parents when they are faced with end-of-life decisions. They assess, as best they can, how much pain and suffering their child is likely to bear. They try to ascertain and predict their child's expected quality of life. And, very often, they measure their own success as parents based on their ability to protect and advocate for their child.[7]

When it comes to religion and spirituality, we know that faith can provide guidance and solace at the end of life; we also know, sadly, that many families hesitate to share this part of their lives with clinicians.[8] We know precious little about the hour-by-hour and day-by-day sojourn of parents facing impossible decisions. Larry Churchill and David Schenck, for example, found that parents described the process less in terms of having "made a decision," and more in terms of a struggle to find their bearings.[9] The process of getting to a decision seemed to have less to do with rational cognition and more to do with making sense, locating meaning, and situating themselves as parents in an uncertain moral universe.

As educators, we appreciate having had the opportunity to share our own thoughts and feelings in response to the rich account offered us by Janvier. We close this commentary with her poignant and prescient words: *death is not what parents have in mind for their child at a particular moment.* Indeed, death is not what parents have in mind for their child, not at this moment or any other moment. It is an impossible reality to imagine. But imagine they must, at times. And if we, as caregiving professionals, aspire to be helpful to them, we will need to imagine along with them. We will need, as the poet Theodore Roethke wrote, "more people who specialize in the impossible."[10]

We are only beginning to understand how families, in complex and remarkable ways, find their way through these impossible times. To understand better, we can learn more about the meaning and impact of parental love on these times, and all the ways it is pushed, pulled and challenged beyond imagination (and beyond *reason*).[11] We can choose to delve more deeply into our ways of thinking, talking, and teaching clinicians-in-training about how these decisions unfold in the lives of real families, and we can cultivate a richer, more sophisticated body of knowledge based on the evidence that is their experience. Finally, we can nourish the values, relational capacities, and ways of knowing that clinicians need in order to be most helpful.

If we're fortunate, we may come to understand, together, what it means to specialize in the impossible.

NOTES

The quotation from Larry Churchill and David Schenck at the beginning of this article is from L.R. Churchill and D. Schenck, "One cheer for bioethics: Engaging the moral experiences of patients and practitioners beyond the big decisions," *Cambridge Quarterly of Healthcare Ethics* 14 (2005): 389-403.

The quotation from Arthur Frank at the beginning of this article is from A.W. Frank, "Ethics as process and practice," *Internal Medicine Journal* 34 (2004): 355-7.

The quotation from Theodore Roethke at the beginning of this article is from T. Roethke, *http://creatingminds.org/quotes/impossibility. htm.*

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9. L.R. Churchill and D. Schenck, "One cheer for bioethics: Engaging the moral experiences of patients and practitioners beyond the big decisions," *Cambridge Quarterly of Healthcare Ethics* 14 (2005): 389-403.

10. T. Roethke, *http://creatingminds.org/quotes/impossibility.htm.*

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Emotion, Suffering, and Hope: Commentary on "How Much Emotion Is Enough?"

Jason D. Higginson

Informed consent in the neonatal intensive care unit (NICU) often involves a frenzied discussion just prior to a pre-term delivery or following a severe worsening of an infant's illness. This can be a difficult process. In the narrative, "How Much Emotion is Enough?" Annie Janvier aptly points out that these discussions may not be an ideal example of informed consent.[1] This often-rushed process is complicated by the emotion that is inevitably involved. Parents may appear to lack insight into the outcomes that neonatologists believe are inevitable. This may lead the parents to make decisions that seem inappropriate to the medical team. The main question posed by the narrative is, *Can a rational decision really be made at such a time?* Janvier relates her own experience, as a neonatologist and expectant mother of a very pre-term neonate. Beautifully described in the essay are the numerous and conflicting emotions families can go through when making these decisions. The author ultimately concludes that emotion and medical knowledge are equally important decision-making tools.

The birth of a child is the birth of the hopes and dreams that parents have for themselves and for their child. These dreams can be shattered when something goes wrong. Discussions of informed consent in neonatology often focus narrowly on outcome data. This can lead discussion away from an analysis of what constitutes an informed and valid decision. These discussions lack an examination into the presuppositions that physicians bring to the counseling process. "How Much Emotion Is Enough?" illustrates some of these assumptions.

There is an underlying belief that knowledge of medical facts makes physicians experts at their application. Janvier notes that her husband "is the master of evidence-based medicine" and asks, "What about *our* informed consent?" These comments suggest

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that their knowledge of neonatal outcome data in some way makes this a less-valid process. Medicine often has an impoverished and unexamined view of human existence. Medical research narrowly focuses on issues that can be measured. As Janvier points out, most decisions in life are not based on measurable quantities. However, this does not make these decisions irrational, as the author contends. A person's desires and preferences are not necessarily irrational because they are not based in scientific fact or because they have an emotional element.

An ethics mentor of mine once pointed out that you cannot prove that one flavor of ice cream is empirically better than another. Yet in the NICU, outcomes data are often interpreted in terms of "good" and "bad," demonstrating a non-empiric or emotional component in research. Notably, NICU research typically joins death and disabilities as a single, value-laden categorical variable: "bad outcomes" or "poor outcomes." I noted this in my training first as a pediatric resident and subsequently during my fellowship in neonatology. The view often presented to those in training is that disability is the worst fate that can befall a pre-term infant.

This view of disability is further advanced in the way pediatric society guidelines are discussed and applied. That is, in cases when a "poor prognosis" is expected, there is no obligation to intervene. What is a *poor prognosis* and what does this mean in practice? Many physicians would likely respond that disability makes for a poor prognosis. Based on this, the rational decision is not to initiate care or remove support if disability were the expected outcome. This has been reported in a survey conducted by Morse and colleagues.[2] The survey asked pediatricians and obstetricians to estimate neonatal handicap rates after delivery at different gestational ages. Physicians consistently rated the level of disability as much higher than the actual rates found in the medical literature. Why is this the case?

Combining death and disability as "poor" outcomes leads providers to overestimate the disabled proportion of NICU survivors. There are a large number of "poor" outcomes at the limits of viability, but separating death from disability is not easy with casual reading of the available research. The twenty-second to the twenty-third week of gestation is considered the lower limit of viability for a neonate. Survival increases with increasing gestational age, but disability free survival does not seem to be affected until the twenty-seventh week. That is, if survival does occur, disability rates are the same across these low gestations up to about 27 weeks gestation.[3] This is not widely appreciated.

The reason resuscitation is considered "optional" at the lowest gestational ages has more to do with survival than with disability. At lower gestational ages, when death is very likely, we assume that the intervention necessary for the preservation of life is often painful and likely to lead to significant suffering. This is an assumption, but likely a true one. The reason intervention goes from optional to obligatory at 25 weeks is not because disability rates drastically change. Rather, it is because survival improves dramatically. The suffering an infant will likely sustain in efforts to allow survival can be seen as too great to justify intervention if the probability of survival is low.

Certainly the effects of future disability play into decisions made in the NICU, but to what extent should they? Is this an overemphasized point in counseling parents? Does disability lead to suffering? That is the assumption made by many in neonatology, usually based on little more than personal intuition. Physicians are a group that generally place high value on intelligence and ability, and this may color the way we view outcomes. There is emerging evidence from a group led by Saigal that disability may not be as disruptive to future quality of life as physicians generally think.[4] These studies consistently report that many extremely low birth weight survivors from the NICU rate their quality of life similarly to age-matched term controls, despite empirically higher levels of disability.

The authors report this trend in numerous studies, from early childhood into now early adulthood. Why, then, do we consistently claim disability is a "bad" outcome? Certainly it is not the desired outcome when we treat a patient. However, Saigal's evidence suggests that life with disability may not be as filled with suffering as most physicians assume.

Why is parental informed consent so important in the NICU? Why do we not attempt to intervene with all infants, despite parental desires? Why do we not withdraw care when we feel it is the most rational decision, even if parents disagree? The answer is that parents are the most likely to feel connected to their child, and thus are usually in the best position to balance the suffering of their child with the hope for the child's future after recovery. Janvier notes that she remembers the pressure to demonstrate that she was a good parent while simply wanting the final verdict. The NICU can be an overwhelming, anxiety and guilt inducing environment for a parent. Acknowledging this with parents and assuring them that no one expects them to demonstrate their worthiness as parents may help them through the NICU course and during other unstable times. Parents are needed to help direct the course of care for their infant. They usually are the best advocates for their child.

I agree that emotion is an important part of decision making in these complex situations, as Janvier suggests. However, I do not believe that it compromises rationality. It allows for an appreciation of both suffering and hope.

I think at times in the NICU we overcomplicate the informed-consent process by relying on statistics and disability rates while ignoring our own inherent biases. Outcome statistics are an important part of the process, but certainly not the only part. Often forgotten in these discussions of statistics are the child and the suffering that may be ongoing.

A valid decision begins with empathy for the child. Few decisions in the NICU are clear-cut. As pointed out in "How Much Emotion Is Enough?", knowing the final outcome does not validate a decision. The decision becomes valid when it is made thoughtfully and with the child in mind.

DISCLAIMER

The opinions expressed herein are those of the author, and are not necessarily representative of those of the Uniformed Services University of the Health Sciences, the Department of Defense, or the United States Navy.

NOTES

1. A. Janvier, "How Much Emotion Is Enough?" in this issue of *JCE.*

2. S.B. Morse et al., "Estimation of Neonatal Outcome and Perinatal Therapy Use," *Pediatrics* 105, no. 5 (May 2000): 1046-50.

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Let's Value, But Not Idealize, Emotions

Jodi Halpern

The courageous accounts by Annie Janvier[1] and Felicia Cohn[2] in this issue of *JCE* describe the most difficult decisions a parent could ever face and show how limited the prevalent model of rational deliberation is for "informed" decision making. For a parent, how can the death of a child be an option to be weighed and balanced against other options? As Janvier and Cohn so vividly describe, parents' raw emotions play a crucial role in registering the values that are at stake in such profoundly difficult situations. Thus, as Jason Higginson[3] and David M. Browning and colleagues[4] argue, emotions need to play a role within decision making itself, and a role that is not reducible to weighing and balancing options. But what role?

If we truly want to incorporate parents' emotions into life-or-death decisions for newborns and babies who cannot speak for themselves, we need to think very carefully about what emotions can and cannot do — what roles they play in informing us about our own needs, versus the needs of others. To meet our ethical obligations to the child as well as to the parents, we need to avoid developing an idealized account of the role that parents' emotions ought to play in guiding such decisions, since there are important limitations to emotional intuition in such cases. To consider the moral guidance provided by emotions in such decisions, we need to clarify what the standards would be for a "good" decision in such difficult cases. Following Higginson and Browning and colleagues, I agree that while there are several important values at stake in such decisions, the two most important ones are the quality of life for the child and respecting the deep values of the parents. A good decision is one that serves these ethical goals. In these two cases, emotions, I will argue, helped very much in illuminating the parents' values, but they were not particularly informative about the suffering, or quality of life, of the child.

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EMOTIONS AND THE VALUES OF THE PARENTS

Let us begin by presuming that detached reason is morally insufficient, that our emotional views, as argued in feminist philosophy, are essential for perceiving moral salience.[5] They help us notice and then focus

on the attachments and vulnerabilities that are most important to us. When people become emotionally detached, they also become impaired in perceiving the suffering of others.[6]

Still, while emotions might help us notice what is morally or humanly relevant, they are not always reliable indicators of our deep and long-standing values. Consider how romantic passion or fear of loss compel our actions and even give us a sense of certainty — and yet both can also feel quite alienating in retrospect. The strength of an emotional feeling does not necessarily reveal how integral the emotional view is to our internal beliefs and values. Consider Ronald Dworkin's famous example of a devout Jehovah's Witness whose fear of dying leads him to seek a blood transfusion.[7]

Annie Janvier's husband felt such a strong emotional intuition that he felt certain of the decision to prolong the baby's life. At that moment in time, there was no way for him or anyone else to know for sure if this intense conviction was or was not truly reflective of his authentic, or most core, values. In fact, there are reasons to be concerned that his emotions resembled romantic passion or fear of loss that blinds us, rather than curiosity or *agape* — emotions that more consistently reveal our values to us. After all, it was seeing the baby suck the pacifier — which could have been a reflex — that moved him so deeply, shutting out all other thoughts. According to his wife, "he could not let go even if she was bloated, marbled, and pale! I was angry that a knowledgable physician could interpret these details in such an irrational manner. . . ."

Fortunately, we need not resolve the question of whether the husband's strong feelings in isolation were a reliable basis for this crucial decision, because he didn't make the decision in isolation. Rather, Annie Janvier and he made the decision together. Perhaps *her* integration of thought and feeling gives us a more useful model for how emotions can reveal core values. Janvier, despite her self-described traumatized numbness, was not completely emotionally detached. In particular, she was moved *emotionally* to change her mind based on her husband's response. She engages with his feelings in a way that exemplifies thought processes through which emotions become internal or authentic reasons to make a decision: "I chose to listen to him because, if she was really in irreversible septic shock, she would not improve and he would change his mind, but I also knew that a period of prolonged low blood pressure is not good for future brain function. I also 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." Janvier's decision making here is guided by core values. While she remains aware of how dismal the prognosis is, she decides that her love of her husband calls for her to be on the same page with him. This illustrates reflective, emotion-guided reasoning.

This example points out that by looking at emotions as social transactions among loved ones, rather than merely private experiences influencing an individual's decision, we are more likely to identify reasoning about emotions, rather than just emotions themselves, as the driver of decisions. One person's feelings can then be a good reason for another to make a decision, even if the first person wasn't able, at the time, to be reflective about them. This is especially relevant for parents making such frightening decisions — when parents are fortunate to have more than one person to help make the decision, this interpersonal process can help transform gut feelings into a reasoned decision by the couple, or in some cases even a larger family group.

EMOTIONAL INTUITION AND THE CHILD'S QUALITY OF LIFE

According to Browning and colleagues, research reports that, in making such difficult decisions, parents care most about trying "to ascertain and predict their child's expected quality of life." Higginson interprets these two cases as showing how parents' emotions helped them to empathize with their children, and thus put them in a better position to make decisions based on what matters most. I am

afraid that I must respectfully disagree, since I think that these decisions, inspired by strong parental emotions, were not tracking information about the child's quality of life. In fact, while I have just argued that these two cases illustrate parental love, and I have no doubt that these parents do empathize with their children, these cases, as described, are not illustrative of empathy for the child's suffering or future quality of life.

Higginson argues that parents, precisely because they "feel connected to their child" are "usually in the best position to balance the suffering of their child with the hope for the child's future after recovery." This is a very strong unproven claim that needs to be carefully parsed theoretically and examined empirically. Instead, Higginson goes on to say that parents can do this because of their empathy for the child. What kind of information, what model of understanding should this empathy involve? He ends the article without going to this crucial next step, leaving this reader with the impression that he feels that the parental emotion and concern described in the two cases are demonstrations of such empathy.

While I think that the parental feeling described in the two cases were demonstrations of love, and of deep parental values — these parents realized how important saving the child was to them — I do not see this as an example of empathy. In fact, if we take the term empathy to mean, specifically, understanding what in particular another person is experiencing and feeling, there was almost no information in either of these two cases about what the babies were experiencing, and even less about what they might feel in the future. These decisions necessarily needed to be made in the face of tremendous uncertainty about what these two children's lives would be like. Given radically insufficient information, various emotional processes fill in, but these processes are not empathy. For example, Higginson rightly worries that physicians in such cases *project* their own "personal intuition," biased by their own valuing of intelligence and ability. He even offers a crucial correction to such unreflective use of intuition — seek more information. He emphasizes data that report that extremely low birth weight infants with disabilities show the same quality of life as age-matched controls. I would argue that it is in seeking this kind of information, rather than in acting out of any gut feeling *per se,* that parents too are more likely to empathically grasp the needs of the child.

Elsewhere I have argued that empathy is a mode of understanding that integrates emotional resonance and curiosity to learn more about what in particular another's life is like.[8] Sometimes, in a rush to idealize emotions over against detachment, we forget that empathic understanding requires different things in different situations. In this situation, what was needed was less emotional intuition and more gathering of *empirical* information about other people's lives.

Thus, we wind up with an important conflict. In these cases, the parents' urgent emotional responses were important moral compasses expressing the values at stake, but this same emotional urgency put them in a worse position to reflect on the data about the child's quality of life. This is precisely what Cohn courageously shows. She vividly describes being unable to seek and take in the very kinds of information that might help with this difficult balancing. Cohn writes, "I knew I wanted her to live, to come home, to grow up, and in light of that, all of the downsides to the treatment plan *were invisible.*"[9]

Interestingly, Cohn goes on to question whether parents, *precisely because of how much they care,* may in some instances be temporarily *incapable* of taking in such information. Inadvertently, she raises a topic with enormous ethical implications, since a lack of capacity would undermine parental rights to make the decision for the child. We need to take care not to reify as incapacity the parents' difficulties in absorbing information, lest we fail to examine how we as caregivers might help parents at precisely such moments. Parents might need extended support networks to comprise a capable unit for decision making, just as Janvier and her husband did better together than they each seemed capable

of doing on their own. Parents might need their own emotional suffering to be addressed more thoroughly than caregivers often do. And people in distress may need other ways of absorbing information — patient-centered decision aids have been shown to help in such cases.[10] We need to address these needs of parents before coming to any conclusions about their decision-making capacities.

CONCLUSION

These articles beautifully demonstrate how parents' emotions humanize the most difficult ethical decisions imaginable. They also suggest ways that emotions are indicators of, and prompts for discussion of, the parents' values. This serves one crucial goal of decision making. However, we should be careful to avoid conflating this with emotions serving another crucial goal — trying, however approximately, to grasp the child's quality of life. Granted, appreciating the child's value is perhaps the necessary grounds for *motivating* an empathic gathering of information. However, the former is far from sufficient for the latter, since the former is about what the *parent* cares about, and the latter is about what the *child's* life will be like.[11]

Finally, importantly, even my attempt at precision on this matter needs to be contextualized against the very profound shift in perspective that, as Browning and colleagues suggest, such tragic choices require. They point out how little we know of how parents actually get through this kind of experience. They usefully note, "parents described the process less in terms of having 'made a decision,' and more in terms of a struggle to find their bearings. . . . in an uncertain moral universe." These articles by courageous caregiver-parents sharing their most difficult moments should serve as a wake-up call to other caregivers to make sure that we support parents and welcome their emotions at such times.

NOTES

1. A. Janvier, "How Much Emotion Is Enough?" in this issue of *JCE*.

2. F. Cohn, "Real Life Informs Consent," in this issue of *JCE.*

3. J.D. Higginson, "Emotion, Suffering, and Hope: Commentary on 'How Much Emotion Is Enough?' " in this issue of *JCE.*

4. D.M. Browning et al., "Reflections on Love, Fear, and Specializing in the Impossible," in this issue of *JCE.*

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7. R. Dworkin, *Life's Dominion* (New York: Alfred A. Knopf, 1993), 226-7.

8. Halpern, *From Detached Concern to Empathy,* see note 6 above.

9. Emphasis added.

10. A. O'Connor et al., "Decision aids for patients facing health treatment or screening decisions: systematic review," *British Medical Journal* 319 (1999): 731-4.

11. This distinction is easier to see when we don't sympathize with a parent's judgment — as for example, when a parent sees a child with mildly short stature as likely to be irreparably socially rejected and subjects the child to very aggressive treatments, while data actually report that shorter children do very well socially if they are otherwise psychologically supported. See E. Parens, "Authenticity and Ambivalence: Toward Understanding the Enhancement Debate," *Hastings Center Report* 35, no. 3 (2005): 34-41; D.G. Gill, " 'Anything You Can Do, I Can Do Bigger?': The Ethics and Equity of Growth Hormone for Small Normal Children," *Archives of Disease in Childhood* 91, no. 3 (2006): 270-2; L.D. Voss and D.E. Sandberg, "The Psychological Burden of Short Stature: Evidence Against," *European Journal of Endocrinology* 151 (2004): S29-33.

Cases and Commentary

Jewish Law and End-of-Life Decision Making: A Case Report

Craig D. Blinderman

CASE SUMMARY

Mr. G, a 77-year-old Jewish man with Alzheimer's dementia, hypertension, and coronary artery disease, was admitted to a New York City (NYC) hospital with altered mental status, fevers, and decreased oral intake. After undergoing an extensive workup for fever of unknown origin and altered mental status, no cause was found. The patient eventually developed severe aspiration pneumonia and bacterial sepsis with subsequent respiratory failure requiring intubation. The patient was unable to be weaned from the ventilator. A tracheostomy and PEG (percutaneous endoscopic gastrostomy) were surgically required for continuous mechanical ventilation and artificial feeding, respectively. While in the intensive care unit (ICU), the patient developed VRE (vancomycin-resistant Enterococcus) and MRSA (methicillin-resistant Staphylococcus aureus) infections as well as multiple deep (stage IV) necrotic sacral, hip, and back pressure ulcers requiring surgical debridement, daily dressing changes, and antibiotics. The patient was comatose, responding to painful stimuli only.

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The family consists of two daughters, Ms K and Ms G. Ms K, who is a secular Jew and lives in Montreal, wanted all "aggressive" care stopped, saying that this is not what her father would want. The second daughter, Ms G, who is an Orthodox Jew living in NYC and Mr. G's healthcare proxy via a co-guardianship document, wished that all treatments be continued as consistent with her Jewish beliefs and with *halacha,* or Jewish law. According to the patient's co-guardianship document, legal decisions regarding the patient's estate were entrusted to his lawyer, and decisions regarding his medical care were entrusted to Ms G. Although Ms G had wanted all treatments to be continued, including mechanical ventilation and artificial nutrition, she agreed that the patient should have a do-not-resuscitate (DNR) order and receive hospice care and comfort measures. The patient was transferred to a separate institution that provides hospice care for mechanically ventilated patients.

Upon initial evaluation of the patient on the in-patient hospice unit, it was determined that the PEG feeds were not being adequately absorbed (large residual volume of feeds were aspirated from the stomach and feeds were excreted from the tracheostomy site). The feeds were temporarily held pending a family meeting to discuss goals of care and pending a nutritional consult. Upon recommendations from the nutritionist, the feeds were changed, and the volume infused was reduced. However, the patient still did not absorb the feeds, and a large residual volume was

noted. At this point, the feeds were held. The team continued to discuss the possible harms of continued feeds with the patient's daughter, including aspiration, increased secretions, and the lack of benefit to the patient, as the nutrients were not being adequately absorbed. Ms G was distressed by the decision not to continue PEG feeds, as she felt giving artificial feeds was part of routine care; not giving feeds was equivalent to starving her father, and, according to her rabbi, once a life-sustaining therapy is started, it cannot be stopped.

CASE ANALYSIS

Before beginning the ethical analysis, we need to understand the religious beliefs and moral framework that the patient's daughter, Ms G, was trying to articulate.

INTRODUCTION TO *HALACHA*

Halacha is the term used to describe the collective body of Jewish religious law. It includes biblical, Talmudic, and rabbinic law, as well as customs and traditions. *Halacha* is derived from the Hebrew word "to walk," and may be understood as a guide on one's way through life. Indeed, *halacha* provides the observant Jew guidance in all aspects of religious practice as well as many aspects of day-to-day life, including medical decision making.

The majority of Orthodox Jews accept the Shulchan Aruch (Code of Jewish Law), composed in the sixteenth century by Rabbi Joseph Caro, as the accepted, authoritative, and binding code for the practical application of *halacha.* However, since the publication of the Shulchan Aruch, there have been large political and sociological changes affecting Jewish life, including scientific progress and medical inventions, which have raised complex *halachic* questions.[1] As a result, a *responsa* literature from rabbinical authorities, for example, the Rabbinical Assembly Committee on Jewish Law and Standards, has developed to provide *halachic* answers to these new questions. These rabbis are expected to have a deep understanding of all the *halachic* sources — the Torah, Mishna, Talmud, the codes, and the Shulchan Aruch — as well as sufficient technical knowledge of the subject in question, whether it be medical, legal, scientific, et cetera. However, it should be noted that there is no final authority or supreme judicial body with the authority to make *halachic* decisions that are binding for all Jews. Thus, which rabbi's decision is accepted is dependent on a variety of factors — clarity of argument, authoritativeness, personal qualities, as well as social and political factors — and has not been formalized.[2]

JEWISH LAW AND END-OF-LIFE CARE

Judaism is grounded in the concept of the supreme sanctity of human life and the dignity of man created in the image of God.[3] The preservation of human life, *pekuach nefesh,* is a divine commandment in Judaism. This concept is derived from several sources. The *halachic* basis for this concept is found in the Torah's commandment, *lo ta'amod al dam rei'ekha,* "You shall not stand idly by the blood of your neighbors" (Leviticus 19:16). The Talmud provides another source in Sanhedrin 73a, which restates this prohibition into a positive *mitzvah,* or commandment. It does this by relating the duty to intervene in life-threatening situations to the commandment in Deuteronomy 22:1 regarding restoration of lost property (*hashavat aveidah*): "every individual, insofar as he is able, is obligated to restore the health of a fellow man no less than he is obligated to restore his property."[4] Indeed, *pekuach nefesh* takes precedence over almost all other religious obligations and considerations, including keeping the Sabbath.

Is there a limit to *pekuach nefesh*? Are physicians obligated under Jewish law to provide treatment even if the treatment has limited chance for improving survival or if the treatment is associated with pain and suffering? The issue is not whether the therapy is effective, that is, achieves expected physiological ends, but beneficial to the patient, that is, is consistent with the patient's interests, values, and quality of life. There are some

sources in Jewish tradition that argue for considering the patient's best interests as the guiding principle in undertaking a particular therapy. The Talmud, in Avodah Zarah 27b, introduces a discussion regarding "the life of the hour" (*chayei sha'a*), which is thought to be the time a person lives after having been diagnosed with a terminal illness. The discussion concludes that we are "not to be concerned with the life of the hour," that is, we are not required to cure a person who, as far as we know, cannot be cured. In Yoma, a treatise in the Mishnah regarding the divine service on the Day of Atonement, we learn that we should violate the Sabbath to remove debris from a person buried under it in an attempt to try to save the person even if we have little hope he is alive.[5] Thus, in this case, we do care about "the life of the hour." In Tosafot, a commentary on the Talmud, the authors reconcile these two seemingly contradictory precedents regarding the value of "the life of the hour" and conclude that in every case we act for the patient's benefit. Benjamin Freedman, in his commentary on these sources, wrote, "Excavating a person from the rubble on the Sabbath is to his benefit, hence it is permitted; allowing a person who will otherwise die to risk his life for a chance of a cure is also to his benefit, hence it too is permitted. In other words, in these cases, a patient-centered risk-benefit analysis serves as the basis for determining whether an action is permissible, rather than some other autonomic formula."[6]

In addition, Rabbi Moshe Feinstein, perhaps the most renowned of twentieth century American *halachic* authorities, states that for a patient with pain and suffering who cannot be cured and who cannot live much longer, it is not obligatory for physicians to administer medical therapy to prolong his or her life of pain and suffering; nature may be allowed to take its course.[7] Therefore, it seems there are limits to the general principle of *pekuach nefesh.* Accordingly, when life-sustaining therapies are being considered, we should take into consideration the patient's subjective assessment of what is beneficial.

According to Jewish law, are we permitted to withdraw life-sustaining treatment in a dying Jewish patient? The patient's daughter argued that, according to her rabbi, once a treatment is started, it cannot be stopped. Is this consistent with Jewish medical ethics? It is interesting that Jewish law sanctions the withdrawal of any impediment that may delay a moribund patient, or *goseis,* from dying. A *goseis,* according to rabbinic references, denotes someone who is imminently dying, that is, within three days or less. Rabbi Moshe Isserles (Ramah) writes: "If there is anything which causes a hindrance to the departure of the soul such as the presence near the patient's house of a knocking noise such as a wood chopping or if there is salt on the patient's tongue; and these hinder the soul's departure then it is permissible to remove them from there because there is no act involved in this at all but only the removal of the impediment."[8]

On the other hand, the Talmud clearly objects to euthanasia, as the *goseis* is regarded as a living person in all respects.[9] Although we may be justified in removing obstacles that are delaying death, we may not perform any act that may hasten the death of a dying patient. The question then arises, is the withdrawal of artificial nutrition in a dying patient a justified act intended not to prolong his dying, or is it in fact an act that is hastening the patient's death and therefore forbidden?

ARTIFICIAL NUTRITION AND HYDRATION

An often-cited belief about artificial nutrition and hydration is that it is not a medical therapy, but must always be provided as an example of routine care. Is artificial hydration and nutrition ethically equivalent to other medical therapies, or is there something unique about this intervention that requires a different analysis?

In the palliative care literature, the issue of artificial hydration in end-of-life care is controversial.[10] It is thought that dehydration in the terminal phase may be associated with

delirium and therefore artificial hydration may be of benefit to the dying patient, although this has not been confirmed in randomized, controlled studies. On the other hand, the role of artificial nutrition in a severely demented patient is thought to be of little clinical benefit and may be associated with unnecessary suffering.[11] Artificial nutrition's "special status" is present in most contemporary traditional Jewish commentaries. Rosin and Sonnenblick argue that every patient must be fed since "food is a requirement of nature, for all people and even for animals, in order to sustain life."[12] Food is also believed to be necessary for the comfort of the patient, and is associated with strong cultural beliefs, including, but not limited to, its relationship to caring. While most contemporary traditional Jewish commentators claim that food and fluids must always be provided, there are some *halachic* authorities that believe artificial nutrition is no different than any medical treatment.[13]

A CASE OF MEDICAL FUTILITY?

How do we take into consideration the physician's clinical assessment that the intervention is not benefiting the patient and may even be causing harm? As Steven Miles, MD, points out, physicians, even when requested by family members, are not obligated to provide treatments that are "fruitless or inappropriate."[14] While the issue of possible harm is inherent in nearly every medical intervention, the risk-benefit ratio is used to assist physicians in determining which treatments are appropriate in a given clinical scenario. In this case, it is hard to find any medical benefit to the patient, so we are left only with the risks associated with the intervention. Indeed, one may even consider this to be an example of a medically futile treatment.

The question of whether artificial nutrition in this case is actually futile requires pause to consider the multiple definitions of medical futility. Four conceptual types of futility have been identified: physiologic futility (the intervention does not have its intended physiologic effect), imminent demise futility (the patient will die before discharge regardless of the intervention), lethal condition futility (the patient has an underlying disease that is not compatible with long-term survival, regardless of the intervention, even if the patient could survive to discharge from this hospitalization), and qualitative futility (the resultant quality of life is too poor).[15] Another way of construing qualitative futility is when the treatment "merely preserves permanent unconsciousness or cannot end dependence on intensive medical care."[16] Futile care may also be defined quantitatively, "when physicians conclude (either through personal experience, experiences shared with colleagues, or consideration of reported empiric data) that in the last 100 cases, a medical treatment has been useless."[17] In this case, artificial nutrition was physiologically futile, as the patient was not absorbing the feeds, even at a reduced volume.

Alluding to physiological futility, Rabbi Immanuel Jacobovits in a 1985 lecture at Cedars-Sinai Medical Center in Los Angeles stated, "physicians need feel no compunctions in removing machines or medications that have not affected the hoped-for medical results."[18] Most commentators on Jewish law would agree that physicians are not required to provide ineffective treatments or treatments that lack a reasonable chance of being of benefit to the patient.

ETHICAL ANALYSIS

The first issue to consider is respect for the patient's autonomy. Since the patient is without decision-making capacity as a result of his medical illness, we must rely on surrogate decision makers. Mr. G gave the legal authority to his Orthodox Jewish daughter, Ms G, to make healthcare decisions for him in the event he loses capacity. Can we assume that the surrogate's religious beliefs and practices should form the basis for healthcare decision making? Unfortunately, we do not know whether Mr. G shared his daughter's Orthodox Jewish interpretations of *halacha,* nor do

we know if he would want such interpretations applied to his own medical care. Indeed, we learn that the patient's second daughter, Ms K, does not believe that he should have been kept alive with aggressive treatment and that he would have preferred that all treatments be stopped. Although legally Ms G is the appointed healthcare agent and her input is crucial in guiding her father's end-of-life care, we must distinguish between *legal agency* and *moral agency.* Ms K may, in fact, be acting on behalf of the patient's best interests, while Ms G, the legally appointed healthcare agent, may be articulating her own religious beliefs, as if they were in accordance with her father's wishes. The fact that Mr. G *chose* Ms G, rather than Ms K, does not allow us to infer that his values are identical to his religious daughter; indeed he may have chosen her based on other considerations, including proximity and personal affinity. Finally, we must ask how much of Ms G's insistence on continuing the feeds is a reflection of her religious commitments and how much is a reflection of her own misconceptions about "starvation," cultural or familial beliefs about feeding, or other psychological factors that impact end-of-life decision making. A family meeting to assess not only the daughters' understanding of their father's wishes, but for the healthcare providers to better understand the daughters' differences and to help them cope with their loss is clearly indicated. In this way, we may actualize what Carol Gilligan describes as the "care orientation," which more readily leads to a model of shared decision making, emphasizing response and relationship, rather than rules and rights.[19]

By extending Gilligan's observation, we may argue that our obsessive focus on preserving the patient's autonomy is not sufficient for arriving at ethically appropriate decisions involving healthcare agents. There are, as Nancy Dubler points out, obligations to the proxy.[20] The healthcare team is obligated to consider the proxy's welfare and provide support and guidance. This is especially true when the decisions are a matter of life and death, and the proxy primarily shoulders the burden. Moreover, John Arras has argued that patients with severe neurological injuries (for example, persistent vegetative state — PVS) seemingly have "no interests," and that a shift in focus to the interests of the family and surviving loved ones should become paramount.[21] Thus, our obligation to Ms G, both as a proxy and as the patient's daughter, would have us consider her moral struggle and well-being, given her father's grave condition. We could certainly reframe the ethical dilemma, by focusing on Ms G's *duty* to honor her father and uphold Orthodox *halachic* principles that involve respecting the sanctity of human life, while at the same time considering the medical opinion that artificial nutrition be withheld, given its lack of benefit and risk of harm.

In attempting to reconcile this ethical dilemma, we could examine Ms G's conclusion about what she believes is acceptable under Jewish law, namely that artificial nutrition must be provided and to not do so is effectively starving her father and forbidden. One might argue that in fact Mr. G was actively dying and his nutritional support was prolonging his death. According to Jewish law regarding a *goseis,* all impediments that prolong death should be removed. If even the knocking noise of a woodchopper outside is believed to prevent the soul from departing, perhaps continuous feeds into a gastrostomy tube could be thought to have the same effect. Aside from the technical challenge of accurate prognostication of death within three days, the assumption that the feeds were "preventing death" under Jewish law is merely speculative, although consistent with previous examples of impediments to death as cited earlier.

A more compelling argument is whether under Jewish law the feeds could be discontinued since they were providing no medical benefit and appeared to be causing harm (for example, excessive secretions, aspirations). The proposed withholding of artificial nutrition turns on it being considered a medical

therapy versus routine care that should always be provided. According to one *halachic* analysis, if artificial nutrition is considered a medical therapy, and that medical therapy provides no benefit and is in fact causing suffering, the terminally ill patient is not obligated to receive it.[22]

CONCLUSION

We began the analysis with a query as to whether autonomy is truly respected in this case. The difficulty in answering this question may be due to the fact that the patient's belief system and values, which would likely guide his end-of-life decision making, are not clearly known, nor are they stated in an advance directive. However, we do have a legally appointed healthcare proxy, his Orthodox Jewish daughter, Ms G. Her struggle with making end-of-life care decisions for her father is apparent. She is obligated to both act on behalf of his best interests and abide by Jewish law, which is based on centuries of rabbinical interpretations. In view of the difficult decision she was asked to make, and in part by our duty to help guide her as proxy, it seemed necessary to involve a third participant — the rabbi — "to give halachic guidance and pastoral support to the patient and physician in their critical decision-making process, and to bring to bear the external values of the Jewish tradition."[23]

After discussing the case with two rabbis from the hospital (both of whom supported the clinical assessment and plan on the grounds that the artificial nutrition was no longer benefiting this dying patient), and after further discussion with Ms G, the medical team decided to temporarily hold the feeds and contact her community rabbi to help facilitate a consensus among the medical team and the patient's daughter. Unfortunately, since this was attempted on Friday morning, as the Jewish Sabbath was approaching, we were unable to schedule a meeting with Ms G's rabbi. The feeds were held over the weekend, and the patient expired the following day.

ACKNOWLEDGMENTS

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MASKING OF THE CASE

The case presented in this article has been changed to protect the identity of the patient and the patient's family members. The names of the patient and family members have not been used; instead, random letters have been used to designate family members. Other details have also been modified to protect their identity.

NOTES

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When Surrogates' Responsibilities and Religious Concerns Intersect

Jeffrey T. Berger

The case of Mr. G, presented by Craig D. Blinderman, MD, raises a number of interesting ethical issues.[1] I wish to examine some of these that are related to surrogacy. In this case, Ms K was the daughter Mr. G did not choose to be his health agent. Nevertheless, Ms K represents her desire to stop aggressive treatment as being consistent with her father's treatment preferences — a substituted judgment. Ms G, the Orthodox Jewish daughter chosen by Mr. G to be his agent, states that her decision to continue treatments is based on *her* beliefs and Jewish law. This healthcare agent's decision-making method does not conform to the accepted hierarchy of standards: known wishes, substituted judgments, and best interests. It also appears consistent with evidence suggesting that religiosity is associated with surrogate decisions to over treat.[2]

Ms G is obviously the legally empowered decision maker, but which of these two daughters is the most ethically appropriate surrogate decision maker? To assess this, a number of questions need to be asked and issues raised. We do not know Mr. G's religious values and treatment preferences (beyond Ms K's representation of the latter). We know little about the parental and sibling relationships in this family, and we do not know which, if either, daughter has a good understanding of Mr. G's wishes. At the time Mr. G assigned proxy authority, what was his level of cognitive functioning? Was he aware that when he designated one daughter as health agent, he legally excluded his other one from participating in decisions and was this his intention? Did Mr. G base his selection of agent on one of several common misapprehensions, such as the agent should be the one most geographically accessible or the eldest of the siblings? Was Ms G Orthodox in her personal religious practices at the time Mr. G appointed her as his health agent and was he aware of this? These and other concerns would need elucidation in evaluating the ethical fitness of Mr. G's surrogate.

For this discussion, let us assume that Ms G is in fact making an appropriate substituted judgment and that her decisions are made

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based on her personally held values and religious requirements. Ms G's approach to decision making is not all that unusual. Evidence suggests that many patients and surrogates do not necessarily follow the normative cascade of decision-making standards.[3] In fact, many patients value trust over accuracy in decisions; many patients prefer that their surrogates exercise judgment in response to actual clinical situations even if decisions depart from expressed wishes; and many patients accept surrogate decisions based on both medical and nonmedical considerations, including the welfare and well-being of their family member-surrogates.[4]

It is likely that Mr. G knew of his daughter's Orthodox Jewish commitment, and perhaps, he selected Ms G because of it. Mr. G may have understood this daughter to be more deeply committed than her secular sister to an obligation in Jewish moral life that is held as primary: *kivod av v'em* — honoring one's father and mother. This obligation, which is rooted in the fifth of the Ten Commandments, would require Ms G to provide for her father's physical needs, to attend to his dignity, and to act with a respectful attitude or spirit, even at great personal sacrifice.[5] Mr. G's confidence in his daughter's filial piety would be an ethically appropriate basis to respect her decision-making authority.

Perhaps Mr. G selected Ms G as his agent not because he thought that she would best represent his medical concerns, but for another reason. A Jewish imperative is *shalom bayit,* that is, maintaining peace and harmony in one's home or family. Not uncommonly, in Jewish families, significant compromises are made to ensure domestic tranquility. It is possible that choosing Ms K as the proxy would have been more disruptive to the family dynamic than choosing Ms G, even though Ms K would better represent Mr. G's medical preferences. This is a trade-off that Mr. G may have made intentionally and willingly.

On a different tack, what is the patient's responsibility in assigning proxy authority? For purposes of discussion, let's assume that Mr. G empowered his Orthodox daughter to be his health agent and also left instructions in an advance directive that she should make decisions according to his secular ethics. Is it fair for the patient to place his daughter in the position of choosing between violating her personal morals and stepping back from participating in her father's care? Conversely, what is the health agent's responsibility? May an agent apply any moral code to decisions? For instance, a semi-estranged daughter returns from Asia as a practicing Buddhist to care for her now-demented father. Is it permissible for her to base decisions on her religious convictions, since she knows little about her father's, or should she proceed in decision making using a more generic ethics?

Is it appropriate for Ms G to apply her Orthodox Jewish religious requirements to decisions on her father's behalf? By virtue of her Orthodoxy, she is likely operating under a different set of assumptions about autonomy and decision making than are the members of the health team. In American secular ethics, the principal of autonomy is generally viewed as *prima facie,* if not frequently inviolate. However, in traditional Jewish ethics, autonomy is not understood as absolute ownership of one's body and life, but instead mere stewardship of that which belongs to God. Moreover, respect for persons comes from the view that humans are created in God's image. Although Judaism accepts the notion of free will, Judaism also understands that a Jew's choices are bounded by the laws of Torah, and therefore Jewish law prohibits Jewish patients from making decisions contrary to *halacha*.[6] To illustrate, in secular ethics, it is permissible to decline a curative or life-saving treatment based on a patient's determination that his or her quality of life is poor. Jewish ethics would essentially prohibit such an "autonomous" choice.

The case of Mr. G illustrates the multilayered ambiguities commonplace in clinical ethics generally and in surrogacy specifically, as well, and the sorts of issues clinical ethics consultants must tease apart. Moreover, it

highlights the profound role religion plays in the lives of many people and underscores the importance for health professionals to recognize, understand, and address the role of religion in health, illness, and family, and to work with clergy for the good of the patient and family.

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A Tale of Two Daughters: Jewish Law and End-of-Life Decision Making

Dena S. Davis

Dr. Blinderman presents us with a difficult case, but one I suspect is not unusual.[1] In trying to respond, I am frustrated by how little we know about Mr. G. My own response is always to put autonomy first — that is to say, to always ask first and last what the patient would want if he could tell us.

Here we have a man with two daughters, each of whom conveniently represents a sharply different perspective on how to respond to questions of care at the end of life. How much weight should we put on the fact that Ms G, the Orthodox Jewish daughter, is her father's designated decision maker? Had Mr. G chosen her as such while he was still mentally capacitated, I would put more weight on that than the author of the case does. It is certainly true, as the author writes, that we do not know if Mr. G shared his daughter's religious views. Perhaps he chose her as his proxy because of geographic proximity or some other reason. However, had he chosen her while capacitated, it is reasonable to argue that he knew of his daughter's religious beliefs and was willing to have his healthcare governed by an Orthodox Jewish perspective. Had this not been the case, he might have attempted to have made his daughters co-proxies, or to limit the scope of Ms G's decision making by executing a living will. It would be helpful to know if Mr. G himself had been a religious Jew during his lifetime. Had Mr. G subscribed to a traditional form of Judaism, he himself would probably not put autonomy first. In traditional Judaism, autonomy is less important than following God's commandments, and one's body is not ultimately one's own property, but a gift from God that one must care for. Thus it is quite possible that had Mr. G been competent to express wishes about his final care, he might well have given

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up the decision to a rabbi he trusted, just as his daughter is doing.

However, even had Mr. G been a secular Jew like his other daughter, that tells us less than we might hope regarding his wishes. In *Six Lives in Jerusalem,* Randy Linda Sturman explores six cases of end-of-life decisions.[2] It is striking that even secular Jews often appropriated religion to give them a sense of comfort and ethical structure as they struggled with the question of how aggressively to maintain terminally ill family members.

Even from Ms G's Jewish perspective, however, there is room to ask her to reconsider. First, the question of whether artificial feeds is part of routine care is not an inherently religious one. Second, although many people are initially horrified at the thought of a family member "starving" to death, it is important to discuss with them that this is not an uncomfortable process with the support of a hospice team who know how to keep patients comfortable. It is crucial to help family members sort out the different meanings of "feeding," and to understand that pouring formula into a PEG tube is very different from the social act of feeding someone.[3] Finally, it is true that many Orthodox rabbis consider that a therapy once begun cannot be stopped, but, as Dr. Blinderman notes, the very influential Rabbi Feinstein disagrees with the position. However, the feeds are not a continuous therapy like a ventilator, but a series of discrete interventions (I hesitate to use the term "treatments," as the feeds are obviously not treating anything). Many rabbis would consider, for example, that if a patient pulled a ventilator tube out accidentally, one would not be obligated to reinsert it simply on the theory that a modality cannot be stopped. A ventilator that turns itself off and on automatically at set intervals has been invented in Israel precisely to circumvent this difficulty; pulling the ventilator before it restarts is not considered to contravene *halakhah.*

In the end, however, there appears to be little ethical or religious conflict. As the feeds are not having the desired effect of delivering nutrition to Mr. G, and are causing discomfort and medical problems to boot, neither *halakhah* nor the daughter's concern for her father's well-being argue for continuing them. Further, continuing a modality that is causing the patient harm goes against the Hippocratic Oath; it is unfair to expect a doctor to practice bad and unethical medicine in order to soothe Ms G.

Ms G has been given a very heavy burden here, but she needs to understand that the course of her father's life is out of her hands.

NOTES

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Commentary on "Jewish Law and End-of-Life Decision Making"

Fred Rosner

In the beginning of Jewish history, religion and healing were inseparable because the priest and the physician were one and the same person, administering healing with divine sanction and mandate. Jewish physicians traditionally consider their vocation to be spiritually endowed and not merely an ordinary profession. Ethical standards for the practice of medicine among Jews have always been high. Jews have always held physicians in high esteem.

Throughout history, Jews have exerted a tremendous influence on the development of medical science. They have and continue to excel in medical practice, teaching, administration, and research. More than 20 percent of all Nobel Prize winners for medicine are Jewish.[1]

The importance of medicine among the Jews is best exemplified by the long line of physician-rabbis, which started during the Talmudic period (Mar Samuel being the most famous) and continued through the Middle Ages (famous examples are Moses Maimonides, Moses Nachmanides, and Judah Halevi).[2]

This trend of Jews becoming physicians continued even after the Middle Ages, through modern times, in part because Jews were excluded from almost all other occupations, including public office. Medicine was and is one of the few dignified occupations by which Jews are able to earn a living and support their families.

The emergence of Jewish Medical Ethics as a distinct subspecialty within Jewish thought and Jewish law is a relatively recent phenomenon. The late Lord Immanuel Jakobovits, Chief Rabbi of the British Commonwealth of Nations, submitted his thesis, entitled "Jewish Medical Ethics," to the Uni-

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versity of London in 1955, and it was published by the New York Philosophical Society in 1959. This was the first use of the phrase Jewish Medical Ethics. In Jewish medical circles, Rabbi Jakobovits, of blessed memory, is known as the "Father" of Jewish Medical Ethics.

Rabbi Jakobovits's landmark publication, now a classic, was considered revolutionary, not only because the term or concept of Jewish Medical Ethics was unknown at the time, but because the subject itself had been entirely unexplored and left without any literary or scholarly expression in any Western language. By contrast, there existed a considerable literature on Catholic Medical Ethics.

We should also consider the fact that Jewish Medical Ethics is not a twentieth century phenomenon. The Jewish people have been studying, writing about, and practicing medicine according to Jewish law for thousands of years. The Jewish tradition, which dates back to Mount Sinai where Moses received the Torah (Bible), is perhaps the longest unbroken tradition in bioethics that is still followed by adherents.

Throughout the millennia, Judaism and medicine have marched hand in hand, as allies and partners in a common endeavor. The mainstream of Jewish tradition places enormous value on human life and health, gives human beings such as physicians an obligation to preserve life and health, and pursues a dual track of encouraging and even mandating both physicians to heal and patients to seek healing from the physicians with faith in Almighty God *as the true healer* of the sick.

Because Judaism and medicine enjoy historical and intellectual kinship, it is only natural that Jewish law is best qualified to apply its reasoned rules of morality to the practice of medicine. For centuries, rabbis and physicians, often merging their professions into one, have been and continue to be intimate partners in a common effort to heal the sick and protect life and health by practicing preventive as well as standard medicine.

In this issue of *The Journal of Clinical Ethics,* Dr. Blinderman discusses in some detail Jewish law and end-of-life decision making in an elderly 77-year-old Jewish man with Alzheimer's disease, hypertension, and coronary artery disease, who had a stormy hospital course and succumbed to complications from his medical conditions.[3] The author describes the conflicts in decision making between two of the patient's children and how the author went about conflict resolution. He clearly outlines the basic nature of Jewish law, describes Jewish law and end-of-life care, comments on the very sensitive issues of artificial nutrition and hydration, and medical futility. His ethical and Jewish legal and moral analyses of the case report are accurate, well synthesized, and well presented, as are his conclusions. Although Blinderman provides an appropriate bibliography, it would have been helpful for the reader unfamiliar with Jewish legal terminology to include a glossary of such terms at the end of the article.

In summary, in Judaism, not only is a physician obligated to hear, but also a patient is obligated to seek healing from physicians rather than relying on faith healing. The second-century Talmud states that no wise person should live in a city that does not have a physician. Twelfth-century Rabbi-Physician Moses Maimonides rules that human beings are obligated to accustom themselves to a regimen of life that will preserve one's body and health and heal and fortify it when it is ailing.[4]

The extreme concerns in Judaism about the preservation of health and the prolongation of life require that a woman's pregnancy be terminated if her life is endangered by the pregnancy, that a woman use contraception if her life would be threatened by pregnancy, that organ transplants be performed to save or prolong the life of a patient with organ failure, and that an autopsy may be performed if the results of that postmortem examination might yield immediate information to rescue another dying patient. Judaism prohibits cru-

elty to animals but sanctions animal experimentation to find cures for human illnesses, as long as the animal experiences no pain or suffering so that analgesia or anesthesia are required, when necessary.[5]

Thus, in Judaism, every human being is considered to be of supreme value. It is the obligation of individuals and society to preserve, dignify, and hallow human life to care for the total needs of all people so they can be healthy and productive members of society. This fundamental principle of the sanctity of life and the dignity of man as a creation of God is the underlying axiom upon which all medical ethical decisions are based.

NOTES

1. *http://www.jinfo.org/Nobels_Medicine.html,* accessed 26 July 2007.

2. H. Graetz, *History of the Jews,* vol. 2, chap. 19 (Philadelphia: Jewish Publication Society, 1941).

3. C.D. Blinderman, "Jewish Law and End-of-Life Decision Making: A Case Report," in this issue of *JCE.*

4. *Mishneh Torah*, [Code of Maimonides], *Hilchot De'ot* [Laws of Temperament], 4:1-forward.

5. F. Rosner, "Animal Experimentation," *Biomedical Ethics and Jewish Law* (Hoboken, N.J.: KTAV Publishing House, 2001), 413-33.

The Case of Mr. A.B.

Peter Sloane and Evan G. DeRenzo

Mr. A.B. was a 70-year-old Caucasian male referred to our institution for coronary artery bypass graft (CABG) surgery. His past medical history included hypertension, diabetes mellitus, peripheral vascular disease, and chronic obstructive pulmonary disease. Three days before Mr. A.B. was transfered to our institution, he had presented to an outside institution with a non-ST elevation myocardial infarction (MI) and mild congestive heart failure. A coronary artery stent was placed, and Mr. A.B. was discharged to home the following morning. On the day before he was transfered to our institution, he presented to the same outside institution with recurrent substernal chest pressure, severe congestive heart failure, and acute respiratory failure requiring intubation and placement on mechanical ventilation. Mr. A.B. underwent repeat coronary arteriography, which confirmed severe multi-vessel coronary artery disease, and the following morning he was transferred to our hospital for consideration of CABG surgery.

After initial evaluation at our hospital, the consensus recommendation by our cardiologists, intensivists, and cardiac surgeons was to target a surgical date for CABG on approximately hospital day three to allow time to stabilize the patient on the ventilator and aggressively treat the congestive heart failure. The patient showed significant improvement by hospital day two and was posted for CABG surgery, as previously planned, for the following afternoon. The patient was assessed to be sufficiently capacitated to consent for his own surgery and signed the surgical consent form after discussion of the risks and benefits of the planned procedure. The family was supportive of the patient's decision to proceed with surgery.

The next day, four hours prior to the planned surgery, the Critical Care Unit (CCU) attending physician (the first author) was informed by the patient's nurse that the family had called the nurse to notify our staff that

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the patient's daughter had died unexpectedly that morning. This daughter had been living with the patient and his wife for some time because she was impaired, but ambulatory, from previous cardiac events. According to the nurse, the family requested that news of the patient's daughter's death be delayed until after the patient's recovery from surgery.

DISCUSSION

The medical team, composed that day of the CCU attending (the first author), residents, medical students, nurses, and a bioethicist (the second author), immediately recognized the ethical complexity of considering the request from the family to delay notifying the patient about his daughter's unexpected, but not surprising, death. The initial opinion of the CCU attending and the bioethicist was that the patient should be told of his daughter's death prior to proceeding with CABG surgery. This judgment was based on the ethical justification that the information was sufficiently material to the patient's ability to make an informed decision about whether or not he wanted to have the surgery at the time presently scheduled.

A counter argument was immediately raised in the general discussion among the team members that delaying surgery might not be in the patient's best medical interest. The team had worked diligently over the days leading to the surgical date to get the patient into a physiological state that would maximize his chances for surgical success. The team felt that proceeding with the surgery at the scheduled time would provide the patient with the maximal chance of a good outcome and that, because of his precarious clinical condition, any delay past his peak physiological state might result in the window closing on providing him the best outcome. The team was particularly concerned that coupling a delay in surgery with the potential for deterioration that such sad news might be expected to trigger in the patient could be factors supporting a sufficiently strong argument for withholding of the news of the daughter's death until after surgery (based on the principle of the primacy of beneficence) rather than proceed with pre-surgical disclosure (based on the principle of autonomy).

Although both positions were argued vigorously, the attending physician and bioethicist continued to believe that the patient should be told.

Shortly after these discussions it was learned that the family was expected in momentarily. The attending physician felt it would be prudent to interrupt rounds to meet with the family when they all had arrived. In preparation for this family meeting, he contacted both the chair of the hospital's ethics committee, also an intensivist practicing in the hospital's CCU, and the CCU chief. These two physicians both advised the team that it would be ethically permissible to withhold the information of the daughter's death from the patient on the basis of prioritizing the patient's immediate medical best interest as overriding disclosure on the basis of patient autonomy. That the family was reported as not wanting the hospital to disclose prior to surgery was, for these two, not governing but certainly a consideration. Disclosing news of the patient's daughter's death to the patient, over the family's objection, would cause additional distress and upset and could only be expected to contribute negatively to the patient's well-being and the morale of the medical team. Nonetheless, the attending and the bioethicist continued to hold their bias towards disclosure.

OUTCOME

A meeting with members of the family, critical care team, nursing staff, and medical ethicist was convened to confirm the family's wishes and resolve the issue of whether or not to disclose news of the death of the patient's daughter. The family included the patient's wife, their two adult daughters, and one sur-

viving adult son. The patient's wife and one of the daughters sat through the meeting quietly, with their only verbal contribution being an indication that they were in agreement with the plan put forward by their son and other daughter. Although the daughter spoke the most and was quite vocal in her opinions, it was clear that all family members were in agreement to withhold the news until after recovery from surgery. The family also requested that the family would be the ones to tell their father of the death after recovery from surgery.

When an attempt was made to discuss the possibility that withholding this information until after the surgery had a chance of hindering post-surgical recovery (if the patient would exhibit profound sadness over the news or anger at the family for withholding the news), the son and more-verbal daughter were adamant that they would take responsibility for such outcome and would be clear with their father that the decision to delay disclosure was theirs.

In the end, the attending physician weighed the conflicting precedent of autonomy at our institution to inform a capacitated patient of the death of a close family member against the principle of beneficence regarding the family's concern about the patient's emotional fragility, the concern about the patient's medical instability, and the family's resolve that they were acting in the patient's best interest. The attending physician informed the family that the medical team would follow their request to withhold news of the daughter's death from the patient until after surgery and that the family would be the ones to inform the patient at that time.

By post-operative day three, the patient was doing quite well medically and was informed by the family of the death of his daughter. The patient's grief was felt to be appropriate and the patient displayed no anger towards the family or medical staff for withholding the news of his daughter's death until his post-operative convalescence.

EPILOGUE

Although the team was, and continues to be, in agreement that the ethically optimal decision was made at the time it had to be made, for some there are lingering discomforts. It is unclear whether the concerns about the potential negative effects of providing the information pre-surgery are based on emotions and myth or sound medical outcomes data. It is unclear whether or not the inclination to weight the potential harm of disagreeing with the family springs from altruistic concern for avoiding family, patient, and/or medical team moral distress, or whether these concerns are inordinately influenced by fears of increasing the hospital's and the physicians' risks of legal liability.

Today, more than two years since the case occurred, this case has become a teaching tool at our institution. It continues to produce vigorous debate, with no reduction in the lingering discomforts some feel about its outcome. Perhaps the case is most instructive in its illumination that refined ethical analysis rarely results in a neat division between what is clearly ethical and what is clearly not. Rather, perhaps the most important lesson to be learned from this case is that resolution of ethical problems in the everyday clinical care of patients most often results in some ethical principles being infringed on more obviously than on others, and that the moral discomforts this phenomenon produces is merely another dimension of the ambiguities and uncertainties inherent in the art of practicing medicine.

Would your institution have handled this case any differently?

MASKING OF THE CASE

The authors have changed details of the case to protect the identity of the patient and the patient's family.

Comment on the Case of Mr. A.B.

Paul S. Appelbaum

The "ethical dilemma" in this case arises from a thoroughgoing misconception about the obligations of physicians and hospitals in obtaining patients' informed consent. To understand why the extended handwringing over whether to disclose information about the death of the patient's daughter was misplaced, we need to return to the fundamentals of the law and ethics of informed consent.

The doctrine of informed consent to medical treatment evolved in the U.S. courts in the mid-twentieth century. It grew out of the earlier requirement that physicians obtain patients' "simple consent" for invasive medical procedures, that is, that patients be informed in advance of the nature of the procedures to be undertaken and indicate their agreement with the proposed interventions. For roughly 200 years, courts operating in the Anglo-American legal tradition had found disclosure merely of the nature of the procedure that was being recommended by the physician — and the patient's subsequent consent — to discharge the entirety of a physician's obligation to provide information to the patient.

By the middle of the twentieth century, however, American courts began to recognize that the choices facing patients had grown considerably more complex since the days when the simple consent rule had been formulated. In many medical situations, patients had to choose among multiple treatment alternatives, with varying sets of risks, disadvantages, and benefits. For patients to make truly meaningful choices, they needed the kind of detailed information about the possibilities for treatment that ordinarily only their physicians would possess. Hence, the courts placed the burden on physicians to disclose information about the nature of the patient's condition, the nature and purpose of the proposed intervention, the risks and disadvantages of that approach, the possible benefits of the treatment, and possible alternatives to the proposed treatment, along with their risks and benefits.[1]

Hence, informed consent to treatment is largely based on judge-made law, driven by concerns of the judiciary, not by the theories of ethicists, who came along after the fact to offer theoretical ethical justifications for the new set of practices. (Rules regarding informed consent to research evolved separately, with little interaction between these two seemingly related areas.) Ethicists often focused on the importance of patients' decisional autonomy, and the desirability of enhancing that autonomy by providing patients with sufficient information so they could apply their

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values to the choices they faced. In this dominant ethical formulation, the role of physicians is to offer medical information to patients, who then use this information — in the context of what they know to be their life situations and in light of the preferences they have — to reach decisions about treatment.

Whether the medical information disclosed to patients should be limited to the categories mentioned above or expanded to include other issues has been debated in recent years. Among the suggestions for additional disclosures is information about the physicians' previous experience with patients facing similar medical issues; the success rate of the physician and/or facility in performing the recommended procedure; the cost of the procedure, even if the patient's insurer will be bearing that burden; and aspects of the physician's own situation that might influence patients' choices (for example, whether a surgeon is HIV positive or a hepatitis carrier). Except when such additional disclosures have been statutorily mandated, the courts have been reluctant to impose additional disclosure burdens on physicians — even when the disclosures related to information that was uniquely available to them.

In this case, the question was raised as to whether the physician was obligated to tell the patient about the death of his daughter. Note that, unlike data about the risks and benefits of the CABG procedure itself, this is not information that was held uniquely by the physician or the other medical personnel. Indeed it was obtained from the patient's family, with the explicit request that it not be communicated to the patient. Information pertaining to the death of a patient's loved one is beyond the scope of disclosure suggested by any reasonable legal or ethical formulation of the doctrine of informed consent. It is the sort of information that is generally communicated by families or other intimates, not by physicians. Whether the family in this case was ethically justified in withholding this information from the patient goes beyond my discussion here. But however one would resolve that question, the choice — and the potential burden of having made an incorrect choice — rests with the family, not the physician or the hospital.

To be clear, because this seems to be at the core of the confusion in this case, it is not the obligation of the physician to disclose all information material to a patient's decision, as this datum arguably may have been. Physicians must disclose relevant medical information, and no more. This case actually provides a good example of the problems that physicians can create when they violate that dictum. For disclosure of the death of the patient's daughter to have been made over the family's objections would not only have caused distress to the patient at a critical time, but would have constituted a major intrusion into the autonomy of the family unit. The patient, perhaps resenting the family's decision, may have been alienated from them at precisely the time when their support was most needed. The repercussions of that perturbation of the family's dynamics are too complex even to be foreseen, but may have extended well into the future.

More than two years later, we are told, staff members at this facility are still in anguish over whether the right decision was made. But the worry is misplaced. It derives from what is at core an assumption that it is the burden of the medical profession to assume responsibility for all aspects of their patients' lives. Ironically, a doctrine meant to undercut medical paternalism here was used to argue in favor of overweening medical paternalism — with physicians and other medical staff assuming the responsibility most properly resting with the patient's family. It is time to reassure those staff members who continue to experience "lingering discomforts" that they can put their concerns aside. The right choice was made here — perhaps not for the right reason, but the right choice nonetheless.

NOTES

1. J.W. Berg et al., *Informed Consent: Legal Theory and Clinical Practice,* 2nd ed. (New York: Oxford University Press, 2001).

Law

Legal Trends in Bioethics

Sigrid Fry-Revere, Sheeba Koshy, and John Leppard, IV

Readers who learn of cases, laws, or regulations that they would like reported in this column are encouraged to e-mail Sigrid Fry-Revere at *sfryrevere@cato.org*.

GENERAL INTRODUCTION

The laws governing bioethics issues are confusing and sometimes contradictory because of several types of tensions inherent in our legal system. Legislatures and courts work in different time frames and with different priorities. The guarantees of separation of church and state and individual rights in the U.S. Constitution make bioethics issues involving personal, moral, or religious convictions particularly contentious.

Each state also has its own constitutional protections, some of which clearly mirror those in the federal Constitution, but others do not.

Legislatures and courts play different roles in our constitutional republic. Legislatures are by nature democratic and can react relatively quickly to changes in the political climate. Courts, on the other hand, are inherently antidemocratic. As a matter of fact, their main constitutional function is to protect the rights established by the federal and state constitutions from violation by legislative and executive action. Courts are also inherently conservative in their reaction to events because they are bound by precedents and procedural processes that are designed to assure that major philosophical changes happen gradually.

Legislatures and courts, in the area of bioethics, also act under the existence of two contrary presumptions. Legislatures tend to act with a presumption in favor of prevailing moral beliefs. The courts, on the other hand, have the structural and theoretical obligation to protect individuals from majoritarian decisions that unnecessarily violate their constitutionally protected freedoms. They also have an obligation to uphold the separation of church and state. So, in bioethics cases, courts often have to deal with preventing govern-

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ments, either through legislation or other state action, from imposing moral or religious preferences on individuals who might not agree. Thus courts tend to show greater deference to individual choice than legislatures do, and tend to become more cautious when confronted with divisive issues.

An understanding of these inherent tensions between legislative and judicial action and the various individual interests being balanced by the courts will make it easier to understand legal trends in bioethics.

It is also important when considering trends to watch how far bills that are introduced advance even if they do not pass. For example, a bill that is introduced and quickly moves through several committees and is voted on by one chamber but not the other before the legislative session ends has a better chance of passing if reintroduced at the next session than a bill that was introduced but never even voted on in committee. If a bill is listed as having died or failed, that means it was voted down either in committee or by one of the legislative chambers. The success of such a bill is not likely even if it is reintroduced in the following legislative session unless there is an election that sufficiently changes the composition of the legislature or some other intervening event rejuvenates the bill's chances. If the session ends without a bill being voted on by both chambers, it has failed; but it has a better chance if it is reintroduced in a later session than if it is voted down. A bill that is reintroduced also probably has a better chance than a bill that is never even voted on in committee. The reason that some bills are listed as having died due to the end of the session, while other bills are still listed as active, is that some states have one-year legislative session cycles and other states have two-year cycles.

Please note that cases, laws, and regulations listed in earlier columns will not be repeated unless there has been a change in status since the last reporting period. Updates on previously reported cases, laws, and regulations are marked with an asterisk (*).

Subject headings are not listed alphabetically. Sections are listed in descending order with those subjects with the most activity or the most significant activity listed first. It is important to note that the order of subject headings can vary from one issue of "Legal Trends" to the next depending on what subjects have the most legal activity in any given quarter.

Acronyms Used in this Column

CME	continuing medical education
DHHS	U.S. Department of Health and Human Services
FDA	U.S. Food and Drug Administration
FPL	federal poverty level
HPV	human papillomavirus
OIG	U.S. Office of Inspector General
PhRMA	Pharmaceutical Research and Manufacturers of America
PRC	People's Republic of China
SCHIP	State Children's Health Insurance Program

INTRODUCTION TO "LEGAL TRENDS IN BIOETHICS" WINTER 2007

Legislative developments have slowed down a little since the last "Legal Trends in Bioethics" column. Many states are either at the middle or end of their legislative sessions and Congress is all but deadlocked because it generally lacks the two-thirds majority needed to override a presidential veto. Nonetheless there are some developments both in the courts and legislatures worth noting.

In the area of reproductive rights, the tension between legislative action and court action I mention in my general introduction is illustrated nicely in this quarter. Earlier this year, state legislative dockets were filled with laws intended to restrict abortion rights and some of them passed, but many seem to be languishing. Also, while the Supreme Court decision in *Gonzales v. Carhart* (discussed in "Legal Trends in Bioethics" in the summer 2007 issue of *JCE*) was a blow to abortion rights

advocates, several court decisions since then have quietly gone the other way. There isn't one court case reported this quarter that can be seen as a right to life victory. *Gonzales v. Carhart*, 550 U.S. ____ (2007) (No. 05-380).

In other areas, progress seems more one-sided. Advocates of expanded health coverage seem to be gaining ground slowly but surely both in the legislatures and the courts. The 2006 Uniform Anatomical Gift Act seems to be meeting with slow acceptance. And legislation to mandate vaccination for human papillomavirus (HPV) has all but died.

The one area where there was significant movement this quarter was in issues having to do with accountability. The new federal Food and Drug Administration Amendments Act greatly increases the authority of the U.S. Food and Drug Administration (FDA) to oversee and regulate the drug and device development processes. The law also creates a mandatory registry for clinical trials and stricter conflict of interest rules for the FDA advisory boards that oversee drug approval and review. Also, the U.S. Supreme Court agreed to hear a case, *Charles R. Riegel, et ux v. Medtronici, Inc.,* in which the primary issue is whether compliance with FDA requirements protects a company from liability. (U.S. No. 04-0412). And several states have passed legislation imposing new or improved reporting requirements on hospitals for patient infection rates.

OVERSIGHT: PATIENT TRUST

Probably the most important development this quarter is the passage of the Food and Drug Administration Amendments Act of 2007. This act greatly expands the FDA's authority. It includes a target number of $450 million in user fees to be paid by drug companies; this is an increase of over $100 million from previous years. The act allows the FDA to issue fines up to $10 million if drug makers fail to complete FDA requested studies. It strengthens conflict of interest rules for FDA drug safety panels by requiring a reduction of scientists with ties to drug companies by 25 percent over the next five years. And it instructs the Secretary of the U.S. Department of Health and Human Services (DHHS) to create mandatory registration and reporting requirements for clinical trials to be posted on a national publicly available database, probably on the National Library of Medicine's website *www.clinicaltrials.gov.* The entire bill can be found at *http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=110_cong_bills& docid=f:h2900eh .txt.pdf.*

Recent Laws and Regulations, July - September 2007

***Federal.** On 27 September 2007, the President signed into law H.R. 3580, the Food and Drug Administration Amendments Act of 2007. The act includes, in addition to the measures mentioned above, new authority for the FDA to require pharmaceutical companies to track adverse events, regulate pharmaceutical marketing, and expand the pediatric exclusivity provisions of the Best Pharmaceuticals for Children Act for another five years. Public Law No: 110-85. Related bills include H.R. 2900 and S. 1082, 110th Leg., Reg. Sess. (2007).

A bill introduced on 6 September 2007 would require drug, medical devices, and biologics manufacturers with at least $100 million in annual revenue to, every quarter, disclose gifts or payments that they make to physicians exceeding $25 in value. The legislation would require the Secretary of DHHS to create a website and post payment information. Penalties would range up to $100,000 per violation. Companies would be required to disclose any payment or benefit made "directly, indirectly, through an agent, subsidiary or other third party," which might include payments by universities and by companies that set up conferences for influential physicians with drug or medical device manufacturer funding. Funding of continuing medical education would also need to be disclosed. No-cost drug samples and financing for clinical trials would not have to be disclosed un-

der the bill. The legislation was read twice and referred to the Committee on Finance. S. 2029, 110th Cong. (1st Sess. 2007).

California. On 1 July 2005 a law went into effect that requires pharmaceutical companies and medical device manufacturers to implement a compliance program that conforms with the *PhRMA Code on Interactions with Healthcare Professionals* and guidance on pharma marketing from the U.S. Office of the Inspector General (OIG); the law also caps expenditures by the industry to healthcare providers. There are exemptions to the spending limits that the manufacturers establish in order to comply with this law, including an exemption for commercial support of continuing medical education (CME), as long as those grants are in compliance with *PhRMA Code* and the OIG guidance. S.B. 1765, 2003-2004 Leg., Reg. Sess. (Cal. 2004), Cal. Ch. 927 (2004) affecting Cal. Code. Regis. tit. 8 § 119400 (2004).

***Delaware.** On 12 July 2007, the governor signed into law H.B. 47, which amends the Hospital Infections Disclosure Act, and mandates the reporting and disclosure of hospital infection rates. Title 16, Ch. 10a (Del. 2007).

Minnesota. In 1993, the state passed a law limiting gifts from pharmaceutical companies to physicians to an annual value not to exceed $50. (Minn. Stat. § 151.461 (2007)). Since the law has been in place, the number of visits by pharmaceutical company sales representatives reported by primary care physicians in the state decreased at about twice the rate reported by physicians nationwide. "Minnesota Law Limiting Pharmaceutical Company Gifts to Physicians Could Lead to Similar Laws in Other States," *Kaiser daily Health Policy Report*, 12 October 2007, *http://www.kaisernetwork.org/daily_reports/rep_index.cfm?hint=3&DR_ID=48157*, accessed 6 November 2007.

New Jersey. The state attorney general announced on 18 September 2007 the formation of a task force that will consider whether the state should require pharmaceutical companies and medical device makers to disclose gifts they give to physicians. The goal will be to examine the effects of drug and device makers' gifts and fees to physicians on the doctor-patient relationship, as well as how much gift-giving informs physicians about new treatments. The task force will also examine ways to prevent and identify abuses, including requiring public disclosure of gifts, limiting payments physicians can accept, or requiring doctors to inform patients about such payments. In an interview, the attorney general said she plans to look closely at Minnesota's legislation for guidance. K. Stark, "N.J. Weighs Requiring Reporting Doctors' Gifts," *Philadelphia Inquirer,* 19 September 2007, *http://www.philly.com/philly/business/homepage/20070919_N_J__weighs _requiring_ reporting_doctors _gifts.html,* accessed 6 November 2007. (A bill was introduced on 14 May 2007 that would require doctors to tell patients about money and gifts over $25 that they have accepted from pharmaceutical firms in the last year. S. 2660, 2007 Gen. Assem., Reg. Sess. (N.J. 2007).)

***Oregon.** On 27 July 2007, the governor signed a law that would require the reporting and disclosure of hospital infection rates. Or. Ch. 838 (2007).

***Pennsylvania**. On 20 July 2007, the governor signed into law S.B. 968, amending the Medical Care Availability and Reduction of Error Act. The law will require more stringent reporting requirements for the rates of patients' infection to state authorities. Public Act. 52

Vermont. On 12 June 2002, a bill was signed by then-governor Howard Dean that requires drug companies to report gifts made to physicians valued at $25 or more. This includes meals, trips, or consulting fees, but not free drug samples. H. 31, 2001-2002 Leg., Reg. Sess. (Vt. 2002); Vt. Act No. 127 affecting 33 Vt. Stat. Ann. tit. 19 § 5 (2002).

***Washington.** The governor signed a law, effective 22 July 2007, that would require the reporting and disclosure of hospital infection rates. Wa. Ch. 261 (2007).

West Virginia. On 21 March 2004 the governor signed into law H.B. 4084, which requires pharmaceutical companies to report

prescription drug advertising costs. H.B. 4084, 76th Leg., 1st Reg. Sess (W. Va. 2004), Ch. 193 affecting W. Va. Code § 5A-3C-1 (2004) through W. Va. Code § 5A-3C-17 (2004).

THE RIGHTS OF MATURING INDIVIDUALS AND THEIR PARENTS

PRE-BIRTH (SEX, FERTILITY, CONTRACEPTION, ABORTION, FETUSES, EMBRYOS, AND STEM CELLS)

The state legislatures and courts are at odds this quarter. Several states passed what could be understood as pro-life measures. For example, Louisiana's governor signed a law requiring that women be informed that a fetus feels pain during an abortion procedure, and Missouri, Louisiana, and Pennsylvania funded alternatives to abortion programs, while North Carolina reenacted its restriction on public funding for abortions. On the other hand, several court decisions can be seen as pro-choice victories. The U.S. Supreme Court refused to hear a case challenging a New York law requiring insurance companies to cover the cost of contraceptives. A U.S. District Court decided it would hear a case in which abortion clinics claim that a new Missouri law will regulate them out of existence. The Arizona Supreme Court found it unconstitutional for a sheriff to have a policy to only provide inmates with transportation for medically necessary abortions; the Georgia Supreme Court held that abortion clinics have a right to sue the state for reimbursement for medically necessary abortions; and the New Jersey Supreme Court held that a law may require that a woman seeking an abortion be informed of the "medical facts," but it may not require that the woman be told that the fetus is an "existing human being."

Recent Cases, July - September 2007

Federal. The U.S. Supreme Court refused to hear an appeal on 30 September 2007 brought by Catholic Charities of New York contesting a decision by the Court of Appeals for the State of New York upholding the legality of a New York law requiring insurance companies to include contraceptive coverage in drug benefit packages. *Catholic Charities v. Dinallo* (N.Y. Case no. 06-1550, 30 September 2007).

The U.S. District Court for the Western District of Missouri heard arguments on 10 September 2007 concerning the constitutionality of a state law reclassifying abortion clinics as "ambulatory surgical centers." Opponents to the new law argue that reclassification would subject abortion clinics to many new, and costly, regulations that could force them to close their doors. *Kaiser Daily Women's Health Policy Report,* 10 September 2007, *http://www.kaisernetwork.org/dailyreports/rep_index.cfm?DR_ID=47377,* accessed 3 November 2007. See related legislation under Missouri below.

***Arizona.** On 25 September 2007, the state supreme court upheld without comment an appellate court decision that found it unconstitutional for a state county sheriff to have a policy only requiring deputies to transport inmates to medical facilities for abortions if medically necessary. *Doe v. Arpaio* (Ariz. CV-07-0104-PR, 26 September 2007).

Georgia. On 24 September 2007 the state supreme court ruled that abortion clinics can sue the state for not paying for some patients who needed abortions for medical reasons. The suit was brought, initially, by a group of clinics and a physician against the state Department of Community Health for not reimbursing them under the Medicaid program when poor women with health problems underwent the procedure. *Feminist Women's Center v. Burgess* (Ga. 2003-CV-78487, 24 September 2007).

***Kansas.** On 30 October 2007, a grand jury will convene to investigate whether George Tiller, MD, broke state law concerning late-term abortions. The state attorney general announced on 27 June 2007 that he has reviewed all the charges against Dr. Tiller's clinic filed by Phil Kline during Kline's tenure as state

attorney, and charged Tiller with 19 misdemeanors for allegedly failing to get an independent second opinion on some late-term abortions. Abortion opponents have garnered enough signatures of registered voters to form a grand jury pursuant to a 1970 state law that allows the public to petition grand juries. *Kaiser Daily Women's Health Policy,* 13 September 2007, *http://www.kaisernetwork.org/daily_reports/rep_index.cfm?hint=2&DR_ID=47348,* accessed 3 November 2007.

New Jersey. On 12 September 2007, the state supreme court unanimously held that while abortion providers are required to discuss medical facts with a patient, they are not required to inform women that the fetus is an "existing human being." *Acuma v. Turkish, M.D.* (N.J. Docket No. 59, 525, 12 September 2007).

A state superior court ruled on 24 September 2007 that a referendum that asks voters to approve the governor's plan (N.J. Pub. Law Ch. 117 (2007)) to borrow $450 million over 10 years to fund stem cell research will remain on the 6 November 2007 ballot, despite assertions that the ballot question is deceptive because it does not explain that the funding being authorized will allow human cloning. *McKenzie v. Corzine* (N.J. Super. Ct. App. Div. A-703-07T3, 24 September 2007).

***Texas**. On 24 August 2007, the state supreme court denied a petition for review of a state court of appeals decision in *Roman v. Roman.* At issue was the proper disposition of three frozen embryos never implanted because of the couple's divorce. The wife wanted to keep the frozen embryos and won, at the lower court level. The husband appealed that ruling and won with the judge ruling that the embryos should be discarded in accordance with a contract signed by both parties concerning what to do with the embryos in the event of a divorce. This is a case of first impression in Texas; the appellate court ruling that now stands can be understood as supporting the proposition that embryos are not persons with a right to life. *Roman v. Roman.* (Tex. Sup. Ct. Appeal No. 06-0554).

Recent Laws and Regulations, July - September 2007

California. On 11 October 2007 the governor signed into law a bill that funds the development of a pilot project that seeks to diversify the umbilical cord blood supply collected in public blood banks. S.B. 962, 2007-2008 Leg., Reg. Sess. (Cal. 2007); Ch. 516. This bill is similar to A.B. 40, A.B. 482, 2007-2008 Leg., Reg. Sess. (Cal. 2007). Also on 11 October 2007, the governor signed into law a related bill that requires pregnant women be informed of the option of umbilical cord blood banking. A.B. 34, 2007-2008 Leg., Reg. Sess. (Cal. 2007); Ch. 517.

***Hawaii.** Two bills to allow all forms of stem-cell research have been deferred until the 2008 legislative session. H.B. 364, H.B. 1261, 24th Leg., Reg. Sess. (Haw. 2007).

***Louisiana.** On 9 July 2007 the governor signed into law a bill that requires women seeking an abortion to be informed at least 24 hours in advance about the pain their unborn child will feel while aborted. The law also requires the abortionist to offer the woman an opportunity to see her baby on an ultrasound. The law went into effect on 15 August 2007. H.B. 25, 2007 Leg. Reg. Sess. (La. 2007); La. Rev. Stat. Ann. § 40:1299.35.6 (2007).

On 12 July 2007 the governor signed into law a measure that will allocate $1 million to alternatives-to-abortion services. What such services might be is not specified. H.B. 1, 2007 Leg. Reg. Sess. (La. 2007).

The governor signed into law two bills on 12 July 2007 that would ban "partial-birth" abortion in the state and create criminal penalties for physicians who perform the procedure. H.B. 614, S.B. 161, 2007 Leg. Reg. Sess. (La. 2007).

Michigan. A bill was introduced on 17 September 2007 proposing a ban on the procedure known as "partial-birth abortion." The legislation includes an exception in the event that the procedure is necessary to save the life of the mother. Violation is a felony and subjects anyone found guilty to up to two years

imprisonment and a fine not to exceed $50,000. SB 776, 94th Leg., Reg. Sess. (Mich. 2007).

***Missouri.** On 2 July 2007 the governor signed into law the Missouri Health Improvement Act of 2007, which includes various abortion-related provisions. In cases of medical emergency (defined as when the pregnant woman's life or a "major bodily function" is at risk), the law allows an exception to the entirety of Missouri's abortion law, including provisions concerning parental involvement, abortion counseling, and post-viability abortion. The measure also includes provisions related to clinic licensing, and funds an alternatives-to-abortion program and sex education. The law went into effect in August. S.B. 577, 94th Gen. Assem., 1st Reg. Sess. (Mo. 2007); Mo. Rev. Stat. § 188.028-335 (2007).

The governor signed into law on 6 July 2007 that, while not an outright ban on abortion, might have a similar effect. The bill reclassifies any facility that performs five or more abortions each month as an "ambulatory surgical center," thus requiring it to comply with many costly new regulations. Opponents of the bill claim that the cost of upgrading facilities to abide by the code would be so high that abortion clinics would be forced to shut down. A temporary injunction preventing the law from going into effect is in place while the issue is being litigated (see above). However, one controversial aspect of the law is already in place. Anyone who works at an abortion clinic, or for an organization that refers patients to such clinics, is prohibited from teaching sex education in state public schools. S.B. 370, H.B. 1055, 94th Gen. Assem., 1st Reg. Sess. (Mo. 2007); LR Number 2503L.04T; Mo. RSMo. ch. 197 § 200 (Supp. 2007).

North Carolina. On 31 July 2007, the governor signed into law the state's budget bill, which reenacts the current restrictions that prohibit public funding for abortion unless the pregnancy is the result of incest or rape, or the woman's life is at risk. S.L. 2007-328. H.B. 1473, Gen. Assem. 2007-2008 Sess. (N.C. 2007).

Ohio. A bill was introduced on 19 July 2007 that would prohibit women from undergoing an abortion without the written consent of the father. Should the identity of the father be unknown, women would be required to submit a list of possible fathers to the physician, who would be required to conduct paternity tests and then seek paternal permission to abort. First-time violators would be charged with abortion fraud, a first-degree misdemeanor. Repeat offenders would be charged with a fifth-degree felony. H.B. 287, 127th Gen. Assem., Reg. Sess. (Oh. 2007).

On 10 July 2007, a bill was introduced that would prohibit all abortions in the state, as well as any distribution of mifepristone (the "morning-after pill"). The bill would also increase the penalties for unlawful abortions and abortion trafficking. H.B. 284, 127th Gen. Assem., Reg. Sess. (Oh. 2007).

Two bills were introduced on 18 September 2007 that would require abortion providers to provide a patient with an opportunity to view an ultrasound of the fetus, at no extra cost, before the procedure can take place. H.B. 314, S.B. 230, 127th Gen. Assem., Reg. Sess. (Oh. 2007).

Pennsylvania. A bill passed the state house that provides for umbilical cord blood banking, and is currently in the senate's Public Health and Welfare Committee. The bill requires healthcare practitioners to give pregnant patients information regarding umbilical cord donation. H.B. 874, 191st Gen. Assem., Reg. Sess. (Pa. 2007).

On 17 July 2007 the governor signed into law a measure that will allocate $4,655,000 to fund alternatives-to-abortion programs and prohibit nonprofit organizations receiving alternatives-to-abortion funds from performing abortion services or counseling. Similarly, another $4,655,000 will be used for grants for women's medical services, including non-invasive contraception supplies. Act No. 42. H.B. 1295, 191st Gen. Assem., Reg. Sess. (Pa. 2007).

Wisconsin. On 19 June 2007 a bill was introduced that would require a physician who

is about to perform an abortion to take certain steps if the woman seeking the abortion seems to have been coerced into making that decision and seems to be in danger of being harmed should she decline. The woman must be informed of services for victims or individuals at risk of domestic abuse and be provided with private access to a telephone if she states that she wishes to call for assistance. S.B. 218, 1007 Reg. Sess. (Wis. 2007).

Interesting Developments in Other Countries

***People's Republic of China**. The PRC's policies for enforcing its one-child policy are raising eyebrows. Recently in the southwest of the People's Republic, enforcement raids resulted in women being forced to have abortions as late as nine months into their pregnancies. Also the fines for violating the law can be as high as $9,000, and when a family cannot afford to pay the "social child-raising fee," government officials destroy homes and seize belongings as punishment, even as soon as three days after the fine was assessed. Unrest resulted in attacks on family planning officials and the torching of government buildings. Riot police were sent into four different towns in Guangxi Province to quell the violence. Officials report that their one-child-per-family policy will not change, but that some enforcement measures will be reconsidered. "Clashes in Southwest China Over One-Child Policy Prompts Officials to Ease Penalties," *Kaiser Daily Women's Health Policy Report,* 23 May 2007, *http://www.kaisernetwork.org/daily_ report.cfm?DR_ID=45092&dr_cat=2,* accessed 14 August 2007.

India. The Indian central government is planning to create a national registry of all pregnancies and abortions in the country in an effort to curb sex-selective abortions. It also intends to set a new criterion whereby abortions will only be permitted when there is a valid and acceptable reason, however just what qualifies as "valid and acceptable" has not yet been clarified by the government. India's Women and Child Development Minister, Renuka Chowdhury, has said that the reason for monitoring abortions is to break up organized illegal-abortion rackets that the government says are contributing to the country's skewed girl-to-boy ration (927 girls : 1,000 boys). C. Chauhan, "Government to Monitor Pregnancies, Abortions," *Hindustan Times,* 13 July 2007.

***Mozambique**. The government is considering lifting or at least loosening its ban on abortions because more than 40 percent of serious pregnancy complications treated at the central hospital in Maputa are a result of illegal abortions, and abortions account for 11 percent of maternal deaths in the country. "Mozambican Government Reviewing Abortion Ban, Justice Minister Says," *Kaiser Daily Women's Health Policy Report,* 11 June 2007, *http://www.kaisernetwork.org/daily_report.cfm?DR_ID=45474&dr_cat=2,* accessed 14 August 2007.

***Poland.** The European Court of Human Rights announced on 25 September 2007 that it would not review its earlier judgment in the case of *Tysiac v. Poland,* despite the Polish government's request that it do so. In March 2007, the court ordered the government to award damages to a Polish woman who was denied an abortion despite warnings from her physicians that continuing her pregnancy would pose a serious risk to her ability to see. Although the woman finally did receive permission for the procedure, by that time, it was too late and she is now seriously visually impaired. *Tysiac v. Poland,* 4 Eur. Ct. H.R. 5410/03 (2007).

***Portugal**. A law legalizing abortions in the first 10 weeks of pregnancy went into effect on 15 July 2007. "Portugal Law that Loosens Abortion Restrictions Comes Into Effect," *Kaiser Daily Women's Health Policy Report,* 17 July 2007, *http://www.kaisernetwork.org/daily_report.cfm?DR_ID=46263&dr_cat=2, accessed 13 August 2007.*

Africa. Representatives from 10 African countries called for legalization of safe abortions at a conference of women leaders in

Nairobi, Kenya, on 26 June 2007. "Leaders of 10 African Countries Call for Legalization of Safe Abortion to Help Reduce Maternal Mortality Rate," *Kaiser Daily Women's Health Policy Report,* 28 June 2007, *http://www.kaisernetwork.org/daily_report.cfm?DR_ID=45892&dr_cat=2,* accessed 14 August 2007.

AFTER BIRTH (PREMATURE INFANTS, NEWBORNS, AND CHILDREN)

The three court cases reported here this quarter deal with quite intriguing scenarios. In two cases the courts made it clear that parental consent laws cannot be used to serve any other political or personal end other than the intended end of notifying parents, presumably to give parents a chance to discuss the decision with their child and to be aware and prepared for the physician and emotional aftermath. The Third Circuit Court of Appeals made it clear that parental consent laws are not there to protect a parent's religious beliefs, and the Mississippi Supreme Court made it clear that such laws could not be used as a shield to protect a mother from potential criminal liability, either. A Missouri Court of Appeals also narrowly interpreted the intent of the state's child endangerment laws not to include what a mother does to her fetus while it is still *in utero.*

Recent Cases, July - September 2007

Federal. The Third U.S. Circuit Court of Appeals in Philadelphia ruled unanimously on 21 September 2007 that a city health clinic did not violate the rights of a 16-year-old girl or those of her parents by giving her emergency contraception (commonly known as the "morning after" pill) without notifying her parents. The parents argued that they opposed abortion and objected to the actions of the clinic on religious grounds. The court held that only the daughter's religious beliefs were relevant, and, since she did not voice such views during her visit to the clinic, no rights were violated. The court wrote: "the Constitution does not impose an affirmative obligation on (the) defendants to ensure that children abide by their parents' wishes, values or religious beliefs." *Anspach v. Phila. Dept. of Pub. Health* (Phila. 3d Cir. Appeal No. 05-3632, 21 September 2007).

***Illinois.** Status unchanged. The Illinois Supreme Court issued rules necessary to implement the state Parental Notice of Abortion Act, Ill. S. Ct. M.R. 21173, in January. But the act still remains unenforceable. The state's attorney general has filed a motion to have those rules put in place, but the matter is still pending.

Mississippi. On 5 July 2007 the state supreme court declined to hear a case in which a mother was sentenced to jail for attempting to hide her husband's statutory rape by consenting to her 13-year-old daughter's abortion. The lower court had ruled that the state's parental consent laws were not a defense in criminal cases. *Kaiser Daily Women's Health Policy Report,* 2 July 2007, *http://www.Kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=45947,* accessed 3 November 2007.

Missouri. On 11 September 2007 the Missouri Court of Appeals in Kansas City upheld a lower court's dismissal of a child endangerment case against a mother whose baby, like herself, had tested positive for marijuana and methamphetamine the day after her baby was born. The court held that the Missouri law that makes it a crime for a third person to harm a pregnant woman, and, consequently, her fetus does not apply to harm indirectly caused by the mother. *State of Missouri v. Janet S. Wade* (Mo. Ct. App. Case No. WD67363, 11 September 2007).

Recent Laws and Regulations, July - September 2007

***Missouri.** On 2 July 2007, the governor signed into law the Missouri Health Improvement Act of 2007, which includes various abortion-related provisions. In cases of medical emergency (defined as when the pregnant

woman's life or a "major bodily function" is at risk), the law allows an exception to the entirety of Missouri's abortion law, including provisions concerning parental involvement, abortion counseling, and post-viability abortion. The measure also includes provisions related to clinic licensing and funds an alternatives-to-abortion program and sex education. The law went into effect in August. S.B. 577, 94th Gen. Assem., 1st Reg. Sess. (Mo. 2007); Mo. Rev. Stat. § 188.028-335 (2007).

Interesting Developments in Other Countries

***Egypt**. In July the government announced a complete ban on female circumcision after a 12-year-old girl died during the operation. While technically a ban has existed for 10 years, an exception in the law allowed the operation to be performed by qualified doctors in exceptional circumstances. The new ban is absolute and no exceptions will be allowed. It is estimated that currently 90 percent of all Egyptian women are circumcised, whether Muslim or Christian. M. Abdelhadi, "Egypt forbids female circumcision," *BBC NEWS,* 2 July 2007, *http://news.bbc.co.uk/2/hi/middle_east/6251426.stm,* accessed 2 July 2007.

***United Kingdom**. In Britain, a Human Tissue and Embryos Bill is being considered, which, among other things, would require birth certificates to identify whether a donor egg or sperm or both were used to conceive the child. Backers of the bill suggest that not to require such information on a birth certificate makes the government complacent in a lie. M. Henderson, "Birth certificates 'should tell donor children who their real parents are'," *TimesOnline,* 1 August 2007, *http://business.timesonline.co.uk/tol/business/law/article2176 357.*

HEALTHCARE COVERAGE

Legislative battles over healthcare coverage continue at the state level, with advocates for expanded coverage making minimal but consistent gains. Beyond issues of whether the State Children's Health Insurance Program (SCHIP) will be simply reauthorized or expanded, the federal battle over expanded healthcare coverage primarily will be decided at the polls next November.

July - September 2007

Federal. Despite a virtually guaranteed veto from the President, the House passed an SCHIP expansion bill on 25 September 2007. The bill would provide an additional $35 billion in funding to the program over the next five years, bringing total spending to $60 billion annually. The additional funding would be paid for by a 61-cent-per-pack increase in the tobacco tax. State Children's Health Insurance Program Reauthorization Act, H.R. 976, 110th Cong., 1st Reg. Sess. (2007).

*A bill was introduced 29 March 2007 in the U.S. House that would provide universal health insurance to all U.S. residents. The AmeriCare Health Care Act would create AmeriCare, a program that would use Medicare to provide health insurance to U.S. citizens who don't receive coverage through their employers and whose annual income falls below 300 percent of the federal poverty level. On 9 July 2007, the bill was referred to the Subcommittee on Health, Employment, Labor, and Pensions, where it is still pending. H.R. 1841, 110th Leg., 1st Reg. Sess. (2007).

Alaska. Lawmakers are considering a universal healthcare proposal after it was introduced 10 September 2007 at a special late-summer hearing of the Senate Health, Education, and Social Services Committee to get a "jump start on the 90-day session" next year, according to the bills sponsor. The bill, called the Mandatory Universal Health Care Act, would require all state residents to obtain health coverage, with the state subsidizing plans for low-income residents. It would create a healthcare board that would determine which medical services would be covered under the subsidized program and would cer-

tify private coverage plans that meet state requirements. The board would also oversee the Alaska Health Fund, funded by both the state and the federal government, as well as contributions from employers and employees. The contributions (read: tax) would fund a sliding-scale voucher system. Residents would be able to use the vouchers to obtain coverage from the Alaska Health Care Clearinghouse, a "marketplace" of various certified policies. S.B. 160, 24th Leg., Spec. Sess. (Alaska 2007).

California. Both legislative bodies passed a bill on 10 September 2007 intended to extend healthcare coverage to all state residents. The legislation would require employers to contribute as much as 7.5 percent of their payroll to cover the cost of health insurance for employees or pay into a state pool that would provide coverage. In contrast to a proposal from Governor Arnold Schwarzenegger earlier this year, the bill does not include an individual mandate. The governor vowed to veto the legislation, and did on 12 October 2007. A.B. 8, 2007-2008 Leg., Reg. Sess. (Cal. 2007).

Colorado. The Colorado Blue Ribbon Commission for Healthcare Reform, created last year by a piece of Senate legislation (S.B. 06-208, 66th Gen. Assem., 2nd Reg. Sess. (2006)), on 23 August 2007 approved its fifth proposal for reconfiguring the state's healthcare system, with an estimated cost in excess of $1 billion. The plan would include an individual mandate for the purchasing of health insurance and would provide subsidies on a sliding scale based on income for low-income families. Additionally, low-income workers who qualify for a government subsidy would be required to use that money to purchase employer-sponsored health insurance if it is offered and costs less than the state insurance plan. The commission is expected to release its final report and recommendations to the General Assembly by 1 January 2008. A.B. 8, B. Scanlon, "Fifth Health Care Plan Unveiled," *Rocky MountainNews.com,* 24 August 2007; *http://www.rockymountainnews.com/drmn/local/article/0,1299,DRMN_15_5681302,00.html,* accessed 2 November 2007.

Kansas. An advisory council representing consumers, health providers, and health purchasers submitted preliminary recommendations to the Kansas Health Policy Authority on ways to reform Kansas' healthcare system. Chief among the recommendations was an individual and employer health insurance mandate to achieve universal coverage. The Kansas Health Policy Authority is scheduled to present formal proposals to the state Legislature in November. *Kaiser Daily Health Policy Report,* 23 August 2007, *http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DRID=47134,* accessed 2 November 2007.

Massachusetts. On 1 July 2007, a law took effect requiring all state residents to have health insurance. Under the law, residents with annual incomes below the federal poverty level (FPL) are eligible for no-cost care. Those with annual incomes up to three times the FPL can enroll in state-subsidized plans, while those with higher incomes can choose their own coverage from new private plans via the Massachusetts "Connector" if they are not offered coverage through their employer. Although 1 July 2007 was the deadline for uninsured residents to obtain coverage; they have until 31 December 2007 before those who remain uninsured will face a financial penalty. Residents who do not have health insurance by that time will lose their state tax exemption, worth about $219. Those who do not obtain insurance after 31 December will face a penalty of up to half the cost of insurance premiums for each month a person is uninsured. Additionally, residents can initially purchase any coverage plan they choose, but, by January 2009, all residents must have prescription drug coverage. Mass. Gen. Laws Ann. Ch. 58, §§ 1-147 (Mass. 2006).

***North Carolina**. On 27 July 2007, the governor signed into law the Mental Health Equitable Coverage Act, formerly H.B. 973, which would require health insurers to provide the same level of coverage for treatment of severe depression, schizophrenia, or other mental illness as they do for physical illnesses. N.C. Sess. Laws Ch. 268 (N.C. 2007).

***Wisconsin.** In July the state senate approved an amendment (Senate Substitute Amendment No. 1) to the state budget (S.B. 40, 2007 Reg. Sess. (Wis. 2007)) that, if adopted, will be "one of the most sweeping health care reform proposals in the country," according to the *Milwaukee Journal Sentinel.* Known as Healthy Wisconsin, the amendment represents the State of Wisconsin's effort to provide universal coverage. It would provide coverage to 276,000 people who have been uninsured for more than one year, financed by a 9 percent to 12 percent tax on employer payrolls and a 4 percent tax on employees' wages. The amendment was eventually stricken by the Senate Conference Committee upon review. G. Boulton, "Is Senate's Health Bill Best for All?" *Milwaukee Journal Sentinel Online*, 21 July 2007, *http://www.jsonline.com/story/index. asp?id=636124,* accessed 1 November 2007.

VACCINES

Out of an original number of more than two dozen states considering mandating HPV vaccination for preteens, several have instead passed laws to study the value of HPV vaccination and a few have passed laws requiring HPV education, but only two states and the District of Columbia have actually passed laws requiring HPV vaccination.

Recent Laws and Regulations, July - September 2007

***Federal.** The session ended without any action on H.R. 1153. The bill was introduced in the U.S. House of Representatives and would prohibit federal funds to be used by states who make the HPV vaccine mandatory. H.R. 1153, 110th Cong. (1st Sess. 2007). However, a similar provision passed on 18 July 2007 as part of the House Labor, Health, and Human Services, Education Appropriations Bill. The amendment prohibits federal funds from being used by states to implement requirements that a student be vaccinated for HPV as a condition of school admittance. "House passes Gingrey amendment to keep HPV vaccination a family decision," press release from the office of Representative Phil Gingrey (R-Georgia), 19 July 2007.

Gardasil, Merck's HPV vaccine, has been adopted by all 55 of the CDC's Vaccines for Children Program immunization projects. This is a program that provides vaccines at no cost to children ages nine to 18 who are covered by Medicaid, the Alaska native and American Indian Children program, and some other programs for uninsured children. *Kaiser Daily Women's Health Policy Report, 1*8 July 2007, *http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=46298,* accessed 18 July 2007.

Arizona. On 25 June 2007, the governor signed into law the Arizona state budget, which included an amendment supported by the Center for Arizona Policy (a family-advocacy group) that prohibits the State Department of Health Services from including the HPV vaccine among the immunizations necessary for school entry. H.B. 2789, 48th Leg., 1st Reg. Sess. (Ariz. 2007); Ariz. Rev. Stat. Ann. § 36-672 (2007).

***California.** A bill passed the state assembly and is currently in the Senate Committee on Rules. The bill would require all girls entering the sixth grade to receive the HPV vaccine. The bill includes an opt-out provision. A.B. 16, 2007-2008 Leg., Reg. Sess. (Cal. 2007).

A.B. 1429 was vetoed by the governor on 14 October 2007. The bill would have expanded any insurance plan that covers cervical cancer screening or surgery to additionally cover the HPV vaccine with a referral from the healthcare provider. A.B. 1429, 2007-2008 Leg., Reg. Sess. (Cal. 2007).

***District of Columbia**. Congress approved on 12 July 2007 a city council bill that would require girls entering the sixth grade to receive the HPV vaccine. The provision has an opt-out provision. D.C. ST. §7-1651.04. Note that City Council Members Yvette Alexander and Muriel Bowser said on 17 September 2007 that they want to repeal this law. N. Stewart, "Two

Council Members Urge Repeal of Law," *Washington Post,* 14 September 2007.

Illinois. The governor signed into law Public Act 95-0422 concerning the HPV vaccine. The bill requires that schools provide parents with information linking HPV and cervical cancer, and that private health plans cover the cost of the vaccine. Ill. Pub. Act 94-0422.

On 24 August 2007, the governor signed into law a bill that requires health plans to cover the HPV vaccine for girls under the age of 18. S.B. 0937, 95th Gen. Assem., Reg. Sess. (Ill. 2007); 410 Ill. Comp. Stat. 225/1 (2007).

***Michigan.** On 5 September 2007 a bill was introduced that will require the Michigan Department of Health to "encourage" every school (both public and private) to provide information regarding the risks associated with the HPV and the availability, effectiveness, and potential risks of immunization to students and parents. The legislation makes no reference to the age or grade level at which this information should be provided. H.B. 5171, 94th Leg., Reg. Sess. (Mich. 2007).

***New Jersey**. On 6 August 2007, the governor signed into law S.B. 2286. The law mandates the distribution of information regarding HPV to parents and guardians and requires vaccination of girls in grades seven to 12. It also proposes a public awareness campaign. N.J. Pub. Law Ch. 134 (2007).

***Rhode Island.** On 7 July 2007, a bill became law without the governor's signature. The bill requires health insurance providers to cover the HPV vaccine. H.B. 5061 Ch. 320.

West Virginia. On 21 August 2007 a bill was passed that allocates $100,000 for HPV "education." H.B. 209, 2007 Leg. 2nd Spec. Sess. (W. Va. 2007); 2007 W. Va. Acts page no. 108.

Wisconsin. On 16 August 2007 a bill was introduced in the state senate which directs the Department of Public Instruction, in conjunction with the Department of Health and Family Services, to collect information about the HPV, including the causes and symptoms of the virus; how it is spread; how it may be prevented; how to obtain additional information about the virus; and the availability, effectiveness, and risks of vaccinations against the virus. The information must include the recommendations regarding the vaccine and prevention of the virus made by the Advisory Committee on Immunization Practices of the Centers for Disease Control and Prevention. The bill directs Department of Public Instruction to make the information available to school districts, private schools, and charter schools, and requires each school board, private school, and charter school, at the beginning of each school year, to provide the information to the parents and guardians of pupils enrolled in grades six to 12 in the school district or school. An identical bill was introduced in the assembly on 28 August 2007 and received its first public hearing on 26 September 2007. S.B. 252, A.B. 492, 2007 Reg. Sess. (Wis. 2007).

Interesting Developments in Other Countries

***Canada.** Several Canadian provinces are considering providing Gardasil at government expense to sixth-grade girls. K. Gillespie, "Girls to get cancer vaccine," *Toronto Star*, 2 August 2007, p. A 1, A18. On 20 September 2007 the Canadian province of British Columbia approved an HPV program, including about $258 million in the 2007-2008 budget to help pay for provincial HPV vaccination programs. The national government recommended providing 40 million Canadian dollars over three years for B.C.'s program. Perry Kendall, B.C.'s medical health officer, has said that girls in the sixth to ninth grade could begin receiving the vaccines at no cost in September 2008 because there are provincial vaccine programs in place for those grades. Kendall added that no vaccine in the province is mandatory and that parents can opt their daughters out of the program. "B.C. to Vaccinate Girls Against HPV," *Canadian Press*, 20 September 2007; *http://cnews.canoe.ca/CNEWS/Canada/2007/09/20/4513270-cp.html,* accessed 1 November 2007.

European Union. In July, the European Committee for Human Medicinal Products recommended GlaxoSmithKline's experimental HPV, Cervarix, for sale and marketing in the European Union. The committee reviewed data on the vaccine from clinical trials involving 30,000 women, and on 24 September 2007 the European Commission approved it for sale and marketing in the European Union. "UPDATE 1-Glaxo Prepares to Launch Cervarix After EU Okay," *Reuters,* 24 September 2007.

***United Kingdom.** The Department of Health's Joint Committee on Vaccination and Immunisation has advised the British government to mandate HPV vaccines for 12- and 13-year-old girls starting in 2008. I. Sample, "Girls could be offered cervical cancer jab by autumn 2008," *Guardian,* 21 June 2007.

ORGAN AND TISSUE PROCUREMENT

It has been a year since the Uniform Anatomical Gift Act of 2006 was passed by the National Conference of State Legislatures. The conference has no legal authority, but it carries quite a bit of persuasive authority. Once it proposes a model law, it is up to the legislators in their various states to introduce the law and help it get passed. The Uniform Anatomical Gift Act of 2006 updated the version with some significant changes. One of the most significant changes was the adoption of first-person consent, meaning that family members do not have the authority to override a deceased patient's known wishes with respect to organ donation. The act has passed in 20 states (Arizona, Arkansas, California, Colorado, Idaho, Indiana, Iowa, Kansas, Minnesota, Montana, Nevada, New Mexico, North Dakota, Oregon, Rhode Island, South Dakota, Tennessee, Utah, Virginia) and the Virgin Islands, and is pending in another six states (Maine, Michigan, New Jersey, New York, Texas, Washington) and the District of Columbia. In Missouri the bill failed for lack of action but is expected to be reintroduced during the next legislative session. The states with movement on bills in this reporting period are included below.

Recent Cases, July - September 2007

***Federal.** (Ongoing case.) The Eighth U.S. Circuit Court of Appeals (Minnesota, Nebraska, North Dakota, South Dakota, Eastern and Western Districts of Arkansas, Northern and Southern Districts of Iowa, Eastern and Western District of Missouri) in *Wash. U. v. Catalona* is reviewing the lower court's ruling that Washington University in St. Louis owned the tissue samples that William J. Catalona, MD, had collected for prostate cancer research while at the university. The U.S. District Court for the Eastern District of Missouri held that the informed-consent documents signed by Catalona's patients, which specifically gave the doctor the patients' tissue samples and included the patients' right to withdraw from the study and request that their tissue samples be destroyed, were "inconsequential" in its decision to grant full property rights to the university. Appeal No. 06-2286 (8th Cir. 15 May 2006). The case was argued 13 December 2006. A decision should be forthcoming shortly. *Wash. U. v. Catalona* (8th Cir. Appeal No. 06-2286, 13 December 2006).

Recent Laws and Regulations, July - September 2007

Alaska. A bill introduced on 13 May 2007 to amend the state's anatomical gift act is under consideration. S.B. 181, 25th Leg., Reg. Sess. (Alaska 207).

***California.** On 13 October 2007, the governor signed into law the Uniform Gift Act of 2006. Ch. 629; A.B. 1689, 2007-2008 Leg., Reg. Sess. (Cal. 2007); Cal. Code. Regs. Tit. 3.5 § 7150 (2007).

***District of Columbia**. A bill was introduced on 9 January 2007 to amend the state's anatomical gift act. The bill received a public hearing on 8 June 2007. D.C. Council, B17-58 (2007).

***Maine**. A bill introduced on 17 March 2007, that would adopt the 2006 Uniform Anatomical Gift Act without changes, was carried

over to the 2008 session. 123rd Legislative Session. L.D. 1505, 123rd Leg., Reg. Sess. (Me. 2007).

***Michigan**. On 19 June 2007 a bill was introduced to amend the state's anatomical gift act. That bill is still under consideration. H.B. 4940, 94th Leg., Reg. Sess. (Mich. 2007).

***Missouri.** A bill passed the Senate on 19 March 2007 that would adopt the 2006 Uniform Anatomical Gift Act without changes. It is currently in the House Health Care Policy Committee as H.B. 723. SB 496, HB 723, 94th Gen. Assem., 1st Reg. Sess. (Mo. 2007).

***New Jersey**. A bill was introduced on 9 January 2007 to amend the state's anatomical gift act. The bill is still under consideration. A.B. 3909, 2007 Gen. Assem., Reg. Sess. (N.J. 2007).

***New York**. A bill was introduced on 25 April 2007 that would enact the Uniform Anatomical Gift Act. The bill is still under consideration. S.B. 5154, 230th Gen. Reg. Sess. (N.Y. 2007).

***Texas**. A bill passed the Senate on 14 May 2007 to amend the state's anatomical gift act. The bill is currently under consideration in the state house. S.B. 1597, 80th Leg., Reg. Sess. (Tex. 2007).

***Washington**. A bill passed the state house on 12 March 2007 to amend the state's anatomical gift act and is currently in the state senate. H.B. 1637, 60th Leg., 2007 Reg. Sess. (Wash. 2007).

INFORMED CONSENT

Informed consent is a legal principle that can be understood as shifting some of the risks for treatment from the provider to the patient who has "assumed the risk" after being fully informed. What constitutes being fully informed from the patient's perspective is clearly the essence of informed-\ consent, but, from a legal perspective, what a reasonable person would want to know creates certain specific disclosure requirements. These requirements can come from standard medical practice, reasonable expectations on the part of patients, and from government standards for disclosure. When disclosure requirements are clear, the question arises whether a provider who complies with those requirements can be held liable if a patient suffers an unanticipated adverse event or one the government established standard did not require the provider to disclose. Of specific interest is that the U.S. Supreme Court has granted *certiorari* in a case in which a medical device manufacturer's defense is that it should not be held liable for the plaintiff's injuries because it complied with all of the labeling requirements of the U.S. Food and Drug Administration (FDA). The Court is also considering granting *certiorari* on a similar case involving a drug manufacturer.

Recent Cases, July - September 2007

***Federal**. The U.S. Supreme Court granted *certiorari* on 25 June 2007 in *Charles R. Riegel, et ux v. Medtronci, Inc.* The case involves an angioplasty procedure in which the catheter balloon reportedly burst, causing complications for the patient. Medtronci claims it should not be susceptible to suit under state law because the device was already subject to federal regulations with which it complied to receive FDA approval. *Charles R. Riegel, et ux v. Medtronci, Inc.* S. Ct. (U.S. No. 04-0412).

*The U.S. Supreme Court is also considering *certiorari* in the case of *Wyeth v. Levine.* In this case, Diana Levine suffered the amputation of her arm as a result of being injected with the Wyeth anti-nausea drug Phenergan. Levine argued and won at the state level (Vermont) that Wyeth was negligent in its failure to provide adequate warnings of a known danger of injecting Phenergan directly into a patient's vein. Wyeth's position is that the jury should not have been allowed to consider Levine's claim because Wyeth's label for Phenergan complied with FDA regulations for prescription drug labeling. The Court's decision as to whether or not it will hear the case is expected within the next two months. *Wyeth v. Levine.* S. Ct. (U.S. no. 06-1249).

Recent Laws and Regulations, July - September 2007

***California**. On 12 October 2007, the governor signed into law the California Routine HIV Screening Bill. The bill revoked the need for written informed consent for HIV testing. Patients will now only need to give verbal consent to HIV testing as part of a routine blood workup. Ch. 550. A.B. 682, 2007-2008 Leg., Reg. Sess. (Cal. 2007); Cal. Code Regs. tit. 106 § 120990, 125090, 125107 (2007).

***Georgia.** On 1 July 2007, the governor signed into law a bill (H.B. 147) that requires every woman seeking an abortion be offered an ultrasound and the option to see her fetus before an abortion may be performed. The attending physician must either offer to perform one or provide the patient with a list of providers, facilities, and clinics that can perform the procedure. "A Woman's Right to Know Act." GA. Act. 207 (2007).

***Massachusetts**. A bill was withdrawn that would have amended existing pre-abortion requirements for a 24-hour period between when a woman receives state-mandated information and performance of the abortion procedure. H.B. 1687, Gen. Assem., Reg. Sess. (Mass. 2007).

UNCONVENTIONAL TREATMENT

Questions regarding the medical use of marijuana seem to be back in the news. While medical use advocates haven't gained any ground in this reporting period, a recap of some of the most recent legislation is in order, particularly since the medical marijuana entries included here weren't included in earlier issues of "Legal Trends in Bioethics."

Recent Cases, July - September 2007

***Federal.** On 7 August 2007, the U.S. Court of Appeals for the District of Columbia Circuit decided in *Abigail Alliance v. Von Eschenbach* that terminally ill patients do not have a constitutional right to access medications that have not been approved by the FDA. The Abigail Alliance and the Washington Legal Foundation argued that terminally ill patients who did not qualify for participation in ongoing clinical trials or otherwise qualify to obtain experimental drugs through existing FDA access programs should have a right to purchase those drugs directly from pharmaceutical companies and take them under the supervision of their own physicians. The U.S. District of Columbia Court of Appeals did not recognize this "other right to life" argument, and the Alliance has decided to appeal to the U.S. Supreme Court. U.S. Ct. App. D.C., 7 August 2007 (Case no. 04-5350).

*On 21 February 2007, a suit was filed by the Americans for Safe Access against the DHHS and the FDA in an Oakland, California federal district court for allegedly violating the federal Administrative Procedure Act by publicly releasing "false and misleading statements" about the benefits of the use of medical marijuana. The suit is calling for the DHHS and the FDA to retract and correct statements that there are no sound scientific studies supporting the medical use of marijuana. The government filed its response on 25 May 2007, and the case is now pending before Judge William Alsup for his decision. *Americans for Safe Access v. Department of Health and Human Services and Food and Drug Administration,* No. 007-01049 (C.D. Ca., Filed 21 February 2007).

***Colorado**. On 22 June 2007, a private citizen, Damien LaGoy, filed suit against the Colorado Department of Health and Environment claiming its five-patient per marijuana provider rule was arbitrary and unfair. On 3 July 2007, the Denver District Judge granted a temporary injunction preventing the state from enforcing its five-patient rule. As yet, no date has been set for a trial on the merits. D. Montero, "Pot law on hold," *Rocky Mountain News,* 4 July 2007.

***Missouri**. The Missouri State Medical Association filed suit in June 2007 to enjoin implementation of a law that would have al-

lowed midwives to deliver infants without the supervision of a trained nurse or doctor. The midwife provision of an insurance law was challenged on the grounds that it was passed without adequate opportunity for discussion; it was added to an insurance-related bill without notifying legislators of the change in the bill. Cole County Circuit Court placed a temporary injunction on the law in June and a permanent injunction on implementing the midwifery portion on 7 August 2007. The group Missouri Midwifery Supporters plans to appeal the case to the state supreme court. "Missouri Judge Issues Permanent Injunction Against State Law That Would Allow Midwives to Deliver Infants at Home," *Kaiser Daily Women's Health Policy Report,* 10 August 2007, *www. kaiser network.org/daily_report .cfm?DR_ID= 46799&dr_cat=2,* accessed 11 August 2007.

Recent Laws and Regulations, July - September 2007

***Federal.** The FDA is still considering regulations to expand its current Compassionate-Use Programs that make experimental drugs available to individuals or groups under certain circumstances. The rules make drugs available during all stages of development, including during Phase I testing, and allow manufacturers to charge the cost of making and providing the drugs, but not to make a profit. Such regulations would allow patients to use drugs before safety trials have been completed (Phase I) and before testing for efficacy has even begun (Phase II). "Expanded Access to Investigational Drugs for Treatment Use," 71 *Fed. Reg.* 75147 (14 December 2006).

New Mexico. On 3 April 2007, the governor signed into law the Lynn and Erin Compassionate Use Act which permits a "practitioner" to prescribe "medical cannabis" to a "qualified patient" with "debilitating medical conditions." Ch. 210. S.B. 523, 48th Leg., Reg. Sess. (N.M. 2007).

Oregon. On 25 June 2007, the governor signed into law a bill (S.B. 161) that would require the Oregon State Department of Human Services (DHS) to conduct a criminal records check for persons who are responsible for a marijuana cultivation site. It also authorizes the DHS to deny an application for a registry identification card to persons prohibited by court order from obtaining a registry identification card. Similarly, it requires the DHS to revoke registry identification cards that were issued to persons prohibited by court order from participating in medical use of marijuana. Or. Ch. 573 (2007).

Rhode Island. On 22 June 2007, the state legislature overrode the governor's veto of the repeal of a law's expiration date. The Edward Hawkins and Thomas Slater Medical Marijuana Act, which was due to expire on 30 June 2007, is still law. The act prevented a qualifying patient who has in his or her possession a registry identification card from being subject to penalty in any manner for the medical use of marijuana, provided that the qualifying patient possesses an amount of marijuana that does not exceed 12 marijuana plants and 2.5 ounces of usable marijuana. Ch. 72, H.B. 6005, 2007 Gen. Assem., Jan. Sess. (R.I. 2007).

LIFE-AND-DEATH DECISIONS

Recent Laws and Regulations, July - September 2007

***Georgia.** The governor signed an act effective 1 July 2007 that revises Georgia's advance directive laws. Among other things, the law combines Georgia's living will and durable power of attorney provisions into one form. It also provides for the creation of a website for the purpose of providing consumers information on the cost and quality of healthcare in Georgia. Ga. Act. 48 (2007).

Interesting Developments in Other Countries

***Canada.** After investigation, the government decided not to press charges against members of the Right to Die Society of Canada for counseling a Canadian citizen to travel to

Switzerland to die in accordance with Swiss physician-assisted suicide laws. The decision not to prosecute in this case was based on a lack of evidence, not on a conclusion that such assistance was legal. J. Lalsevac, "No Charges Laid in Nova Scotia Assisted Suicide Case," *Lifesite.net,* 5 July 2007, *http://www.lifesite.net/ldn/2007/jul/07070511.html,* accessed on 5 November 2007.

***United Kingdom**. The Mental Capacity Act of 2005 will incrementally go into effect between April and October 2007. Under this act, patients are permitted to write advance directives that specifically refuse treatment if their illness meets statutorily specified conditions or to appoint what the British call "lasting powers of attorney," that is, durable powers of attorney or healthcare proxies. Patients can refuse and request the withdrawal of life-saving/life-sustaining treatment including the withdrawal of nutrition and hydration. Under the law, if physicians or nurses refuse to comply with qualifying patients' directives, they could be prosecuted for "willfully neglecting" an incapacitated patient or for assault. A copy of the act can be found at *http://www.dca.gov.uk/menincap/legis.htm.*

THE RIGHT TO ACCESS AND CONTROL MEDICAL INFORMATION (INCLUDING MEDICAL TESTING, PRIVACY, AND DISCRIMINATION BASED ON TEST RESULTS)

Recent Cases, July - September 2007

***California.** (Ongoing litigation.) *Taus v. Loftus, et al.* is a case in which a child abuse victim gave permission (at age 17) — and so did her father — to be interviewed, and for the taped interview to be shown for "educational purposes." A case study was published that referenced "Jane Doe," but other identifying information was disclosed about the young woman when the researcher gave presentations about the case, including videotaped interviews with the subject in which the subject's first name was used by the researcher, and the city where the subject lived as a child was disclosed. Based on this information, in conjunction with information disclosed in the researcher's published case study, reporters discovered more about the case and published allegedly defamatory remarks about the subject and the researcher's claims regarding her recovery of repressed memories. 2005 Cal. App. Unpub. LEXIS 3048, 22 media L. Rep. 1545. *Taus v. Loftus, et al.,* 2006 CA S. Ct. S133805. On appeal, the opinion was affirmed in part and reversed in part, and the matter is remanded to the court of appeals for further proceedings. 2007 Cal. LEXIS 2340 (26 February 2007) (Case # S133805).

Recent Laws and Regulations, July - September 2007

***Federal.** There has been no action on a bill that was introduced in the House that, among other things, would encourage the use of electronic health records. The bill was referred to the House Ways and Means Committee Subcommittee on Health on 25 April 2007. H.R. 1952, 110th Cong. (1st Sess. 2007). C. Itkowitz, "Clinton to Reintroduce Health IT, Respite Care Proposals," *Congressional Quarterly,* 17 February 2007, "Health-Beat."

The FDA, however, is working on a proposed rule to regulate the electronic health records that are transferred directly from a medical device to a database. The justification for such regulation is that such records are part of the device itself. J. Miller, "FDA to propose rule on e-health records," *Government Health IT,* 5 June 2007, *http://govhealthit.com/article102901-06-05-07-Web&printLayout,* accessed 6 June 2007.

There were two bills introduced in Congress on 16 January 2007 (placed on Senate calendar 30 April 2007 and referred to the HELP Committee by Senator Edward Kennedy, D-Massachusetts) that would make it illegal for an employer or health insurer to access genetic information and then make either insurance coverage or decisions regarding the hiring, firing, or promotion of an employee based on such information. The house version of the Genetic Information Nondis-

crimination Act was passed and the senate version is still in the senate committee. H.B. 493, S.B. 358, 110th Cong. (1st Sess. 2007).

***Pennsylvania.** A bill passed the state house that amends the Newborn Child Testing Act**.** The bill is currently in the Senate. The bill provides a list of required newborn screening tests and allows the Department of Health, with the approval of the board, to add to the list. H.B. 883, 191st Gen. Assem., Reg. Sess. (Pa. 2007).

HIV

All states have complied with the name-reporting requirements under the Ryan White Grant Program. Anonymous HIV testing is now a thing of the past in the United States.

Recent Laws and Regulations, July - September 2007

***Federal**. By the end of 2007, all states and D.C. will be required to report their HIV cases by name, not anonymously, if they wish to receive funding from the DHHS under the federal Ryan White Grant Program. 42 U.S.C. § 201.

On 25 September 2007, the U.S. House of Representatives passed by voice vote a bill that would alter HIV testing requirements for federal prison inmates. The bill would require inmates to be required to undergo an HIV test upon entering and leaving prison. There would be an opt-out provision, unless it is determined that the inmate was exposed to a state-defined HIV risk, such as a pregnancy or a sexual encounter, while in prison. Additionally, the measure would require the Prisons Bureau to report to Congress its procedures for testing, treating, and preventing hepatitis and other sexually transmitted diseases, and those transmitted through intravenous-drug use. The Prisons Bureau would also be required to provide legislators with statistics on the results of the HIV tests. The bill has been read twice in the Senate and was referred to the Committee on the Judiciary. H.R 1943, 110th Cong. (1st. Sess. 2007).

***California.** On 11 September 2007, the governor signed into law S.B. 443. The law will allow HIV-positive men to use their own sperm in fertility treatments (there is a process by which sperm can be "washed" of HIV). Ch. 207 (Calif. 2007).

On 12 October 2007, the governor signed into law a bill to amend sections of the Health and Safety Code relating to HIV/AIDS. Previously, physicians were required to test pregnant women for HIV unless the test was explicitly refused in writing. This bill removes that stipulation and instead merely requires that women be told that an HIV test is planned and made aware of their right to refuse. Ch. 550. A.B. 682, 2007-2008 Leg., Reg. Sess. (Cal. 2007); Cal. Code Regs. tit. 106 § 120990, 125090, 125107 (2007).

***Georgia**. The governor signed a bill that would require doctors to offer all pregnant women an HIV test effective 1 July 2007. Women can opt out of the test, but such refusal becomes part of their medical record. GA. Act. 60 (2007).

Illinois. On 14 August 2007, the governor provided an amendatory veto for a measure that would have required healthcare providers to test a pregnant woman for HIV, unless she declines the testing in writing. In his veto message, the governor proposed changes that would allow a woman to give her refusal verbally and mandate testing of newborns whenever the mother's HIV status is unknown.

Both houses have since accepted the amendatory veto and the bill will go into effect on 1 June 2008. H.B. 1759, 95th Gen. Assem., Reg. Sess. (Ill. 2007); 410 Ill. Comp. Stat. 335/10 (2007).

Massachusetts. A bill was introduced on 10 January 2007 and received a hearing in the Senate Committee on Public Health on 26 September 2007. The legislation would require any healthcare provider attending to a pregnant woman to supply her with information relating to HIV and AIDS, and to also give her the information necessary to make an informed decision about testing, including information about the availability of anonymous testing, and present her with the option of

being tested. The woman would be required, in a manner to be prescribed by the Massachusetts State Commissioner of Health, to acknowledge receipt of the information. If she elects to undergo testing, the healthcare provider must arrange such a test to take place as early as possible or within four weeks. S.B. 1293, 185th Gen. Assem., Reg. Sess. (Mass. 2007).

***Rhode Island.** On 2 July 2007 and 6 July 2007, two identical bills initiated in the Rhode Island House and the Rhode Island Senate became law without the governor's signature. The bills permit a healthcare provider to perform an HIV test on a pregnant woman unless she explicitly refuses the test. H.B. 6095, Gen. Assem., Reg. Sess (R.I. 207) and S. o841, Gen. Assem., Reg. Sess. (R.I. 2007), Ch. 170; Ch. 279.

Interesting Developments in Other Countries

Canada. A new law in Alberta allows emergency workers who believe they may have been exposed to HIV to request a court order from a judge requiring the person responsible for the possible exposure to submit to a blood test. *Kaiser Daily HIV/AIDS Report,* 17 September 2007, *http://www.kaisernetwork.org/dailyreports/rep_index. cfm?DR_ID= 47528,* accessed 4 November 2007.

***India.** Star Health and Allied Insurance, an Indian insurance company based in the Chennai province, in July launched that country's first insurance policy that covers people living with HIV/AIDS. Under the policy, an HIV+ individual with a CD4+ T-cell count of 500 copies per cubic millimeter of blood or more will pay an annual premium of 3,000 rupees (about $74) for coverage. If the disease progresses to full-blown AIDS, the company will pay a one-time compensation of 50,000 rupees (about $1,200) to the individual. Star Health and Allied Insurance has partnered with 1,800 hospitals and laboratories across the country to administer tests to measure the CD4 counts of those seeking coverage. V. Jagannathan, Chair of Star Health, told the *Times of India* that "at present, we have fixed the premium at $74. However, we plan to revise that and lower it at the next renewal." K. Sinha, "Insurance Coverage for HIV+ Likely," *Times of India,* 12 July 2007.

***Libya.** On 16 July 2007, the Supreme Council commuted the death sentences of five Bulgarian nurses and a Palestinian doctor who had been convicted of intentionally infecting 426 children at Al Fateh Children's Hospital in Benghzi, Libya with HIV-contaminated blood products, after a $460 million compensation package for the families of the HIV-positive children was arranged through an international fund supported by several countries including Bulgaria and other Balkan nations. "Libya's Judicial Council Commutes Death Sentence for Medical Workers in HIV Infection Case," *Kaiser Daily HIV/AIDS Report,* 17 July 2007, *http://www.kaisernetwork.org/daily_reports/rep_index.cfm?hint=1&DR_ID=46261,* accessed 13 August 2007.

Peru. All blood banks in Peru have been closed because at least four people were infected with HIV after a blood transfusion performed in a public hospital. Associated Press, "HIV Spurs Peru Blood Bank Closings," MSNBC.com, 13 September 2007, *http://www.msnbc.msn.com/id/20765564,* accessed 4 November 2007.

CONSCIENTIOUS OBJECTIONS (HEALTHCARE PROVIDERS AND RELATED PROFESSIONS)

Recent Cases, July - September 2007

***California.** The state supreme court agreed to hear a case involving two physicians who refused to provide intravenous fertility treatment to a lesbian couple. The state supreme court granted review on 14 June 2006, but is accepting briefs until October 2007. After that the court will set a date to hear the case. *North Coast Women's Care Medical Group, et al. v. Superior Court of San Diego County, Guadalupe T. Benitez (Real Party in Interest).* Cal. Supreme Ct. Case. No. S142892.

Recent Laws and Regulations, July - September 2007

Washington. On 26 July 2007, two new regulations went into effect that require pharmacists to sell emergency contraception, commonly known as the "morning after" pill, regardless of any moral or religious objections they may have. The rule does make an allowance if the pharmacist can find a coworker to fill the prescription, but only if the patient is able to get the drug in the same pharmacy visit. Several pharmacists have since sued the state, saying the rule violates their civil rights by forcing them into "choosing between their livelihoods and their deeply held religious and moral beliefs." See discussion of case above. Wash. Admin. Code § 246-869-010.095 (2007).

MENTAL HEALTH

Recent Laws and Regulations, July - September 2007

Federal. On 27 September 2007, The Joshua Omvig Veterans Suicide Prevention Act was sent to the President for his signature. The act directs the Secretary of Veterans Affairs to develop and implement a comprehensive program designed to reduce the incidence of suicide among veterans. H.R. 327, 110th Leg., 1st Reg. Sess. (2007).

***The Senate passed** on 18 September 2007 a bill that would require insurers to cover mental illness at the same level as they cover physical illness. The bill is now being considered by the House. H.R. 1424, S.B. 558, 110th Leg., Reg. Sess. (2007).

NEW TECHNOLOGIES (NANOTECHNOLOGY, HYBRIDS, XENOTRANSPLANTATION, AND MORE)

There is not much to report in this category right now, but with time, the number of entries is sure to grow.

July - September 2007

***Federal**. The FDA Nanotechnology Task Force issued its report on 25 July 2007. The report essentially concluded that there was no need for the FDA to rush to regulate the advertising of nanotechnology. The FDA should consider each product using nanotechnology on a case-by-case basis, since there is nothing inherent about nanotechnology that warrants a special form of labeling or special warnings to consumers. FDA, "Nanotechnology: A Report of the U.S. Food and Drug Administration Nanotechnology Task Force," 25 July 2007, *http://www.fda.gov/nanotechnology/taskforce/report2007.html,* accessed 25 July 2007.

Interesting Developments in Other Countries

United Kingdom. On 5 September 2007 the Human Fertilisation and Embryo Authority decided it has jurisdiction to look at protocols considering the creation of embryos that are part human and part animal. The authority is expected to make its first decisions as to the acceptability of hybrid embryos in November. R. Weiss, "Britain to Allow Creation of Hybrid Embryos," *Washington Post,* 6 September 2007, A11.