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At the Bedside

When Should Ethics Consultants Risk Giving their Personal Views?

Edmund G. Howe

There is, perhaps, no scene more wrenching in all of literature than the last scene of Goethe's *Faust, Part One*. After Faust loves and leaves Gretchen, she loses her mind, and kills her mother and then the baby she has had by Faust. When Faust comes to her in prison, to free her, she asks,

And do you know, my love,
do you really know
who it is you're setting free?¹

In the special section included in this issue of *JCE*, six ethics consultants describe five cases that haunt them most. Of these, the one that haunts *me* most is Jeffrey Spike's "The Sound of Chains: A Tragedy."

In this case, Spike relates that a social worker called him for assistance on a case that every other consultant on the service had avoided: the staff did not want the mother of

a shaken infant to be allowed to visit her baby. The baby had suffered brain damage so severe that he was ventilator-dependent, and most on the staff, although they doted on the beautiful baby, believed he would be better off dead. Even though the mother and her boyfriend were charged with the abuse, for some unknown reason the mother continued to be the baby's surrogate decision maker. The staff hoped that the mother would allow the ventilator to be removed — but, if the baby died, the mother might be charged with murder. Spike suggested that the mother should be allowed to visit.

Spike writes that this case haunts him because is it tragic; of the cases in this special section, it is the case that most haunts me, for that reason and for another: in making this suggestion, Spike put himself at risk. For example, the mother may have, on seeing her infant, picked him up and dashed him against a wall. Perhaps I was as affected as Spike was by this case because I have taken risks like this; unlike Spike, in one case I had the worst of outcomes: a child died as the result of parental neglect when I took a risk on them.

Whether Spike should have taken a risk is one of the questions he raises in his case. A

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broader question addressed in this column will be: What criteria should careproviders use when they decide to take a risk?²

Spike relates that his suggestion swayed other careproviders who disagreed with him about the mother's visit; he was surprised that it did. This leads to a second question: When (if ever) should ethics consultants try to have their voice rule? And another question that is further to the point: Should ethics consultants attempt to increase the likelihood that their personal moral views will prevail?

Ethics consultants take a risk when they do this, because others — patients, family members, staff — may assume that ethics consultants have “special ethics expertise.” They may assume that ethical expertise or ethical analysis can assist in deciding which of two reasonable but competing values should prevail. But this is erroneous: ethical analysis — and, therefore, ethics consultants — can't tell us which of two important and mutually exclusive values to choose; for example, it cannot tell us whether or not abortion is “right.”

Given that their views may erroneously be seen as “more valid” than others', should ethics consultants even share their views? Of course, ethics consultants' views may be more valid because they are based on insights consultants possess that others may lack, but this validity does not depend on their being ethics consultants *per se*. Then again, if an ethics consultant has a special insight into a case and the others involved don't realize it, they may assume that the consultant has offered her or his view because the consultant thinks it is superior — for example, others may think that the consultant believes she or he is more compassionate than other people. If this is assumed, others involved in the case may feel offended and resolve to avoid ethics consultation in the future. As a consequence, other patients may be harmed. Given these various pitfalls, what are ethics consultants to do?

WAS SPIKE RIGHT?

In Spike's case, it is unclear why careproviders changed their minds after Spike sug-

gested that the mother could visit her infant. When ethics consultants share their own moral views, their views are not devoid of clout; others may fear opposing them for a number of reasons:

- They may fear that later they may be at legal peril, because, if someone sues them, they may be more vulnerable if they have opposed an ethics consultant;³
- They may fear that opposing a consultant would be an unethical act;
- They may assume that they should afford the views of an *ethics* consultant greater moral weight.

These views may be mistaken. Ethics consultants' exceptional expertise is in knowing how ethical decisions should be made, not in which value or values should prevail. Since value errors are possible, however, consultants should have clear criteria for deciding when to share their personal views, before they go ahead and express them. What could these criteria be? To answer this, let's return to Spike's case and ask, using his case as a paradigm: What risks are worth taking? Why?

We want to trust all of our patients. We can be more helpful if we do. Most times, we choose to trust patients fully for this reason, even when we have reasons not to.⁴ Thus, it is emotionally wrenching when we encounter a patient we can't or shouldn't trust. We aren't good (and perhaps it's good that we're not) at making the transition from trusting to distrusting, especially when we are face-to-face with a patient. The need to make such a shift is exemplified by Spike's situation, because the mother in this case could have responded by harming her infant. This possibility is the only valid reason to not allow her to see her baby. An inferior reason would be to punish her further. This so-called punitive basis for making decisions is ethically flawed, as will be discussed further below.

Why might the mother do such a thing — for example, as hard as it is to imagine, hurl her child against a wall? All ethics begins with accurate awareness. Those who do not work regularly in the area of criminal behavior may

not have an accurate awareness of what some persons can do. Thus we should briefly consider this. There are actually several possible reasons (and this is not meant in any way to be all-inclusive):

- The mother may have an epileptic condition and do this involuntarily; the reaction could be triggered, for example, by intense emotion.⁵
- The mother may have used a drug in the past that can cause sudden violent behavior, such as PCP, and, out of the blue, have a flashback. This violence would also be involuntary.⁶
- Or she could suddenly react in this way due to an underlying psychosis; she could appear normal, but without warning respond to a delusion in a violent way.⁷
- Much more likely is the possibility that the mother might do this voluntarily: she might have chosen to harm her infant out of rage and revenge against society in general — again, a possible human action that we don't like to consider. Yet some persons are motivated to seek revenge even when it is strongly against their best interest.⁸

My purpose here is not to indicate that any of these disorders are at all likely, but rather that it is possible that a woman could act this way. Knowing this, making a decision like Spike's may become even more difficult. Should Spike have done what he did?

I say, unequivocally, *Yes*. What is important here is the reason why, based on the ethical premise stated above. Ethics consultants should not share personal views when they are based only on personal preference; for example, based on their religion or what their parents taught them; rather, consultants should acknowledge these beliefs, but should make clear that they are not based on an exceptional skill at ethical reasoning. But consultants should share their personal views *when they think their views are based on an exceptional insight*. Further, they should share their insights even when others can't fathom

what their insight is, or why the insight supports their personal views. As stated earlier, ethicists have skills that may enable them to sometimes see better ethical answers than others can.

Ethics consultants should share their own views because, if they don't, in the larger scheme of things, less good and/or greater harm (deontological and consequential) may result. To better understand what should "count" as an insight, let us imagine what skills may have allowed Spike to arrive at the conclusion he did. I can imagine, out of hand, three.

1. KNOWING EXCEPTIONS CAN BE MADE TO "THE RULES"

Spike may have recognized that, rather than responding reflexively to a rule such as "take no risks with possible criminals," in most cases, better ethical outcomes may be achieved by allowing exceptions to the rules. He and other ethics consultants may know that all rules, such as laws and codes, are very useful for many reasons, but are limited as ethical guidelines, because they don't — and can't — take into account all of the potentially relevant extenuating circumstances and situations. A paradigmatic example is the commandment "Thou shalt not kill." Many who believe in this commandment also believe that they would and should kill if an armed burglar in their house endangered them and their family.

Spike may know that it is sometimes ethically optimal to respond in a manner that is strictly "by the book," but that, at other times, this approach can be downright dangerous. He may have reasoned, applying these not-always-self-evident considerations, that it was a remote risk that the mother might harm her son, that she might have a seizure, a PCP flashback, a sudden psychotic break, or even willfully wreak revenge. When thinking this, Spike may have made a distinction between the magnitude of risk and its probability. Further, he may have imagined that, even if the magnitude of risk should be granted moral

weight, the risk might not be too great, as, in some persons' view, the infant would be better off dead.⁹ Spike may have been wrong. The mother might have killed her child. If she had, it would not mean that it was wrong for Spike to share his personal view.

2. APPLYING A NARRATIVE APPROACH

Spike might have known how to use a narrative approach or a thick description of a particular patient; that is, he may have known that although, statistically, a suspected criminal may be more likely to commit a crime to be vengeful, a thicker description of the person may strongly suggest that this is highly unlikely. Thus, it might be a sound bet that the mother would be an exception to the rule, and letting her see her baby would not create a risk. Spike knew that, if the mother did kill her baby, it would increase the seriousness of her crime to murder. Still, she could have acted out of revenge. Spike observed the mother closely as she visited her baby; this was another way to reduce possible risk. He noticed her tears as she spoke to her baby.

3. CONTEMPT FOR THE MORAL WEIGHT GIVEN TO THE DESIRE TO PUNISH

More than others involved in the case, Spike may have eschewed and felt contempt for any moral weight others might have wanted to give to their desire to punish the mother. He may have recognized that punishing her involved the presupposition that she deserved this response.¹⁰ Such a claim would depend strongly on a supposition that the mother deserved punishment because she started on an equal genetic and social footing with the rest of us. Spike may have felt: There, but for the grace of God, go I.

This response indicates the kind of awareness recommended by many who write about ethics, such as John Rawls.¹¹ We may choose to see others as being culpable in ways that we are not, to heighten our own sense of self-regard. We may want to see ourselves as being superior and unlike others, because we don't commit criminal acts, as they do. We

may, however — even if we have the luck of good genes and a wholesome upbringing — be more vulnerable to heinous acts than we would like to admit.

The insights that we have attributed to Jeff Spike may or may not be those he actually had, although I presume that he had them and many more in this case. The few listed here are intended to convey what I mean by exceptional insight. I hope they illustrate what I mean when I write that, if ethics consultants do not express their insights, greater wrong may be done. In Spike's case, all of the staff were content to remain passive. If Spike had remained silent, all would have allowed harm to the mother, who would have lost what may have been her last opportunity to be with her baby.

The ethical rationale for consultants to always speak up when they have an exceptional insight is nowhere better expressed than by Elie Wiesel, who, when in his teens, was deported from his home in Hungary to the Nazi camp at Auschwitz. Wiesel's father, mother, and younger sister who were with him died. He has spent his life trying to teach others what he feels he learned from this horrific experience. He says, "Indifference reduces the other to an abstraction . . . to be indifferent [to the suffering of others] is what makes the human being inhuman."¹² Aren't most of us susceptible to being indifferent? Couldn't something like this happen on a ward, where staff care for patients? Spike's experience would suggest a painful answer.

We may have already known this answer, or should know it from well-known events, the most famous of which may be what happened to a woman named Kitty Genovese, who was stabbed to death, over time, in public, while many watched and listened, but did not respond to her cries for help, although even an anonymously placed phone call to the police would have saved her.¹³ Lauren Slater, a psychologist, reviewed this event and the scientific studies related to it, and came to this conclusion: the more people who wit-

ness an event, the less responsible any one individual feels. Diffusion of responsibility is compounded by a social etiquette so strong that it overrides even life-and-death situations.¹⁴

If Slater is right, we have a possible reason why no one spoke up for the mother until Spike did. We can imagine, also, that, rather than seeing the mother as different and wholly unlike us, we could see her as more like us than we would like to admit. But is there scientific data to support this? Slater reports on a study conducted by John M. Darley and Bibb Latané, in which the researchers mimicked and studied the Genovese murder. In their study, an actor, pretending to have a seizure, cried out for help from another room, saying he was choking and dying. Subjects in the study could confer with each other and could have easily sought help at no risk to themselves, but most did not.¹⁵ Further, if the subjects didn't act immediately, Darley and Latané found, they were unlikely to act later. And the greater the number of persons in the group, the less likely people were to act. Slater notes that Darley and Latané's experiment contradicts the evolutionary adage that there is safety in numbers.¹⁶ Thus, there are empirical as well as ethical grounds for consultants' speaking out when they believe their views are based in insight — regardless of the risk.

Slater describes another study that found that people may change when they can see the dangers of passivity. In one study, Arthur Beaman showed participants films of the study by Darley and Latané described above, and explained five stage that persons go through to act responsibly:

1. Notice what is happening.
2. Interpret the event as one in which help is needed.
3. Assume personal responsibility.
4. Decide what action to take.
5. Take action.¹⁷

After this instruction, participants were found to be twice as likely to take helpful initiatives as the control subjects were. Still, when I think

of Kitty Genovese, read about these studies, and read Spike's case, I have increased appreciation for all ethics consultants who act as Spike did. Which leads to the next question: When should we act this way?

OTHER EXAMPLES OF EXCEPTIONAL INSIGHT

The sole criterion we should use to decide to share personal views is this: when we genuinely believe that we have an insight that others may lack. We have considered the kinds of insights that Jeff Spike may have had. The five other ethics consultants who present cases in the special section in this issue also offer superlative examples.

Denise M. Dudzinski presents the case of a 50-year-old woman who had severe chronic pain in her arm, who wanted to have it amputated not only because of the pain, also but because it smelled badly and frightened her young grandson. Her doctors wouldn't amputate because they thought that, even with surgery, the woman would likely still have phantom pain. Dudzinski became involved not because she was formally consulted, but because she took the initiative to do so when she first heard about this patient. She tries to become involved in cases, she says, *before* they become dilemmas. "Wow!" as John Fletcher used to say. This proactive initiative exemplifies the caring that Elie Wiesel, in condemning indifference, espoused.

As Dudzinski points out, the unusual and bizarre nature of the patient's request led some of her careproviders to question her competency. Dudzinski supported the patient in her request. What insight may have prompted this? It may have been that, over time, as the patient remained in pain and continued to request surgery, the merits of not honoring her wishes progressively decreased. This moral view is based on the deontological value given to respecting patients' dignity by giving them autonomy. The moral weight accorded to most patients' wishes should, accordingly, increase over time. This principle is based on essen-

tially the same values as “sliding scales” that are used to determine patients’ capacity to make decisions. With the passage of time, if there is relatively less we can offer a patient, the more we should respect her or his autonomy. Respecting patients’ autonomy to a greater extent is something that we can offer as their range of treatment options decreases.

Dudzinski presents her insight this way: “At most, an amputation would have been a zero-sum game, leaving the patient in the same pain, but without an arm.” Dudzinski did not believe that the patient’s decision-making capacity was too badly compromised because a psychiatric assessment confirmed her decision-making capacity.

There is an additional instructive and slightly sad aspect to this case. Dudzinski relates that a student later brought her attention to a patient who had been admitted with apotemnophilia, an illness that caused the patient to want his arm to be amputated, even though it was healthy and he was not in pain. Dudzinski says that she really wanted to speak with the patient, but did not. This is sad because I have no doubt that she could have helped; I wonder if the stress of interacting with the surgeons in the earlier case took a toll.

Doing what Spike, Dudzinski, and the other authors of cases in this special section did is likely to exact an emotional toll. Dudzinski and Paul J. Ford say in the introduction to the special section that it is easy to feel isolated when we have few colleagues with whom to confer or debrief in a confidential manner; to which I say: Hear, hear! This is particularly the case when ethics consultants intervene by sharing views that “go against the grain.” The study by Darley and Latané, cited earlier, indicates how important peer support is.

A second example of exceptional insight is offered in a case written by Paul J. Ford in the special section. Like most ethics consultants, he has greater insight regarding the importance of deontological values. In the case he describes, he attempted to assist a family who did not think that sustaining their loved

one’s life was futile, as they struggled through the repeated discharges and readmissions of a cognitively impaired patient who was experiencing multiple-organ failure. Ford says, “I empathized with the family’s frustration. . . . Each new medical team believed that the family must not ‘understand’ the situation: otherwise the family would withdraw all therapy.” The insight that different views may be equally valid is related to the notion (also held more commonly by ethicists than others) that respecting a person’s dignity may mean not only respecting rational thoughts, but respecting, to some degree, desires that are irrational.¹⁸ I think in this regard of a family who had called an ambulance long after a loved one had stopped breathing. In this instance, which occurred long ago, there were clear signs that the family member had been dead for some time, and that cardiopulmonary resuscitation (CPR) couldn’t possibly succeed. The ambulance staff wanted simply to take this deceased person away. The family was, however, irate: they strongly wanted the drivers to attempt CPR. So they did. They tried and failed. The family felt much relieved.

Ford also writes about the importance of follow up in ethics consultation: “I am haunted by the thought,” he says, “that a careful, consistent follow up of the original consultation could have bettered the overall situation.” The ethics consultation process, he laments, is often reactive, rather than proactive. To this, I would add: “Me, too.” I think here of the case that most haunts me, in which I consulted with a patient who wanted to die. We were able to begin a very positive relationship, and together formed a plan for treatment. As per our plan, I left the task of following through on the plan to others. But they didn’t follow through, and neither did I. In short order, the patient returned to her former state, and she died as she initially intended, by refusing interventions that could have kept her alive for many years, with a life that she agreed would be a good one.

Ethicists may also tend to have exceptional insight in regard to feelings. This is demonstrated in the case discussed by Joy D. Skeel

and Kristi S. Williams in the special section, who were treating a 36-year-old man with a diagnosis of borderline personality disorder. He was admitted to the hospital repeatedly after having swallowed rat poison and other poison many times, which caused his careproviders a great deal of anguish — and anger. Skeel and Williams recognized the importance of the staff's anger, and identified how the needs of the staff and the patient collided. They saw how the staff's anger affected their behavior — which the staff themselves couldn't see. Emotions can be contagious, and, as Darley and Latané report, it is extremely important for persons to agree with others. This is another example of an instance in which ethics consultants should speak out.

Ethics consultants may be more able to feel, and bear, what patients and their families truly experience.¹⁹ This is exemplified by Richard M. Zaner, who writes in the special section about how he sat with a couple, bearing their pain and uncertainty as they tried to understand an early prenatal diagnosis of serious disability. "I was left with a strong sense of my own vulnerability in the face of such uncertainty," Zaner reports. He identified with the parents' frustration that they must decide, even though they were uncertain. Reading this, I think of the rare patients one sees in psychiatry who have suicidal feelings that are not severe enough that they need or are willing to be hospitalized. Yet they say honestly that they can't be sure that their feelings could not suddenly become stronger and overwhelm them, so that they end their life. They report that they fear this greatly. The only and best option may be to merely be with them and share their fear. This is an awareness that Zaner clearly had; there is no doubt that, because of this, the couple he sat with were grateful to him.

ERRORS ETHICS CONSULTANTS MAY BE MORE LIKELY TO MAKE

Ethics consultants may be more vulnerable than others to certain risks; they may, for instance, not have become hardened, and so may

underestimate some risks. Wanting to trust and help, they may inappropriately try to rescue.

A cognitive error to which ethics consultants may be especially prone is to become caught up in theory. Trained to think in the abstract, they may become overly rigid, placing undue importance on a principle when nuances should be taken more into account.²⁰ I think here of a not-uncommon example: ethics consultants sometimes insist that the precise wording on an advance directive be interpreted and acted on literally, when it would be better to try to imagine what the patient would have wanted if he or she had been able to more accurately anticipate future events.

Ethics consultants, and careproviders, may not respond optimally to patients they aren't sure they can trust, such as parents who bring their child to the emergency room when the child's problem may have been caused by abuse. The following case is an example of this general difficulty. Staff suspected the parents of a hospitalized child of abuse when the toddler was found to have calcium deposits on his head, which were consistent with multiple beatings. In fact, the child's chart documented that this had been caused by spontaneous bleeding a few years before, but those notes were not noticed until later. The staff told the parents an outright lie: that they had to stay in the hospital overnight, while the staff performed a brain scan, because their child might stop breathing and die. In fact, the staff wanted to keep the parents at the hospital in case the scan gave them a better indication that the child had been abused. The parents were petrified with fear at this, and also because they knew the staff suspected them of abuse, and might try to take their child away from them. The parents were left alone for six hours, feeling isolated, frightened, and paranoid. They still feel dread when they have to bring their now-teenaged son to the hospital, because staff inevitably notice and comment on the concern about abuse that is documented in the young man's medical record.

While this case is an outlier, it echoes Spike's experience. Surely, all careproviders

can do better. We pay too little attention to how we can, and should, most respectfully change from a trusting to a less-trusting role. Even in situations like these, careproviders should visit parents who are isolated and fearful, at frequent intervals, and should attempt to empathize with them. We can say something like, "I'm sorry. This must be excruciating. As I hope you know, we don't have any other choice. If there is one, I wish we knew of it. I hope you can understand."

CONCLUSION

It is essential that ethics consultants express their views when they have insights others may lack. They should do this even when they fear they may be wrong. Doing anything else smacks of indifference. Further, all persons, including careproviders, are highly susceptible to the influence of others, and so may remain passive as long as others present respond in the same way. It may be that the only way that right will be done in these situations is for ethics consultants to speak out.

Six authors in this special section describe cases that haunt them. All give different reasons, but all had to stand, in one way or the other, "against the crowd." It is possible that the stress from doing this is part of what haunts the authors. In any event, this is a price of expressing one's views when others disagree.

Spike, more than anything else, perhaps, allowed himself to respond on the basis of his human feelings. The mother may remember and cherish this last memory of holding her baby, regardless of where she spends the rest of her life. I think of a mother who felt this way after giving birth to a 19-week-old fetus who died. Her memory of the joy of briefly holding him was the only positive memory she had of the otherwise excruciating experience — but the joy of that moment has never gone away.

The pain of patients like the mother in Spike's case, who remain in touch with their dreadful reality, can only be imagined. Al-

though Gretchen in *Faust* is a fictitious character, her story may provide a window through which the pain of patients like Spike's can be better understood. Gretchen drowned her baby and then went mad. In her dungeon cell, she begs Faust,

Grab it! Hurry!
It's trying to rise! Kicking!
Save it! Save it!

Frantic with grief and remorse, she says to him,

I am in your hands now, at your mercy.
But first let me nurse my baby.²¹

NOTES

1. J. W. von Goethe, *Faust, Part One*, trans. C.R. Mueller (Hanover, N.H.: Smith and Kraus, 2004), 193.

2. G. Adshead, "Evidence-Based Medicine and Medicine-Based Evidence: The Expert Witness in Cases of Factitious Disorder by Proxy," *Journal of the American Academy of Psychiatry and the Law* 33, no. 1 (2005): 99-105; H. Schreier, "Munchausen Syndrome by Proxy," *Pediatrics* 110, no. 5 (November 2002): 985-8.

Pate v. Threlkel, 661 So. 278 (Fla. 1995). In this case a patient had thyroid cancer, a "genetically transferable disease." When her adult daughter acquired the cancer, the daughter and her husband sued the mother's physicians, claiming that if they had warned the mother that she was at risk and if the daughter were tested, "more likely than not, the daughter's disease would have been detected while it was still curable." The court concluded that when such an outcome is foreseeable, physicians have a duty to warn the parents. C. Kachigian and A.R. Felthous, "Court Responses to *Tarasoff* Statutes," *Journal of the American Academy of Psychiatry and Law* 32 (2004): 263-73, and B. Ginsberg, "*Tarasoff* at Thirty: Victim's Knowledge Shrinks the Psychotherapist's Duty to Warn and Protect,"

Journal of Contemporary Health Law and Policy 21, no. 1 (Winter 2004): 1-35.

P.S. Appelbaum and T.J. Rudegeair, "On the Duty to Protect: An Evolutionary Perspective," *Bulletin of the American Academy of Psychiatry and Law* 20, no. 4 (1992): 419-26. These authors assert that the Tarasoff holding that therapists should protect unknown victims over known patients violated predispositions to those for whom we feel closest acquired through evolution.

3. For this reason, the oft-cited belief that ethics consultants and committees can merely make recommendations may be misleading — and an understatement.

4. The conflict between choosing to trust patients or their family members and "sleuthing" arises most commonly when careproviders distrust the motivations of surrogate decision makers, such as when they stand to inherit parents' wealth. Careproviders cannot, however, "have it both ways." If they choose to trust, to be as supportive of the family as they can, they have to give up sleuthing; or, they can sleuth more, but at the price of losing their capacity to give the family optimal support.

5. This possibility is further complicated because persons may have psychomotor seizures that are neurologically generated or pseudoseizures that are "psychological." They also may have dissociative responses. D.M. Treiman, "Violence and the Epilepsy Defense," *Neurologic Clinics* 17, no. 2 (May 1999): 245-55; N.C. Thompson, I. Osorio, and E.E. Hunter, "Nonepileptic Seizures: Reframing the Diagnosis," *Perspectives in Psychiatric Care* 41, no. 2 (April -June 2005): 71-8; J.G. Akyuz et al., "Dissociation and Childhood Abuse History in Epileptic and Pseudoseizure Patients," *Epileptic Disorders* 6, no. 3 (September 2004): 187-92. In this last study, female patients with pseudoseizures showed higher levels of dissociation.

6. P.N. Hoaken and S.H. Stewart, "Drugs of Abuse and the Elicitation of Human Aggressive Behavior," *Addictive Behaviors* 28, no. 9 (December 2003): 1533-54. J.B. Leikin et

al., "Clinical Features and Management of Intoxication Due to Hallucinogenic Drugs," *Medical Toxicology and Adverse Drug Experience* 4, no. 5 (September - October 1989): 324-50, pp. 331-3.

7. M. Oberman, "Mothers Who Kill: Cross-Cultural Patterns in and Perspectives on Contemporary Maternal Filicide," *International Journal of Law and Psychiatry* 26, no. 5 (September -October 2003): 493-514; M.G. Spinelli, "Maternal Infanticide Associated with Mental Illness: Prevention and the Promise of Saved Lives," *American Journal of Psychiatry* 161, no. 9 (September 2004): 1548-57. In animals, a chemical deficiency has been identified that may cause infanticide in male mice. T. Matsumoto, S. Honda, and N. Harada, "Neurological Effects of Aromatase Deficiency in the Mouse," *Journal of Steroid Biochemistry and Molecular Biology* 86, no. 3-5 (Sep 2003): 357-65.

8. From the earliest times, stories of revenge have been told in which persons seek revenge, notwithstanding the cost to themselves. The stories have existed from Homer's first epic and the plays of the Greek playwrights in ancient times to *Madame Bovary* in modern times. K. Yamamoto, "The Ethical Structure of Homeric Society," *Collegium Antropologicum* 26, no. 2 (December 2002): 695-709; R.M. Gottlieb, "Refusing the Cure: Sophocles's Philocetes and the Clinical Problems of Self-Injurious Spite, Shame and Forgiveness," *International Journal of Psychoanalysis* 85, part 3 (June 2004): 669-89; J.A. Arlow and F.D. Baudry, "Flaubert's *Madame Bovary*: A Study in Envy and Revenge," *Psychoanalytic Quarterly* 71, no. 2 (April 2002): 213-33.

Neuroscientific studies have revealed most recently that the response of seeking revenge can take place in humans when certain neural pathways are more active in the brain. Evolutionary theorists even argue that such an "eye-for -an-eye" strategies makes sense, as they may preventing future damage to one's kin. B. Knutson, "Sweet Revenge?" *Science* 305, no. 5688 (Aug 2004): 1246-7.

A new diagnosis as been suggested to incorporate this possibility: M. Linden, "Post-traumatic Embitterment Disorder," *Psychotherapy and Psychosomatics* 72, no. 4 (July - August 2003): 195-202.

9. Obviously, some persons would disagree, believing that this infant, or perhaps all infants, would always be better off alive.

10. Persons may or may not be "geared" to be caring, rather than punitive. Meissner, a psychoanalyst, does not assume that we can take persons' caring for granted. "It has been argued, since Darwin [1872]," he states, "that man is by nature disposed to altruism, that is, he is naturally attuned to group loyalty and sensitive and responsive to the social expectations and needs of his fellowmen." W.W. Meissner, *The Ethical Dimension of Psychoanalysis* (New York, N.Y.: State University of New York Press, 2003), 311. See, related to this, P.S. Appelbaum and T.J. Rudegear, note 2 above.

11. J. Rawls, *A Theory of Justice* (New York, N.Y.: Oxford University Press, 1971).

12. E. Wiesel, "The Perils of Indifference," speech given at the White House as part of the Millennium Lecture series, hosted by President Bill Clinton and First Lady Hillary Rodham Clinton, 12 April 1999, www.historyplace.com/speeches/weisel.htm, p. 3. Wiesel, with his father, mother, and sisters, was deported to Auschwitz in the summer of 1944. He was liberated from Buchenwald, where his father, mother, and a younger sister died in April 1945.

13. A.M. Rosenthal, *Thirty-Eight Witnesses: The Kitty Genovese Case* (Berkeley, Calif.: University of California Press, 1999).

14. L. Slater, *Opening Skinner's Box* (New York: W.W. Norton, 2004), 102.

15. J.M. Darley and B. Latané, "Bystander Intervention in Emergencies: Diffusion of Responsibility," *Journal of Personality and Social Psychology* 8, no. 4 (1968): 377-83.

16. Slater, see note 14 above.

17. A. Beaman et al., "Increasing Helping Rates through Information Dissemination: Teaching Pays," *Personality and Social Psychology Bulletin* 4 (1979): 406-411, discussed and cited in L. Slater, see note 14 above, pp. 108-110 and 258.

18. For a study suggesting that irrationality is caused by having suboptimal strategies present and is elicited by state-dependent decisions, see C. Schuck-Paim, L. Pomilio, and A. Kacelnik, "State-Dependent Decisions Cause Violations of Rationality in Animal Choice," *PLoS Biology* 2, no. 12 (December 2004): e402, E-pub, 23 November 2004, www.pubmedcentral.gov/articlerender.fcgi?tool=pubmed&pubmedid=15550984.

19. M. Sandelowski and J. Barroso, "The Travesty of Choosing after Positive Prenatal Diagnosis," *Journal of Obstetric, Gynecologic, and Neonatal Nursing* 34, no. 3 (May - June 2005): 307-18; M.L. Moutard, "Prenatal Diagnosis of Cerebral Malformation with an Uncertain Prognosis: A Study Concerning Couple's Information and Consequences on Pregnancy," *Annales de Genetique* 47, no. 1 (January - March 2004): 41-51.

20. G. Gillett, "Reasoning in Bioethics," *Bioethics* 17, no. 3 (June 2003): 243-61. A. Bradshaw, "Yes! There Is an Ethics of Care: An Answer for Peter Allmark," *Journal of Medical Ethics* 22, no. 1 (February 1996): 8-12.

21. See note 1 above.

Goethe's awe for the nursing mother may have affected his choice of delusion. He states, "In the Palazzo Tanari there hangs a famous picture by Guido of Mary suckling her child. . . . Her expression, as she looks down on her child and her breast, is one of speechless and utter submission, as if it were not a child of love and joy to which she is giving her breast, but a heavenly changeling; she cannot do otherwise and, in deep humility, cannot understand why this should have happened to her." J.W. von Goethe, "Italian Journey (1786-1787)," in *Selected Works*, trans. W.H. Auden and E. Mayer (New York: Knopf, 2000), 283.

Special Section: Cases that Haunt Us

Specters, Traces, and Regret in Ethics Consultation

*Paul J. Ford and Denise M. Dudzinski,
Editors*

As clinical ethics consultants, we inevitably participate in cases that haunt us long after our formal involvement ends. With patients, families, and careproviders, we are moral agents who are culpable for our interactions and our recommendations. When we consult, we weave ourselves into the story of the case. In doing so, we influence the path of the story and are altered by the encounter. The standard way to write an ethics case is to focus on a particular ethical issue, rather than the role of the consultant in the case and the impact of the case on the ethics consultant. There are times when no good solution exists, when organizational or legal constraints

seem insurmountable, and/or the consultant is unable to bring about the result that she or he desires.

Although we need to discuss patients' ethical dilemmas for their own sake, we must also share the affective nature of complex situations. In trying to act with integrity, we strive to recognize our shortcomings and to improve our practices. Having the courage to write about these cases is important for helping new people in the field, because these expositions highlight the personal and professional risks of ethics consultation. Sharing haunting cases may improve the practice of clinical ethics consultation by addressing the character and professional development of consultants.

Ethics consultants influence how cases play out, if in no other way than to bring greater understanding of individual and professional values, fostering decision making. While clinical ethics consultants may encourage others to courageously express and negotiate values, consultants also risk harming others and being harmed themselves.¹

To practice ethics consultation well, we invest ourselves in the devastating circumstances of others, and we genuinely want to

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assuage suffering by facilitating critical reflection and trying to improve outcomes. Emotions and facts play an important role in the dynamics that we must understand. To communicate effectively, we should recognize the ambiguity, sorrow, uncertainty, and lack of closure inherent in many consultations.

We must not allow haunting cases to paralyze us. Rather, being haunted should foster our further professional growth. To whatever degree that these special cases influence our activities by means of paralysis, growth, or anxiety, it is clear that there is an affective component that extends beyond our professional activities. We return to our families and social circles, where grief can linger from the interactions borne of tragic and frustrating cases. Given the small community of bioethicists in any given geographic area, it is easy to feel isolated, as there are few colleagues with whom to confer or debrief in a confidential manner.

For this special section of *The Journal of Clinical Ethics*, we present a set of haunting ethics consultations, told by experienced clinical ethics consultants. Authors were asked to focus on their role and the challenges they faced as consultants during and after the consultation. Although each story raises unique challenges, there are several overarching themes. Each case calls into question who can or should make healthcare decisions, and most cases include a question of the patient or decision-maker's capacity to make decisions. These cases go beyond being tragic; they touch on uncertainty, lack of power, and unclear professional boundaries. These are elements that contribute to the complexity of many consultations.

Clinical ethics consultation is haunting for several reasons. First, the ethical issues that are presented are often challenging in themselves, and it is stressful to help others negotiate them. Second, often the ethics consultants judge when and how to intervene. This involvement is not always beneficial, and may occasionally cause harm. Third, consultants experience moral distress and uncertainty

similar to the distress and uncertainty experienced by those they help. Fourth, like the patients with whom we work, we often feel powerless to facilitate positive change, as tragedy and suffering are pervasive or organizational constraints seem intractable. Finally, once we begin consulting, our values are part of the complex dynamics, and are either incorporated constructively or stumbled over on the road to clarity.

In the first case in this special section, Denise M. Dudzinski recounts the story of a woman who requested the amputation of her arm because of a regional pain syndrome. This case prompted Dudzinski to reflect on the moral distress encountered by a consultant and its impact on professional integrity. The patient appeared rational, yet the actual request she made was not reasonable by medical standards, as it was unlikely to alleviate her pain. The patient suffered and had few good therapeutic options. The case prompted Dudzinski to consider when an ethics consultation is appropriate and how the consultant's own interests play into the decision to become involved in informal consultations. The case prompts consideration of professional boundaries and integrity.

In the second case, by Joy D. Skeel and Kristi S. Williams, the patient made decisions that may not be in his best interest. The patient's decision-making capacity was in question, and the patient himself was labeled "hateful." The consultant found herself mediating between medical services (medicine, psychiatry, nursing) as well as between the patient and healthcare providers. In the end, the case leaves questions about the power to help and perhaps prompts regret that something more effective was not attempted.

In the third case, by Paul J. Ford, the patient had limited and sporadic cognitive function. The designated decision makers were at odds with the medical team on what would be best for the patient and what would be acceptable medical practice. The consultant was stuck in a process that protected various interests, but this process was neither expedi-

ent nor smooth in assisting a satisfactory conclusion. The case leaves questions about the reactive nature of consultation and the need to try to break out of processes that exact a heavy cost for all parties.

In the fourth case by Jeffrey Spike, the presumed decision maker had significant conflicts of interest. The infant patient had severe neurological damage, from which he would not recover. The consultant was forced to balance a number of competing visceral reactions to an incarcerated mother who was in chains at her baby's bedside. Was the mother, who allegedly hurt the baby, entitled to see him? The consultant found that many caregivers had already decided that the answer should be no. The consultant resisted being persuaded by consensus, but was sympathetic to the caregivers' anger and desire to protect the vulnerable child, as well as the mother's love for the child. The nurses, consultant, and mother all experienced grief and distress. The consultant had to carefully consider his own and others' affective responses to be effective. He was haunted by uncertainty and powerlessness long after his involvement in the case ended.

In the final case by Richard M. Zaner, parents were faced with a complicated pregnancy with a greatly uncertain prognosis. The 22-week-old fetus might have had spina bifida, suggested by ultrasound and alpha-feto protein tests. The physician thought the mother was angry at the suggestion that therapeutic abortion was an option. In speaking with her, Zaner discovered a more subtle source of distress: the mother was astounded that this profound decision was to be made before the age of viability, without adequate clinical information. Was she also reacting to *how* the clinicians communicated with her? Zaner reflects on the familiar haunting of moral decision making when the possibility for a devastating "mistake" is so immense and the patient's vulnerability is so great. He describes the kind of haunting that is at the very foundation of clinical ethics consultation.

Haunting cases are not unique to ethics consultation. They exist in many areas of medicine. In particular, they are common with surgical interventions. When candidacy for surgery is discussed in patient management meetings, it is not uncommon to hear people say, "This case looks like another Mr. Smith. . . . none of us want that," or, "Remember Mrs. Jones? We still don't know why surgery failed to work." These anecdotes are not only cautionary, but also a sign of being troubled by outcomes and processes. They are not a warning to "remember this type of procedure failed," but an attempt to give voice to an inchoate experience that remains mysterious, anguishing, and puzzling. We invite readers to reflect on the following cases, which describe challenges in systems, practice, and personal involvement that haunt clinical ethics consultants.

NOTES

1. M.J. Bliton and S.G. Finder, "Traversing Boundaries: Clinical Ethics, Moral Experience, and the Withdrawal of Life Supports," *Theoretical Medicine* 23 (2002): 233-58; R.M. Zaner, "Listening or Telling? Thoughts on Responsibility in Clinical Ethics Consultation," *Theoretical Medicine* 17, no. 3 (1996): 255-77.

“Amputate My Arm Please — I Don’t Want It Anymore”

Denise M. Dudzinski

A STORY OF CINDY

All of the names and some of the details of this case have been changed or omitted to respect the privacy of those involved.

Cindy Johnson was 50 years old. While working on an assembly line 10 years ago, she injured her wrist. Since the injury, she suffered from complex regional pain syndrome (CRPS) in her left hand and forearm. CRPS is a neuropathic pain disorder that arises after painful trauma affects a limb.¹ A gentle breeze passing over Cindy’s exposed skin would cause excruciating pain and a burning sensation. She kept her forearm protected with an Ace bandage and a hard brace, often resting her arm on a pillow — a minor protection and visible sign to others to keep their distance. She needed a spinal block to endure the excruciating pain of dressing changes. As the

block wore off, the pain would become unbearable. On the last admission, she returned to the emergency department shortly after a dressing change to receive a continuous infusion of levobupivacaine to anesthetize her arm. Her last dressing change was over a year ago. Due in part to suboptimal hygienic management that was inevitable with such infrequent dressing changes, she suffered from cellulitis and edema in her left hand and forearm. She also had joint contractures in her left hand, and her muscles atrophied from lack of use. Her arm was red and swollen. She took neurontin, percocet, trazodone, and methocarbamol to relieve pain and associated symptoms. Without more frequent dressing changes, her cellulitis would spread, causing ulcers and recurrent infection.

Cindy willingly received psychiatric treatment, because, as is often the case with CRPS, the severity of her pain did not correspond to the severity of the underlying injury.² She received counseling and took an antidepressant. Her decision-making capacity was intact and, except for minor depression, she had no other psychiatric issues. Despite Cindy’s faithful

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cooperation with psychiatric, palliative, and physical therapies, her pain continued.

Cindy lived with her husband and cared for her five-year-old grandson James. She was existentially and physically exhausted by constant pain and her inability to properly clean and protect her arm. Her in-patient team of physicians, including general medicine, psychiatry, the pain service, and anesthesia, presented treatment options. Treatment options included intrathecal opioids, a spinal cord stimulator, and dorsal rhizotomy (cutting the spinal nerve roots). She did not want the dorsal rhizotomy because it would cause her face to droop, and she might experience numbness on her left side. She was not a candidate for a spinal cord stimulator because there were too many nerve endings in the area, and the contractures in her hand were a contraindication.

Cindy refused all proposed treatments and requested amputation. Her physicians warned that amputation would probably not alleviate the pain because phantom pain would be likely to continue.³ Cindy wanted amputation for hygienic and personal reasons. She would take the risk of phantom pain. Her arm was alien to her and negatively impacted the quality of her relationships, especially her relationship with her grandson, James. The child was always afraid that he would hurt Grandma.

The treating physicians repeatedly spoke with Cindy about treatment alternatives and the risks of amputation. Cindy consistently assured them that she understood that amputation was unlikely to alleviate her pain. While Cindy was certain, members of the team (including myself) remained uncertain about whether amputation was medically or ethically appropriate or beneficial. As we grappled with the ethical dimensions of the case, we asked ourselves the following questions. Was her capacity to make decisions compromised by desperation? Was amputation a reasonable elective treatment alternative? Did the harms outweigh the benefits for Cindy? If so, should surgeons refuse her requests for amputation?

Whose perspective should take precedence — the medical team's or Cindy's?

MY MOTIVATION FOR INVOLVEMENT IN THE CASE

A formal ethics consultation was never called, hence, my role was not to help facilitate resolution of an ethical conflict, as it is in formal ethics consultation.⁴ The process of moral deliberation had begun among those who had most at stake. The deliberation was proceeding as one would expect — physicians were talking to one another, and the patient was trying to decide what was best.⁵ I learned about Cindy during my routine attendance at multidisciplinary rounds. By attending rounds, I try to offer assistance with emerging ethical issues before they become dilemmas and identify areas of ethical concern for resident physicians and other healthcare providers for discussion and education in various forums, both formal and informal. After talking with the resident physician after rounds, I asked the attending physician, Miriam Lam, MD, if she would mind if I talked with Cindy about her choice. Lam welcomed my involvement, as the treating team was divided about how best to proceed. Still, my involvement was unsolicited. So why did I involve myself in the case?

First, I want ethics consultation to be more proactive than reactive. By making this shift, we can focus on giving careproviders the skills to address ethical issues and spend our time supporting staff, patients, and families in their ethical deliberations. This strategy is better than sweeping in at the final hour when an avoidable dilemma has arisen. Hence, informal consultations are routine in my practice, but informal consultations usually do not involve visiting patients, since I am most often responding to careproviders' concerns about ethical dimensions of patient care.

Second, I want to help. Vulnerable patients call out for a special kind of attention and care, inspiring a desire to protect. I feel this desire strongly. While I am intellectually aware of

the dangers, the sentiment remains. The desire to protect, especially in the role of a clinical ethics consultant, can lead to meddling and ineffective consultation. Rather than focusing on facilitating conflict resolution, excavating shared values, and collaboratively envisioning creative solutions, it is possible to become distracted by the drive of one's own conviction.

I visited Cindy before I reflected on the motivations just outlined. When I asked her if she would mind speaking with me, she was receptive, willingly telling her story and answering my questions. Cindy described a crisis of corporeal and personal integrity. She told me, "This arm just gets in the way. I'm sick of being careful with it and telling everyone else to watch out. I can't play with James for fear of bumping into him. If it's gone I won't worry about that anymore." She sometimes described it as "this arm," not "my arm." Her arm created dissonance in her relationships. When I asked her if her husband and children agreed with amputation, she offered a knowing smile. She had been asked this question before. She said, "They wish I didn't have to do it, but they see how much I've been suffering. No one can assure me the other treatments will cure my pain either, at least not without side-effects I don't want to live with. It's a risk, but it's what I want. And my family supports me."

Cindy's vulnerability was different from the vulnerability I often see in my work. She was capable of making her own decisions. Any question of her decision-making capacity was motivated by her unusual request, not unclear thinking. She knew what she wanted, to the point that she proposed an unorthodox treatment plan. She was vulnerable because she was trapped in her own body and only a surgeon could "save" her. While clinicians worried that amputation was an elective disfigurement that would not alleviate her pain, Cindy thought of amputation as a liberation. Her arm had become alien to her, marked by a sustained disruption to her sense of self because of a disruption in the relationships that

shape her.⁶ She experienced a crisis of corporeal integrity. She wanted to be free.

The third reason I became involved was because I was curious. The particular vulnerability Cindy displayed had intrigued me for some time.⁷ How do people learn to live with an illness or injury that forces them to change their very notion of themselves? Not only corporeal but personal integrity has been radically challenged, and the patients courageously find and recreate themselves. I admire them and want to hear their stories. While I have no problem asking patients to teach us, in Cindy's case I was inexcusably unaware of how my own curiosity and professional self-interest compelled my involvement. At the end of our conversation, I asked Cindy if I could tell her story, especially in my work teaching residents. She willingly agreed, and my interests once again prevailed. I believed at the time that my involvement was more about wanting to help, but there was a clear conflict of interest. At the time I did not see it.

Finally, I became involved because I wanted to assist the treating team in dealing with their moral distress. By report, Cindy sounded both desperate and absolutely convinced that amputation was best. Maybe by speaking with her I would better understand the paradox and quench my desire to help. We genuinely did not know what was best to do. We all wanted to be certain. Once again, I should not have been seduced by the comfort of certitude. I should have known better. The moral life entails living with uncertainty — doing what we think is best without the benefit of knowing if our actions will bring the good we desire. Ethicists collaborate with others to provide clarity in a complex situation, but striving for *clarity* does not mean striving for *certainty*. Maybe I confused the two.

MORAL DISTRESS AND PROFESSIONAL INTEGRITY

Moral distress is itself a kind of haunting. Moral distress arises when we identify the

right course of action but feel constrained to act upon it.⁸ Likewise, moral *uncertainty* breeds moral distress. Moral uncertainty is marked by nebulous, negative feelings or “warning” intuitions that are experienced when individuals have not yet identified the source of their discomfort. Moral uncertainty can be addressed by gathering more information and by clarifying and naming the source of distress. In Cindy’s case, our moral distress arose from moral uncertainty. Moral distress influences professional integrity because it is a visceral response to a conflict between our personal values and our professional obligations.⁹ If our primary obligation is to help patients restore the personal integrity that is jeopardized by illness and injury, then acceding to Cindy’s request would be ethically warranted. But if Cindy’s request for amputation conflicts with the professional or personal values of healthcare providers, then a challenge to professional integrity would arise.¹⁰ If we did not believe that amputation would be beneficial, should we have condoned it, even if Cindy believed it was her best option? Wouldn’t this have compromised our own integrity? If we did not actively discourage amputation, would we have failed Cindy?

The attending physician, Miriam Lam, resolved her moral distress by talking with Cindy. Miriam said, “As I talked to healthcare providers and Cindy, I felt ambivalent. I wasn’t sure what was best to do and this troubled me. Amputating an arm is irreversible! What if she changed her mind? What if her pain got worse? At first I wasn’t sure what we should do. But that slowly changed. The more I talked with Cindy, the more I felt amputation was right for her. And I just accepted that it was my job as her doctor to do what was right for her, even if I didn’t completely understand.” Cindy’s clear autonomous expression of her wish to amputate assured Miriam.

But not everyone was assured by Cindy’s clear, consistent, autonomous request. Several surgeons refused to amputate, citing a conflict between obligations of nonmaleficence and beneficence. Some careproviders on the

pain and psychiatric services also disagreed with the option of amputation. Caregivers may refuse to offer medically indicated procedures that conflict with their personal or professional values, provided another healthcare provider is willing to care for the patient, and they certainly did not need to offer treatments that were outside the standard of practice.¹¹ Amputation was not medically indicated for treating CRPS. The surgeons had no obligation to amputate, but *only* a surgeon could grant Cindy her wish.

After speaking with Cindy, I came to the same conclusion as Miriam. Cindy knew what she was doing and knew what was best for her. While individual surgeons refused to operate, I believed amputation was ethically permissible, given that Cindy understood the possible repercussions. Had I succumbed to the lure of a patient’s informed autonomous request — the “autonomy trump card”? There were at least two ways to think about this dilemma. On the one hand, when a patient is capable of making decisions, we should trust her thoughtful assessment regarding harms and benefits when she suffers from a disability that negatively impacts the quality of her relationships. On the other hand, Cindy’s physicians had an obligation to minimize harm or provide benefit, neither of which was expected by the careproviders in this case. At most, to perform the amputation would be a “zero-sum game,” as it would leave Cindy in the same amount of pain, but without an arm. To this day, I think favoring Cindy’s assessment of benefit over a more objective “medical benefit” was ethically justifiable, but reasonable people disagreed on this point, particularly when they believed that Cindy’s pain compromised her decision-making capacity. I did not believe this was the case, especially because a psychiatric assessment had confirmed Cindy’s decision-making capacity.

WHAT HAUNTS ME?

Ethics consultants, like their partners in consultation, experience moral distress and

disequilibrium, as well as remarkable opportunities for moral and professional growth. Bliton and Finder wrote: "Faced with intense, specific, and explicit attention to the actual circumstances, to the genuine agony and potential disruption encountered by vulnerable patients and their loved ones, and by clinicians, the ethics consultant's own sensibilities and judgments may undergo a kind of *disequilibrium*."¹² Clinical ethics consultants experience disequilibrium when they encounter tragic cases; when, despite all efforts, tragedy and suffering prevail. In such cases, consultants often feel powerless. My involvement in Cindy's case represents a different kind of disequilibrium — the subtle haunting that arises from critical reflection and the belated acknowledgment that I could have done better.

First, I am haunted because, in retrospect, I see that my moral distress took center stage. I was so relieved when Cindy assured me that amputation was best for her. Her assurance was a gift. Cindy's conviction made amputation, an irreversible intervention unlikely to alleviate her chief complaint, ethically permissible. With that assurance, the case was closed for me and many members of the treating team. Was this the "respect for autonomy" trump card? Did I find it easier to agree with Cindy because doing so would relieve my moral distress? Cindy might truly be harmed by amputation. That reality did not change with my relief or her conviction. My distress arises not because I am haunted by the outcome, but because I see that the process was flawed.

Second, I am haunted by the fact that evidence suggests I did little to help. In fact, I might very well have contributed to Cindy's distress. Despite my attempts to be nonthreatening and to let her know that she did not have to speak with me, she probably perceived me as another institutional hurdle to clear before someone would grant her wish. She had to tell a painful story to yet another stranger. After living in pain for so long, why should she have had to speak to an ethicist when her

discussions with her doctors were genuinely ethically productive? Also, because there was no formal consult, I did not speak with all of the people who were struggling with the decision to amputate. If I had truly wanted to help my colleagues, I would have spoken with more of them.

Third, I failed to recognize clear conflicts of interest. I had almost nothing to lose and a lot to gain from talking with Cindy. I was curious and worried about her. She might quell my curiosity and address my uncertainty. My conversation with Cindy has benefited me professionally as well. I add a valuable teaching case to my repertoire. At the end of our pleasant conversation, in which we discussed both her values and the ethical concerns of the treating team, I asked Cindy if I could use her case for teaching. She agreed without hesitation. Even in retrospect, I do not think I exploited Cindy, but I was not as sensitive as I should have been. Was I trying to make myself useful to the medical team, blind to the price (however small) that Cindy would have to pay? Probably, as I was new to the institution at the time and wanted to make a good impression. I wanted to be an interested, collaborative, and proactive ethicist with a gentle and respectful demeanor.

OUTCOME

After several surgeons declined to amputate, one agreed to operate. Cindy did not experience any major complications from surgery, although, several years after her surgery, she continues to be treated for pain. How is Cindy doing now? Was amputation best for her? Does she regret it? How is her relationship with her grandson? I honestly do not know. I have not spoken with her since her hospitalization years ago. But later, when we admitted a patient with apotemnophilia, a condition in which an able-bodied person wants limb amputation for nonmedical reasons, I did not speak with him. I really wanted to, but I did not. Instead, a student who was working closely with the patient pulled me

aside at multidisciplinary rounds, and we talked at length about the ethical dimensions and our professional responsibilities to a patient who was vulnerable but capable of making his own decisions. I offered to help if she, the patient, or team needed it. I think this informal consultation reflects an improved practice, because I was able to be proactive without unnecessarily interjecting myself into the therapeutic relationship.

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Helping Staff Help a “Hateful” Patient: The Case of TJ

Joy D. Skeel and Kristi S. Williams

“Ted Jacob,” or “TJ,” was a patient who tested the ethical resilience of most of the health professionals who worked with him.¹ He expanded the types of conflicts that can be generated among the principles of nonmaleficence, beneficence, respect for persons, and autonomy.

TJ was 36 years old when KSW, the attending psychiatrist on the Consultation-Liaison (C-L) Psychiatry Service, first saw him. Both authors had heard about TJ from numerous health professionals because of the enormous problems he created on each admission. Ted Jacob, diagnosed with borderline personality disorder (BPD — a personality disorder characterized by intense emotional relationships, frequent crises resulting in suicidal ideation, and impulsive behavior) had been physically and sexually abused by his adoptive mother and ignored by an emotionally unavailable

father. Beginning at age 11, he had numerous psychiatric admissions for attempted suicide and poly-substance abuse. His longest period of sobriety was during a marriage that lasted several years. TJ attended college for three years and majored in psychology. By history, he was bisexual, although his only known homosexual relationship was with his sponsor from Alcoholics Anonymous.

TJ had 10 admissions for intentional drug overdoses and alcohol withdrawal within 12 months. He was first labeled a “hateful patient” when he was admitted to the hospital after telling his out-patient psychiatrist that he had eaten multiple boxes of rat poison with the intention of killing himself — many more admissions due to sequelae of rat poison ingestion would follow. TJ wanted to be on the Psychiatric Unit, not the general medical floor, but previous psychiatric admissions were not therapeutic; that is, admission to a short-term psychiatry unit only provided temporary relief for several problems that resumed once TJ was discharged. During a lengthy admission to stabilize him hematologically (the rat poison was warfarin), TJ wreaked havoc with relationships among the medicine team, but especially between Medicine and C-L Psychiatry.

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The patient infuriated the Medicine team when only intravenous (IV), not oral, vitamin K would bring his prothrombin time closer to normal limits. It became clear that TJ was not swallowing his oral medication but was destroying it after the nurse left, although he denied it. TJ refused to go voluntarily to the county Crisis Stabilization Facility (CSF) until the IV was removed. (The CSF was where all county mental health patients were sent when they had been put on a “pink slip,” that is, involuntary status, for assessment for transfer to an in-patient psychiatric unit in the county, or for discharge, or short-term stabilization and discharge from the CSF.) Despite the anger and turmoil that surrounded him, and in part was generated by him, TJ talked about the hospital as “a safe environment,” versus his apartment, which he described as “a black hole I crawl into at night and can’t come out of until morning.”

The Medicine team was extremely frustrated that Psychiatry did not “fix” the patient, did not accept him on the Psychiatry Unit, nor get TJ permanently discharged. C-L Psychiatry, recognizing the “splitting behavior” that is part of BPD, was frustrated by the behaviors of TJ and the Medicine Service. (Splitting behavior is a coping process in which an individual pits one person against another.) Medical students on the Internal Medicine rotation were so overwhelmed by the patient’s behavior and the resulting discord that they presented him to the weekly ethics conference twice — with the C-L psychiatrist present. Many staff had talked with the clinical ethicist (JDS) about TJ, and a formal ethics consult was requested to try to help the Medicine Service focus on what was best for the patient: that is, respect him as an individual and help him to make “safe” decisions for himself.

The ethicist worked with C-L Psychiatry to help mediate the splitting behaviors among staff, which were unacceptable recorded in TJ’s chart. The behaviors were harmful not only to TJ, but also to relationships between staff, and potentially to the institution legally; this is an example of the frustration portrayed

in TJ’s chart by a member of the Medicine team: “I am still not clear how Psychiatry evaluates a patient for suicidal potential, as every time they say it is OK to send patient home, patient comes back in not more than three days. Is there any way to predict at least one week?” and, “His mood is much improved, believe it or not, since admission.” The potentially harmful notes in TJ’s record were discontinued when the real and potentially negative outcomes of the comments were made clear to all involved.

Members of the staff realized that the dynamics of their interactions with this patient were different from other patients, and that relationships among staff were increasingly strained. Ironically, the relationship between the Psychiatry attending and Internal Medicine (IM) were not as strained as they could have been because the IM attending was a personal friend of KSW (and JDS) — but, at the same time, this relationship increased the pressure to manage TJ’s care effectively, and provide relief for the IM service in dealing with this difficult patient.

Despite the anger and frustration of both Medicine and Psychiatry precipitated by TJ’s behaviors, empathy was rekindled when TJ talked about his loneliness, and how his father never paid attention to him. TJ wondered aloud what it would take to get his father to show he cared. KSW wondered if he would ever find out before he died. The psychiatrist and ethicist worked together with the staff at these times to help them understand how sick and lonely Ted Jacob was, and how badly he needed our care — with carefully set and consistently maintained boundaries.

Trying to respect his right to make decisions for himself was difficult, since we did not know when to trust that he would not harm himself. When given choices about where to go when able to be discharged, he was clear he did not want to leave the hospital; he refused a group home; and refused to sign himself into the CSF voluntarily. When he continued to refuse the available options, he was sent involuntarily to the CSF. He re-

turned to the hospital five days later due to nosebleeds (from the rat poison) and told us that the CSF had released him just 45 minutes after his arrival. The latest admission was more serious because he had ingested cadmium (while denying he had eaten batteries). TJ manipulated the system, not seeming to care whether he lived or died. He appeared to be almost euphoric to be in the hospital, despite complaints of boredom.

The ethicist and the C-L psychiatrist worked with staff individually and in groups to facilitate a healthy ventilation of their anger — especially after a nurse yelled at the C-L psychiatrist about getting TJ, who smoked, off suicide precautions to cut down on her work. (Patients on suicide precautions must be assessed every 15 minutes and must be accompanied by staff to smoke outside.) We made Groves's article, "Taking Care of the Hateful Patient," available to the staff, and worked to identify the negative and positive aspects of labeling.² We also asked staff what they believed they could do to help this man, while recognizing that patients with a diagnosis of BPD have been labeled "the Hemophiliacs of Emotion" in the literature, due to the extraordinary amount of time and energy they consume.³

We all realized TJ harmed himself more dramatically each time he was discharged from the hospital, and we tried to work together, for the most part, to do what we thought would help him, but anything we did was undermined by the patient. The needs of staff and of the patient collided; staff felt they were going in circles. Groves described how "A psychologically naïve medical staff may regress to a helpless or vengeful position in response to the patient's ingratitude, intractability, impulsivity, manipulateness, entitlement and rage."⁴ Groves seemed to be describing how everyone involved with Ted Jacob felt at times.

The authors were not immune from strong feelings about both the patient and the staff. Our feelings covered a wide range, from impotence at not being able to protect the pa-

tient from himself — which we recognized was not always possible — to deep frustration with the system that seemed, at times, to assist TJ in harming himself. We were both amazed and ambivalent about the patient's tenacity; for example, he took massive doses of coumadin (warfarin) when he swallowed the rat traps, he overdosed on thorazine (an antipsychotic), he swallowed batteries, and drank heavily. We didn't dare to guess what he might do next, as he was both "creative" and tenacious. Due to experience, we were also probably more cognizant than most (that is, able to see beyond the "bad" behavior) of TJ's ability to be very pleasant when he was not taunting staff regarding what he had done. We were both frustrated with the notes written in the patient's record by the Internal Medicine residents, but this was particularly disturbing for KSW, as the notes became inappropriately personal toward Psychiatry.

JDS was frustrated at the unprofessional and unethical behavior of many of the staff, including the physicians, who were involved with the patient's care. Unfortunately, staff were noisily angry at each other in open areas of the nursing station, where comments could be overheard by other patients and families. While we recognized that the staff were ventilating their frustration and anger, this was not the appropriate place to do it. When health professionals need to express angry feelings, a secluded place, for example, an empty room, is better than an area where angry words can be overheard. (And this sounds simpler than it is!) There were also times when JDS became caught up in the splitting behaviors and had to step back to regain some balance. While both the psychiatrist and ethicist were glad to see progress in the recognition of splitting behaviors, this progress could vanish quickly when TJ flaunted his destructive behaviors. The phrase "hateful patient" blossomed for JDS in working with TJ and the staff. Working closely with the psychiatrist was helpful and supportive. Working with the staff was difficult and frustrating, but was often therapeutic.

Another issue was the hospital “grapevine,” which raised serious ethical issues about how negative labels are used and the harm they may cause. Fortunately, in this situation, the article we distributed by Groves facilitated discussion of the label of “hateful patient,” and helped to increase the staff’s awareness of the dynamics of TJ’s situation. It was evident that most of the health professionals who worked with TJ felt anger and frustration. Increasing staff’s awareness of how their feelings were expressed, and learning how to deal with them — even on a small scale — seemed to be helpful.

TJ had more admissions to our institution before he was finally committed (to our relief) to the state psychiatric hospital by the CSF, because of his escalating self-destructive behavior. TJ continued his destructive behavior at the state hospital. He placed a plastic bag over his head, but was found before he was harmed; the entire ward was placed on suicide precautions as a consequence, however.

TJ was discharged and re-admitted to medical and psychiatric units several more times both in and out of his hometown. Six months after TJ’s last admission to our hospital, many of us involved in his care were sobered to read his starkly brief obituary in the local newspaper:

Ted Jacob, age 39 years, died suddenly in [large Midwestern city] where he had resided the last 6 months. He was employed as a carpenter and previously as a construction worker. He is survived by his father, wife, and brother. He was preceded in death by his mother. There will be no visitation and interment will be private.⁵

After reading of TJ’s death, a number of us could step back from the chaos he generated and agree that we learned important lessons from him about caring for very difficult patients. He helped us acknowledge that there are times when we will feel powerless because we cannot protect patients from their self-

destructive behaviors. TJ reinforced the authors’ belief in the importance of thoughtful early intervention with healthcare professionals and patients to pre-empt the splitting behaviors generated by patients with BPD, which can irrevocably distort relationships between patients and staff, and among healthcare professionals. While TJ forced us to identify biases and limitations (as mentioned throughout this article) that affect how we care for such challenging patients, TJ also left us with the nagging question of whether there was anything more, any other intervention that was missed, that we could have implemented to save him.

NOTES

1. Ted Jacobs is not the patient’s real name; it was changed to protect the patient’s privacy.
2. J.E. Groves, “Taking Care of the Hateful Patient,” *New England Journal of Medicine* 298 (1978): 883-7.
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5. The obituary was edited to preserve the patient’s family’s privacy.

Misjudging Needs: A Messy Spiral of Complexity

Paul J. Ford

THE CASE

A 60-year-old patient was admitted to the hospital with ischemic brain injury secondary to an unwitnessed cardiopulmonary arrest.¹ The patient had a medical history of end-stage kidney, liver, and heart failure, and needed chronic dialysis three times a week. In the patient's first week of stay in the intensive care unit (ICU) after his arrest, a neurologist informed the patient's family that, based on brain imaging, the patient had no real chance of waking up or regaining any significant cognitive function. Although the patient was not brain dead, the patient would not significantly recover. The family was on the verge of agreeing to withdraw aggressive therapies when the patient began to respond to external stimuli.

Several weeks after the patient's cardiopulmonary arrest, and subsequent to his being

discharged from the ICU to a regular hospital ward, a hospitalist requested a clinical ethics consultation. According to the hospitalist, the family failed to understand the futility of aggressive therapies. The hospitalist believed that the patient sooner or later would die from an infection, if not from his other end-stage organ diseases. At the time of the clinical ethics consultation, the patient had begun to follow basic commands, which the family interpreted as a sign of the patient's overall recovery.

I met with the patient's family along with the medical team. The family only desired a chance to see how much cognition the patient could regain, given that the original neurologist had been wrong about the impossibility of cognitive improvement. The ethics consultant signed off the case once there seemed to be an agreement to give more time to evaluate whether the patient's cognition would improve. Subsequently, the patient was moved between several different hospital units, with each new medical team taking it upon themselves to have the same discussion with the family about futility. (The ethics consultants were not aware of this at the time.) The patient was subsequently discharged to a nurs-

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ing facility after being able to say basic words and recognize family members.

A month after the first ethics consult, the patient was re-admitted to the hospital, but was no longer responsive. Again, bioethics was consulted briefly to facilitate a family meeting. An intensive care physician believed the current treatment regimen was futile. The ethics consultant, a different ethics consultant from the first, recommended that the intensivist have this case reviewed by the ethics committee. Given that our institution runs an individual ethics consultant model with a backup of a small group ethics committee review, it is strongly recommended that the ethics committee be consulted if the attending physician believes it is necessary to withdraw therapies based on futility. The attending physician did not follow this recommendation and continued aggressive therapy. The individual bioethics consultant again signed off the case, since the attending physician chose not to pursue withdrawal of therapy based on futility, and the family was satisfied with the current therapies. The patient subsequently was transferred from intensive care to a regular nursing floor within the hospital.

A month after the second ethics consult, yet another attending from an intensive care unit requested an ethics consultation. The patient's dialysis catheter had stopped functioning properly, and the intensivist believed that placing a new catheter would constitute an inappropriate escalation of therapy. Given the grim prognosis of the patient due to his liver and cardiac disease and the patient's neurological devastation from the arrest, the ICU attending believed it would be against medical practice to escalate treatment.² Neurology again evaluated the patient, and stated, given the patient's comorbidities, that the patient would not regain meaningful cognition. The request for an ethics consultation prompted not only an individual ethics consultation (my return as consultant), but also an ethics committee review, since the intensivist invoked futility as a reason to withdraw treatments.

After a further four weeks of discussion, debate, and posturing, the patient again started following basic commands (such as eye opening.) Two weeks after this cognitive improvement, the patient was discharged to a skilled nursing facility. It was decided by the medical staff that the patient would not benefit from further ICU intervention in the future and that he would not be re-admitted to the ICU. This was discussed with the family, who agreed that the patient would not be returned to the hospital's ICU. Many months later, a family member contacted bioethics and said that the patient had died a couple of weeks after being discharged from our institution. The family accepted this as a sad but expected outcome.

WHAT HAUNTS ME AS A CLINICAL ETHICS CONSULTANT

The above is a very brief description of a case that spanned several months. Many ethics questions arose throughout the case and were resolved, dissipated, or persisted. Ethicists, physicians, ombudsmen, nurses, general counsel, and family members all spent many hours on this case. The case appears generic in many respects, as it centers on the appropriate uses of intensive medical treatments for a patient with multi-organ system failure in the presence of extensive ischemic brain injury. The invocation of futility in cases such as this continue to be widely debated.³ For me, futility of medical treatment is not the central haunting element. The case is most troubling in the interface between the family and the medical institution, as well as in the nonlinear and unpredictable course of this terminal illness. Although the outcome of the patient's illness was inevitable, the path to that inevitability was strewn with false indicators, missteps, and misunderstandings. A messy complexity of circumstances resisted categorization of the case into a single ethics question.⁴ From an ethics consultation *process* point of view, this case raises questions about an ethicist's role, about ethicists inserting

themselves into situations, about the appropriate length of time for continued involvement, and about what counts as a good outcome in ethics consultation. This case haunts me because of these process questions. Our system may, in the end, have functioned as intended, but this case demonstrates elements on which we can improve. A suboptimal outcome of this consultation prompts a reevaluation of the frequent lack of proactive efforts in clinical ethics consultation.⁵ To understand what haunts me about this case, I will first explore the outcome before raising issues of regret and uncertainty in process.

The outcome in this case was that the patient survived to discharge (twice) with some ability to cognitively “be in the world,” that is, to react and respond with some level of intention. At base this was a good, since the patient’s life was extended and the family valued the additional time they had with the patient. However, the case took several months and hundreds of hours of time for institutional employees and family members to resolve. Hospital security was called to deal with several disturbances surrounding pictures and recordings being taken by family. Several family members involved the ombudsman’s office because of frustrations with the medical team. There were threats of court action and considerable negotiation. Although one family member was the legal decision maker, documents in the chart listed another family member as the decision maker. The inconsistent contact practices with family members further confused the situation. The confusion prompted great anxiety and frustration in the family. These were all “bad” outcomes in terms of experiences of participants in the process. The anxiety, animosity, and stress negatively affected all involved parties.

As I ponder the outcome, I do not feel pride that I helped to navigate and resolve a particularly complex case. I feel dread, powerlessness, and frustration because of the excess negative emotions generated by so many individuals over such a long period. In retro-

spect, there must have been better ways to resolve the situation. I fear that, given the current model of consultation, this case could easily repeat itself. Although the process works well in most cases, it fails to be fully effective in some cases, even if an equitable, fair, and just end is achieved.

The ethics consultation process was reactive rather than proactive. The first two consults were in the standard critical response mode that most ethics consultations take, that is, a value conflict had already occurred between parties and the bioethicist was called upon to facilitate resolution of an acute problem. I am haunted by the thought that a careful, consistent follow up of the original consultation could have bettered the overall situation. I could have created a liaison that would have decreased animosity between the health-care team(s) and the family. However, it is not the role of clinical ethicists to be “ethics cops” through close monitoring of all physician activity and to interject themselves into a patient’s case. Unlike institutional review boards (IRBs), which are responsible for monitoring all research projects, clinical ethics consultants become involved either by invitation to a particular case or through regular programmatic participation during patient care activities, such as rounds or patient management meetings. In the end, uninvited interjection can be counterproductive to training physicians in handling the majority of cases themselves and can destroy trust with the medical team. Even though the role and obligation of the ethics consultant changes once he or she is involved in a case, there is still a point at which the ethicist needs to trust professionals to enact the plans that have been put into place. In the current case, the ethics consultant gave guidance to the treating medical team during each consultation, but the medical teams frequently rotated, as they do in large academic medical centers. This reactive nature of ethics consultation follows the model of many medical subspecialty consultations, in which the subspecialist consults

on a single issue, gives recommendations within his or her sphere, and follows the case only as far as the primary service requests.

Given the limited time resources of ethics consultants, it is impractical to follow every ethics question and case until all value conflicts have been resolved. Consultation models are premised on the assumption that healthcare teams and patients are capable moral agents who only need assistance with subtle or complex issues. Cases such as this one seem to have a lack of continuity, which the ethics consultant may or may not be responsible to rectify. If I had followed this case throughout the hospitalization, I would have needed to use the least-intrusive way to preserve the patient's privacy. To access the patient's record without *justifiable cause* would indicate a lack of respect for the patient's privacy. Because I was consulted on this case, I had a right to access the patient's medical information, and I understood that access to be limited to the amount necessary to discover all of the relevant ethics issues, to make recommendations, and to document those recommendations.

To follow up on a case, several levels of access may be justified. One level of inquiry would be to discuss the case with a physician on the primary service. The physician acts as an "information filter" between the raw data (chart information) and the consultant. This is a relatively nonintrusive method when the physician uses good judgment. A second level of inquiry would be to talk with the family (or the patient, if the situation allows). Although this might be more intrusive, it allows the family to control the release of information. Finally, if firsthand knowledge of documented events is important for follow up, the patient's chart could be used, up to the point to which it no longer would be needed to answer the ethics questions. Simple curiosity regarding how a case ends would not justify access to a patient's chart.⁶

To believe that ethics consultations involve only a small, isolated question within the dynamic hospital setting is to misunder-

stand the complex nature of the hospital environment. Except in published cases, issues of values or ethics seldom are well-defined or limited to a single problem that responds to a simple solution. The initial issue addressed in the consult indicated that there might be a number of concerns that would arise as time passed. In retrospect, it seems that it would have been best to aggressively follow up on the case, but this ran the risk of overstepping professional boundaries, as it might have been seen as continued involvement in the case beyond any identifiable ethical concern. I was not asked to be a permanent patient advocate for this patient or to oversee his medical treatment. To fall into the error of believing that an ethics consultant's role is only to be a patient advocate is to forget the consultant's myriad other obligations to institutions, care-providers, and society. There is an obligation to explore all of the relevant ethical questions in a case, to articulate those problems, and to give written recommendations and advice. Although I was charged and obligated to address all identifiable ethical problems in the case, an indefinite involvement would not be appropriate.

I empathized with the family's frustration that each new medical team asked them to come to the hospital (during regular working hours) to have the same discussion about withdrawing therapies because of futility. Each new team believed that the family must not "understand" the situation; otherwise the family would withdraw all therapy. This was despite prior ethics consultation notes placed in the chart detailing the first sets of interactions with the family. Although one team began to enact a plan of action agreed upon by the family and medical staff, the next medical team felt obligated to re-evaluate the situation. This placed a tangible burden on the family when each medical team wanted firsthand knowledge and interaction from family members, particularly during regular working hours.

Finally, this case haunts me from a policy viewpoint. I understand the wish of the fam-

ily to discover how much cognitive improvement the patient could attain before they judged whether the patient's quality of life merited going forward with aggressive therapies. When the patient's course did not exactly follow what the first neurologist had outlined, the family began to doubt all of the medical judgments being made. According to the family, the patient was "stubborn." Because of this, the family interpreted the patient's periodic fluxes between minimal consciousness and unconsciousness as his desire to stay alive. The claim that a catheter occlusion moved the patient's treatments into the "futile" arena reinforced the family's skepticism and distrust.

Although I understood and empathized with the family, I also understood the medical team's position that the patient's life-span was extremely limited by his non-neurological illnesses, and that the medical team could do nothing but prolong the dying process. The ICU beds were full in that particular unit, and ICU physicians are trained to treat patients who have a chance of overcoming acute problems. On these two points, the patient was inappropriate for continued ICU treatment by this set of doctors. Of course, this goes to the question of the purpose of ICUs in general, and of responsible stewardship of resources. In individual cases, we avoid discussing the allocation of resources. However, resources and rationing often loom in conversation, and are indirectly considered. Until there is some consistency in policy or there is a quantifiable shortage of ICU beds in an entire community, it would be inappropriate to consider rationing in the consideration of this case. The well-reasoned and understandable demands of the family made no economical sense for the general healthcare system, but did serve their interests. Everyone on the medical team knew that in the question of how ICU resources should be used was present, in the background, as well as the question of perceived harm being done to the patient by physicians who were trained to return people to

a healthy state. As an ethics consultant, I felt like a cog that continued to turn in a reactive system that, for political and public relations reasons, does not easily change.

My frustration in this case has something to do with the inherent uncertainties in the course of the patient's illness, and this frustration carries over to my current practice. I dread not being able to predict whether a case will become a messy spiral, as this case did, after I "sign-off" on it. There is little way to know when bioethics questions are fully answered for either those with chronic illness or those with terminal illness that progress slowly. Because consultants must rely on others to identify where we are needed, it is inevitable that there will be other cases like this one. It is impossible to follow every case until all possible ethical issues are resolved. I hope that when I am again asked to perform a second bioethics consult, I will be more successful at efficiently addressing the issues. Given the complexity and uncertainty in clinical cases and in the hospital environment, I am skeptical it is possible for these rare but important cases to have uniformly good resolutions. Such cases often come with long histories, medical and social, and complex social/psychological circumstances of families, patients, and medical teams that are unresolvable in the limited time and scope of an ethics consultation.

As I sign-off on complex cases, it is not uncommon for me to envision this patient or one of his family members, and to wonder if I am in the middle of another haunting case. I wonder what the emotional cost might be if the family and medical staff are crushed by the system when the patient's disease process changes unexpectedly but the patient still has an inevitable outcome of death. The system is set up to bring about resolution of complex value disagreements and to protect healthcare workers, patients, and families from unreflective decision making and abuses of power. However, these goals come at significant emotional costs, which should not be underesti-

mated. Looking back, it is simple to see lost opportunities to intervene. However, there were few hints at any particular time that the case was not about to be resolved. This case keeps me questioning whether there is a quick and effective resolution at any step in any complex case. I look for ways out of messy spirals into complexity that may not find resolution.

NOTES

1. Details have been omitted and changed in this case to protect the confidentiality of the patient.

2. This was partially based on nephrology standards that were related to professional standards that surrounded the provision of dialysis. See A. Moss (for the Renal Physicians Association and the American Society of Nephrology Working Group), "Shared Decision Making in Dialysis: A New Clinical Practice Guideline to Assist with Dialysis-Related Ethics Consultations," *The Journal of Clinical Ethics* 12, no. 4 (Winter 2001): 406-14.

3. Council on Ethical and Judicial Affairs, American Medical Association, "Guidelines for the Appropriate Use of Do-Not-Resuscitate Orders," *Journal of the American Medical Association* 265, no. 14 (1991): 1868-71; N.H. Cohen, "Assessing Futility of Medical Interventions — Is It Futile?" *Critical Care Medicine* 31, no. 2 (2003): 646-8; D.B. Hinshaw et al., "When Do We Stop, and How Do We Do It? Medical Futility and Withdrawal of Care," *Journal of the American College of Surgeons* 196, no. 4 (2003): 621-51; J.E. Kurent, "Case Presentation: Medical Decision-Making in Hopeless Situations: The Long-Lost Son," *Journal of Pain and Symptom Management* 25, no. 2 (2003): 191-2.

4. R.M. Zaner, *Ethics and the Clinical Encounter* (Englewood Cliffs, N.J.: Prentice Hall, 1988).

5. R.B. Miller, "Extramural Ethics Consultation: Reflection on the Mediation/Medical Advisory Panel Model and Further Proposal,"

The Journal of Clinical Ethics 13, no. 3 (Fall 2002): 203-15.

6. This becomes a gray area when considering needs for education and quality improvement.

The Sound of Chains: A Tragedy

Jeffrey Spike

THE CASE

This is a case I will never forget. I think it was so clear from the beginning that it involved nothing but misery that no one else on the Ethics Consultation Service wanted to get involved. It fell to me because I was the director of the service. I didn't realize it at the time, but this contributed eventually to the haunting aura of the case: it was one of those few cases that I had no choice but to perform; I couldn't say no. Looking back, each of those cases (there were a few others, but never more than one a year) is especially memorable, as if the forces that put me into those situations and held me there added to the intensity of the experience.

It was an anomalous case from the beginning. The request came from social work, which is not strange in and of itself. Most of

our requests came from a resident or attending physician, but social work was the next most common source of requests.

It was the nature of the request that was unusual, rather than its source: should the mother of a patient be allowed to visit her child? Of course, the question was followed by further details: the child was a shaken baby, and the mother was a suspect in the crime. From my phone conversation, I inferred that many people on the team felt the answer should be "No."

My gut reaction was that a mother should be allowed to visit her child unless we have solid evidence that it will endanger the child. And unfortunately the harm was already done. Furthermore, even if the mother was the one who had harmed the child, it was most likely due to a momentary loss of control — terrible yes, culpable yes, inexcusable yes, but unlikely to happen again, especially when interacting in a controlled and supervised environment.

But I try never to give my first "gut" reaction over the phone. Even when I know it is a well-justified opinion, and a slew of articles

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come to mind that could serve as references for the eventual consult note, I didn't know enough of the individual circumstances to know if the references or paradigms influencing my opinion were truly appropriate to the case.

After talking to the social worker, the situation was more complex and confusing than I first realized: the mother and her boyfriend said they were both home with the baby the evening the baby was injured, and each said that they hadn't done anything to the baby, and neither had the other person. One was the perpetrator, and the other was willing to defend the perpetrator. And they were acting as each other's alibi. They both were most likely lying, but no amount of effort by the police helped to coax either one to confess. Logically, it was an example of the prisoner's dilemma, a well-known paradox that philosophers learn in graduate school. Each person will receive the lightest sentence if they can rely on the other to not confess.¹

As with any consult, I went to see the patient so I could establish my own opinion, rather than basing it on the reports of others. The baby's name was "Angel," a name that only made the story sadder, with its intimation of a spiritual being that lives in a better, less violent world. And, adding to the poignancy, Angel indeed looked peaceful, lying there.² His eyes were closed, and he looked like he was sleeping. He had no marks on him, not a scar, not a bruise, nothing. He had beautiful color and the fat cheeks of a healthy, well-fed baby. In my memory — clearly false — he was smiling.

But Angel was still ventilator-dependent and in a coma after two weeks, and the neurological prognosis was that either the coma would be permanent or the coma would lighten, and Angel would emerge into a persistent vegetative state (PVS). Some neurologists use the phrase "awake but unaware" to describe PVS. Having seen adults in a PVS, I knew that many people would find that an even worse outcome: the baby would remain unaware (according to the best neurological

science), but everyone involved in the baby's care would be plagued by doubts (and even nightmares) about whether the baby was suffering. Most people, when asked, think it would be better not to "wake up" in that case; they consider PVS to be a fate worse than death.

When I went back up to the unit the next day, I realized that my initial intuition about the staff wanting to prevent the mother from seeing her baby was correct. Whatever reticence I heard over the phone from the head social worker I had spoken to was not present in the bedside staff, who were clearly angry. Some of the nurses on the pediatric intensive care unit (PICU) team were very attached to this beautiful little baby, and they were so outraged at the mother that they did not think she should be allowed to visit. It was impossible to tell how much that was to punish the mother and how much it was to protect the baby. But I think the two motivations were inseparably mixed together in the emotional swirl. Those who would even consider it as an option did so only in the hope that it would make the mother confess to what had happened.

Furthermore, as the prognosis began to sink in and be accepted, there was a feeling among many members of the team that the mother should let her baby die in peace, with the loving nursing staff by his side. Perhaps in an effort to protect the baby, the nurses saw themselves playing a maternal role — a kind of maternalism — which may be a relic of the traditional professional role in nursing, much like paternalism in medicine. Preliminary reports from the jail, where the mother was being held, were that she refused to withdraw life-sustaining treatment. That only further angered the staff, who saw this as prolonging Angel's suffering or prolonging his dying, rather than prolonging his life.

Of course there were legal twists that made the whole case seem to have the logic of *Catch-22*. If the mother allowed her baby to die, then the charge would become murder. So, to put it mildly, she did not have any incentive to

make that decision. Even the best of parents have trouble “letting go” of children. But, in this situation, the mother had already lost her child, and any confession would mean that she would go to jail, or her boyfriend would, or both.

If ultimately the mother refused to withdraw life support, then Angel needed to be placed in a long-term care facility for the rest of his life. At the time, there were no long-term care ventilator beds for children in town. Let me clarify; I do not mean that the beds were filled, so none were available, but that there were no beds for that level of care for children in the whole 14-county metropolitan area. The social workers in the hospital knew this, of course, but this was not why they felt it would be better to stop the ventilator. Nor was it primarily an issue of financial cost to society. Had Angel’s mother been someone who would be able and interested in visiting him regularly, I believe they still would have felt it would be somehow cruel or inhuman to keep him alive. My impression is that this is a widely held opinion in the population at large. From what I have heard over the years, I speculate that this option is based on two independent feelings (and I choose that word deliberately): first, there may be some neurological *hubris* in the received view that such patients cannot be aware of anything, and that if the experts might be wrong about this state, then such a life (in what is more akin to the “locked-in” state) would be so terrible that no one would wish to live that way; and, second, whether the patient is aware of it or not, the resulting life is really not a human life, and is so undignified that no one would want their body preserved and treated by strangers in such a way, for a protracted period of time, when there is no hope of recovery.

The staff was still divided on whether the mother should be allowed to visit, the reason for the initial call. The nurses who were willing to let the mother visit also wanted me to be there, with the hope that I could persuade her to stop the life-sustaining treatment, not to increase the severity of the legal charge, but

for the sake of the baby. But what could I say to persuade the mother to withdraw life-sustaining treatment? According to the best neurological knowledge, Angel was not suffering. The people most likely to suffer in cases of patients in a PVS are the caregivers.

I wrote a short note and also explained to the social worker (a very experienced and skilled pediatric social worker) that I felt the mother should be allowed to visit, and that I would be willing to be there at the time, if that’s what the doctor and the staff wanted. This short handwritten note did not provide justifications (that would be saved for the final note, typewritten and researched), but my sense was that even if the mother was responsible for the injury, she no doubt deeply regretted it now, and there was no reason to further punish her by not allowing her to see her child. That it also meant her seeing the consequences of the act could not be a reason to prevent her from seeing the baby; if anything, it would be better for her to make a decision based on a full understanding of the situation and the consequences of the decision.

Once an ethics consultation is called, it is standard procedure for the ethics consultant to join family meetings. There are many reasons for this. First, the family should have a chance to meet and talk with every person involved in the process. Imagine the distrust ethics could engender if it were somehow kept secret or appeared to be “behind the scenes.” Second, it is often the case that the ethics consultant can aid the communication by making explicit some things that the medical experts take for granted but members of the family don’t know. It is not unusual for me to go to a meeting unsure of whether I can add anything valuable, only to find later that I contributed an insight that would have been overlooked, and that afterwards leads people there to thank me for my participation. The lesson is that there is no way to know *a priori* if my presence will be needed, and hence it should be done as a matter of routine process. But I also cautioned the staff that they should not expect me to be able to change the mother’s

mind, although I thought it would be right for someone on the team to discuss the baby's prognosis with the mother when she visited.

In such cases, what I might be able to add is assurance for the parent that the decision to stop life-sustaining medical treatment is among the reasonable options, ethically and legally, and that others have made that choice and had it respected in similar circumstances. But even when that topic is presented fairly to parents who have their baby's best interest at heart, it can be hard for them to know what to do. Many of the clinicians involved in this case, however, hoped that perhaps actually seeing what Angel was going through would make his mother more willing to make the ethically best decision and "let go."

I never should be the one to describe the prognosis. I am always careful to tell patients that I am a PhD and not an MD, and that I am not there to give them any medical information or advice. But I may be able to clarify some things for them, and even when I cannot answer their questions, I may be able to help them ask the right questions of their doctors. In this case, as I typically do, I had spoken to the attending by phone to make sure I understood all of the essential clinical information in advance. He assured me that the injury was devastating and irreversible. I told him that I would be at the meeting being planned for a few days hence. I assumed that he would be at the meeting as well. When I arrived, the meeting seemed already to have begun. A nurse, the social worker, the mother, and two police escorts were crowded into the small room, and all spoke in hushed whispers. But I was surprised as I looked around the still room: there was no doctor in the group. The mother was by Angel's bedside, with the nurse on one side of her and one of the police on the other.

The mother was dressed in the orange jumpsuit of the local prison. I had not thought about what she would look like, and the prison uniform surprised me. However, much more disturbing was that she was in chains. One

heavy chain connected to metal bands around her ankles, presumably so she could not run. A second heavy chain connected to metal bands around her wrists. And a third connected the two chains together, so she couldn't raise her arms much above her waist. Indeed, either due to their short length, or their weight, or the weight of her guilt, she could barely move. A slow shuffle was all I ever saw, and whenever she moved there was a sound of heavy chains.

I at first felt like an intruder because everyone was standing up, close together, and facing the bed. But when I introduced myself, I quickly sensed that everyone there had been waiting for me. The mother had tears in her eyes, and was talking to her baby. At that moment, my feeling was just of overwhelming tragedy, not anger.

The baby's mother mumbled something so quietly I couldn't hear her. But there seemed to be some discussion of what she had said, and then the social worker turned to me as if to ask what I thought. I had to ask what she had said, and the social worker explained to me that the mother wanted to hold her baby. I didn't think this was a bioethical issue, yet I often have admonished other ethics consultants not to avoid difficult issues by saying it wasn't a bioethical issue. All too often an issue can be seen in different ways, and will only be handled fairly if everyone is willing to acknowledge that they have a legitimate role in helping to resolve it. Otherwise too much authority will settle into the hands of one person who is willing to take control. Ethicists are there to help balance the equation, if nothing else. And to deny this woman her request seemed punitive, all the more so because there was no way to know if she would ever see her baby again. So I spoke up, and said I thought she should be allowed to hold her baby, even though (I added) I didn't really think that decision was mine to make.

To my surprise, after some whispers between the two police guards, one took out a key and unlocked the prisoner's handcuffs. The social worker helped pick up Angel and

put him in his mother's arms, and she sat down in the rocking chair that is in every PICU room and held him. She talked to him, and no doubt hoped for some kind of a response. But she got none. There was still no doctor there, and it only then gradually began to dawn on me that nobody was waiting for a doctor to show up. The meeting had begun, those there had been waiting for me to show up, and now this was "my meeting" to run.

I was becoming more aware of the continual sense of surprise this case presented, as it did not follow the usual rules. I felt that I had been unexpectedly conferred with more of the role of an agent in the drama and less of an adjudicator than I typically assume, and this too contributed to the haunting quality that the case has, in retrospect. No one had ever suggested to me that this would be my meeting to run, or, if they had, it was in language so polite and veiled that I had missed it entirely. While I had run meetings before, it was more common for me to attend meetings that were run by either a social worker or an attending. And I most certainly never ran a meeting that in effect was both the first and last chance to discuss a grim prognosis, as it is called in the medical world.

I had to think on my feet, carefully choosing each word that needed to be said almost simultaneously with saying them, internally deliberating so as not to exceed the limits of what I was capable of saying. I wanted to be accurate, and not coerce the mother into a decision, but I also did not want to pull any punches. This was not a case in which there would be other chances to have the information sink in, or for her to return with more questions. By now nearly a month had passed since the injury, and not a single note in the chart indicated any hope of meaningful recovery. I told her that, and explained just what the alternatives were: stop the ventilator and let Angel die in his sleep, or continue his life indefinitely in a nursing home once one could be found that would take a baby. I told her that while the decision was hers to make at that point, many people, including many of

the people at the hospital who were taking care of her baby, felt that the kindest and most respectful thing to do would be to let Angel die in peace. I added that I had known other parents that had made that choice, and no one condemned them for it; in fact, they had received understanding and empathy for their difficult decision. But, I also admitted, I had known other parents who chose to not stop life-sustaining treatment, and although their babies never improved, were never able to walk or talk or even to sit up or respond to their mother's voice, no one could condemn the parents for that decision either.

She listened to me but said nothing. After what felt like too short a time, the guards indicated that her time was up. She placed Angel back in his bed and thanked me, and said she needed time to think about the alternatives. That was the last time I saw her.

CONCLUSIONS

As expected, Angel's mother did not choose to stop his life support. In this story, the mysteries were never solved. I don't think we will ever know who committed this horrible crime, and I think that contributes to its unforgettable quality.

Many people who hear of this case wonder why the mother was even considered a valid surrogate decision maker for her child. And there are things that many people would say only in private: paying for this level of care for years or even decades is a terrible strain on society. In a country where paying taxes is often resented, and good institutions are subject to continual cutbacks, many people who can gain a lot from small services will suffer due to a single costly case like this one. One often senses that people who call for an ethics consult are expecting miracles: to rectify all the injustice, or at least to call to task all of the people who created it. These unanswered questions and unspoken doubts contributed to the palpable sense of anger toward the mother and dissatisfaction toward the ethics consult that I felt from the many good and

well-meaning people who were involved in this case.

There are other cases that haunt me. But as I sort them out, I see that most of them haunt me because of a lack of support or even opposition from sources that one would have hoped to be allies of clinical ethics. But that is more disillusionment with one's department of health, or attorney general, or hospital counsel. It is not caused by the case *per se*, which could have been handled more humanely, had only others listened to good advice and put the patient's interests ahead of their own legal fears, financial interests, personal needs, political agenda, or religious beliefs. But more haunting is this case of Angel, which nothing could have helped to improve. Some might want to call this a sense of futility, but that word is overused in bioethics, with far too many different meanings. It is not the futility of the treatment that is haunting, if indeed that term is appropriately applied here.³

Instead of futility, I prefer to consider this case to be an example of the true meaning of a tragedy. In many of my other cases, I knew there was no good alternative, but there was a "least worst" choice, and it was my place to explain or even occasionally try to persuade everyone that that choice was the best of the alternatives open to us, even if it was not a happy decision to have to make.⁴ But in Angel's case, there was no consolation and no redemption to be found for anyone.

NOTES

1. For example, see the discussion in R.M. Sainsbury, "The Prisoner's Dilemma," in *Paradoxes*, 2nd ed. (Cambridge, U.K.: Cambridge University Press, 1995), 66-71; or N. Rescher, *Paradoxes: Their Roots, Range, and Resolution* (Peru, Ill.: Open Court Press, 2001).

2. I have used the baby's real name because this case was public, not just from being in the court system but also reported in the newspaper. And his name adds to the poignancy and haunting quality of the case.

3. On the topic of futility, I have often surmised that futility is in the eyes of the beholder. Continuing life-sustaining medical treatment might keep Angel alive for decades, especially if he emerged to a PVS and was no longer ventilator dependent. See "Persistent Vegetative State," in *The Encyclopedia of Science, Technology, and Ethics* (New York: MacMillan Press, 2005).

4. A good example of the consultant and persuasion is a case of a patient with a recent traumatic injury who refuses treatment. I do not believe coercion should be allowed, but do think some degree of time to consider the alternatives might be imposed, while one satisfies one's own concerns that the patient's decision is fully informed. See J. Spike, "Controlled NHDP for a Fully Conscious Person: When Death Is Intended as an End in Itself and It Has Its Own End," *The Journal of Clinical Ethics* 11, no. 1 (Spring 2000): 73-7; and J. Spike, "Author's Response: The Limits of Persuasion," *The Journal of Clinical Ethics* 11, no. 1 (Spring 2000): 92-3.

“But How *Can* We Choose?”

Richard M. Zaner

I had been at Vanderbilt only a short time when I was asked by one of the physicians in the Maternal-Fetal Unit to consult on what was said to be an “abortion” problem — a consult that has stayed with me for many years.¹ A 22-year-old married woman, I was told, a Mrs. Judy Nelson, had been referred by her own obstetrician (OB) for evaluation and management of her first pregnancy, which was thought to be problematic because of an ultrasound (US), although the obstetrician was unsure precisely how to read the several USs she had performed. Mrs. Nelson’s pregnancy was thought to be about 22 ± 2 weeks gestational age.

Physicians and specialists in our Maternal-Fetal Unit confirmed the estimated fetal age. They also noted a myelomeningocele, however, along with possible ventricular dilatation — “spina bifida” with patent spinal lesion and protrusion. Presumably, Mrs.

Nelson’s OB had actually seen something, enough to refer her to our unit, although uncertainty made her reluctant to tell her patient very much.

Informed of these results, the woman was also told that the radiologists couldn’t be “completely certain” of many aspects of that diagnosis; for greater accuracy, serial USs — several taken over a week or so — would be needed to determine whether, beyond the spinal protrusion, the apparent hydrocephalus was growing worse with time.

In any event and in light of their diagnosis, Mrs. Nelson was told, by the maternal-fetal specialist who had taken on her case, that she faced several options. On the one hand, she could “continue with the pregnancy,” but that, if developing hydrocephalus were to become clear, there was a “real chance” that she would likely have to undergo a c-section. When she asked why that might happen, she was told that the fetal head size might preclude vaginal delivery.

Clearly stunned by this news, she was immediately informed that there was another option: “abortion,” described as a “therapeutic option.”

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“What do you mean, ‘abortion?’” she demanded.

A bit taken aback by her tone and demeanor, the physician — he told me how he felt, later when he asked for the consult — tried to point out, “Well, you see, if what is described as. . . .”

“‘Described as?’ what in the world does *that* mean?”

“Well, you see, if you’ll just give me a chance to say it, . . .” As he said to me, he was at once confused by her insistent questions, and beginning to get a bit nervous over what she was really trying to say to him. It seemed pretty evident to him, he told me, that she was already quite upset, and she seemed to be getting ever more angry.

“So, say it, then: what is this all about? I mean, there I was, all happy and warm and, my baby on the way, and then I’m told to just come here and see what’s going on, and I don’t know what that’s all about. . . .”

“What it’s all about is that our ultrasound techs have seen what they believe is spina bifida, and I understand that they talked with you about what that is, what it means, and so on.”

“Sure,” she said, “they talked about that, and they mentioned that other thing, that hydro thing. . . .”

“Hydrocephalus.”

“Right, that, and, well, then, you come along and talk about ‘described as,’ and ‘there’s a chance,’ and then talk about abortion. . . .”

As the physician continued on, more carefully, more gently, so he told me, to tell her about why there may be a need to abort, and that the gestational age of her fetus was rapidly approaching the “cut-off” date, she only grew more and more agitated. As he saw it, he told me, when he pointed out that “state law prohibits abortions after 24-weeks gestation” — without, he added, a documented threat to her own life — she just “exploded.”

“What exactly made you think she was ‘exploding?’” I asked when we first discussed the consult.

“I don’t know what else you’d call it,” he explained. “I mean, she grew red in the face, her voice escalated way up the scale, and she, well, she just exploded — no other word for it.”

She was of course rapidly approaching that cut-off date; in fact, if serial ultrasounds were performed, she might well go beyond the date before “developing hydrocephalus” could be confirmed or disconfirmed. It was, I should add, at just this point that the physician had backed off from what he took to be “real anger” at him, telling her that he would get “someone” to talk with her. So, there she sat, by herself in the so-called “quiet room,” waiting for “someone” to explain everything — hopefully, it was clear to me, also to help her calm down.

One other thing was mentioned just as I was about to take off to see her.

“I also pointed out,” he said, “that an alpha-fetoprotein test might be helpful, with results known within a day or so — still well within the time left before the cut-off date.”

“Was it done?”

“Well, sure, of course, we had to do it, you know?”

“So, okay, then, but what results?”

“Don’t know yet, but they should be back today sometime.”

The test had been done, and she was at this moment awaiting both me and the results. So I had to be sure not to get ahead of the tests, but still, I had to begin to address what needed attention.

In fact, when I got to her room, someone, a nurse as I recall, was already there, and she and Mrs. Nelson were already talking about the alpha-fetoprotein (AFP) test results. I waited in the hall for a few moments, until the nurse came out. The nurse saw me and told me that she had informed Mrs. Nelson that the AFP was positive for a neural-tube defect. She also pointed out that she made a point of telling Mrs. Nelson that results from these tests were not 100 percent certain. Indeed, the nurse had emphasized that test results show a “statistically significant” num-

ber of false positives (as well as false negatives).

"You know, she is really upset, that Mrs. Nelson," the nurse told me.

"What do you mean?"

"I mean she is upset; I'm not even sure she understood what I told her."

So, I stepped into her room, noted her husband was also there, and introduced myself to them. I was met with both glares and tears. Clearly agitated, they nevertheless seemed quite willing to talk with me.

"Anything," she said straight off, "anything that can help clear up this mess."

"Mess?"

"I don't know what else you'd call it," she said. "I mean, what is this, can't anybody be straight about this? I thought that coming here and seeing all these specialists, so-called, I'd get some answers. But all I get is 'maybe this' and 'maybe that,' and 'perhaps,' and, my lord, nothing straight, all these dodges, all this 'we're not sure' and. . . ."

"Whoa," I broke in. "Maybe, Mr. and Mrs. Nelson, we'd better try and see what's been going on, what you've been told, why you're so angry."

Talking with the couple, I noted she was obviously agitated, anxious, and angry, as was he, although not as much. But not at the doctor. I first told them that my role was to help them to think carefully about their situation in light of their own beliefs, and for that I had to listen to what they had to say.

They obviously understood matters quite well. They knew, for instance, that if the pregnancy continued, and hydrocephalus were severe, there was a "good chance" that labor might have to be induced before full term, probably by cesarean section (because of fetal head size), with neonatal care thereafter: shunting the hydrocephalus, surgery to close the spinal lesion, ventilator assistance, et cetera.

"You rarely find such clarity or intelligence," I thought to myself. Still, there was something else bothering them. She asked, "How in the world can we decide what to do?"

The doctor just doesn't understand what it's like for us. It's not that we are opposed to abortion, but what if the tests are wrong, and there is nothing wrong with our baby? But if the tests are right, and we don't abort, that's not right, either; it's just not right to bring a baby into the world with all that going against it! Put yourself in our shoes: we know we've got to decide, but it's just not fair to ask this when things are not clear!"

The "problem" was clearly not "abortion," for them or for the physician. As evident as it was compelling, the issue posed a harsh dilemma for them. Any decision they could make would be irreversible (even not deciding would soon be set in stone, with the 24-week date coming up so soon), yet could only be based on information that was at once uncertain and not a little confusing.

"How," Mr. Nelson blurted out, "can anybody be asked to make such a decision when the tests could be wrong?"

His wife asked, "But how can we decide to continue with the pregnancy if the tests are right? I know they're only trying to do their best," she continued plaintively, "but the way they talk, we don't know what to think. Once we've decided, we can't 'undecide,' and the basis for it is just not certain enough for that kind of decision. For that, you ought to be able to be more certain!"

My observation, given as gently and sincerely as I could, went something like this: "Isn't moral life like that? Most often very critical matters have to be decided when we're not entirely sure either of the basis or the consequences." My opening remark was received, I must say, with understanding, but anguish as well. We also probed the options if the pregnancy were continued and the baby did have patent spina bifida, as well as the other possibilities if it did not, or if the spinal lesion were minor (an almost normal baby). The important thing was for them to be very clear that they really had thought about each of the possibilities as thoroughly as they could at this time, so that in the aftermath of no matter what decision they made, they would be less likely

to berate themselves with thoughts of “if only we had . . .” — that is, experience subsequent guilt, anger, and resentment.

“You mean,” Mrs. Nelson responded, “that all we can do is just decide, even if it turns out we’re wrong?”

“No,” I said, “perhaps it means that you have to try and figure out just what they’re telling you about the US and the AFP test: they said there is a ‘statistically significant chance’ that the AFP was a ‘false positive,’ and that the radiologists were ‘75 percent confident’ of their interpretation.”

“But what does all that mean?” Mr. Nelson asked.

“Well,” I responded, “if ‘statistically significant’ is translated, it means something like, oh, maybe 3 to 5 percent.”

“What?” she broke in, “doesn’t that mean that there is a 95 percent to 97 percent chance the test is *right*?”

“Not only that,” I responded. “The radiologists think their reading is very likely correct — three out of four chances. Put that together with the AFP test: both are more likely correct than not.”

I have obviously shortened the actual conversation. I should mention, too, that an equally key part of this consult focused on the physicians (and nurses). It was important, after all, to stress how the couple had interpreted the statistical formulation of uncertainty, and to be very clear about the basic moral issue they faced.

This situation involved a relationship among different persons, each with their own experiences and interpretations. The sense of that relationship became apparent contextually. Although textured by their different feelings and thoughts, each of the individuals felt caught up in a kind of perilous adventure. Their respective involvements had the sense of uncertain and forbidding paths and eventualities, of a troubling trial or test. To listen to the wife’s words, for instance, was to be immediately alerted to hazards faced by her baby and by them; alerted as well to their sense of alarming inability to know what to do. Im-

PLICIT in the equally passionate words of the doctor about their “anger” was also an alert — “Watch out when you’re dealing with this couple, for they are given to anger” — and a clear warning that, since abortion was the presumed “problem,” one needed to be on guard for the well-known controversies that abortion always provokes.

Mr. and Mrs. Nelson’s various conversational and physiognomic expressions were thus marked at the outset with harbingers of possible pitfalls and precarious risks. But there was more to it. Their poignant plea for help in understanding things and reaching a decision, for instance, made their sense of vulnerability quite prominent. Though *they* had to make the decision, they yet had to trust *others* — the doctor and the radiologists — for vital information without which no right, good, or just decision could be made. The doctor, on the other hand, was both cautious yet impatient — which may account for the Nelson’s sense that he was trying to “push” them to abortion. Yet he was confident that the diagnosis was correct, and he was in fact somewhat disturbed that things were not immediately obvious to the couple.

That peculiar mixture of caution and impatience was, doubtless, communicated to the couple. It certainly became a permanent part of my own understanding of the complications implicit to clinical life. Too, it may well have been responsible for their reactions, which were seen by the doctor as “anger” toward him, and even for their sense that “the doctor just doesn’t understand what it’s like for us.” This relationship thus turns out to be fundamental to apprehending the moral dimension of such encounters.

Of course, something inevitably falls out of this for any clinical ethics consultation. What Arthur Frank says, rightly I think, about illness narratives, or what he terms “telling-illness,” is also true for those of us who tell stories, not about our own illness, but about those suffered by others.² To undergo illness is to undergo an uprooting of the natural attitude — that quiet, unquestioning acceptance

of “things as they are,” which Schutz insisted is fundamental to social life.³ In Frank’s compelling words: “The loss of the taken-for-granted world — being wrenched out of the natural attitude and facing the fundamental anxiety of death — induces panic, in the mythic sense of unexpectedly encountering the terrifying god who screams in despair.”⁴

The issue of every consultation, I am led to conclude, is extraordinary caution, for what illness always bodes — more in its serious forms, of course — is the shattering of the ill persons’ world. It is also an appeal to others, the consultant in particular, to help in re-moralizing, in normalizing, what has been shattered. And this — I think Frank is right — means understanding, listening to those who are sick as they talk their way in and through their circumstances, thus recognizing the need to help “create conditions for [stories] to occur.”⁵

Like many clinical encounters, this situation was remarkable for the range of passionate feelings (wishes, aims, hopes, et cetera.) that were variously expressed by the main characters. These feelings reveal remarkable significance. In the first place, the feelings that were manifested were evoked strictly by the fetus’s condition (and to a lesser degree, the parents’), were directed to the fetus as “now presented,” and were aimed at the range of possible future prospects (as efforts to “do something” for the fetus and the parents). In this complex sense, the feelings were *oriented* expressions of moral concern: efforts to do the right thing, to be good people, and to act fairly as regards everyone concerned. They were efforts to be responsive to the present (the now-presented and -diagnosed fetus) and responsible for the future (the fetus and themselves as parents, whether the aftermath was an abortion or an impaired infant).

In the second place, Mrs. Nelson at one point exclaimed: “The doctor just doesn’t understand what it’s like for us!” In almost the same breath, she seemed to plead with me: “Put yourself in our shoes: is it right to force a baby to be a hero just to stay alive . . . ?” Which

was also meant for the doctor, of course: to understand “what it’s like for us,” he and I needed to put ourselves in the Nelson’s shoes.

Not to belabor the obvious, Mrs. Nelson was urgently asking the doctor at once *to understand* and, more importantly, *to be understanding*. I’ll never forget this sense as they conveyed it to me; how powerful it was, how heart rending, how difficult it was for them to face the irreversibility of what they knew was necessary yet could hardly, if ever, be justified. Is an ethics that truly takes account of uncertainty possible? Can it be anything else?

For that matter, and more personally, I was left with a strong sense of my own vulnerability in the face of such uncertainty. I know I’ve often used the words, thinking I knew what they really meant: we’ve got to have an ethics that is responsive to the realities of genuine uncertainty, vagueness, not knowing what seems necessary in order to decide, much less to act. But do I understand? I know that the Nelsons brought home a sense that, in truth, I probably didn’t understand, even while I know, too, that they were grateful for this chance to talk, to open up, to share their own vulnerability. And so, I’m left with this — what shall I call it? — this sense of my own not knowing, not really, just what is best, for them, or for me.

NOTES

1. All characteristics that might identify any person, except myself, in this narrative have been altered to protect privacy.

2. A. Frank, “Experiencing Illness through Storytelling,” in *Handbook of Phenomenology and Medicine*, ed. S.K. Toombs (Dordrecht, the Netherlands: Kluwer, 2001), 241.

3. A. Schutz, “Symbol, Reality and Society,” in *Alfred Schutz: Collected Papers I*, ed. M. Natanson (the Hague, the Netherlands: Martinus Nijhoff, 1971), 287-356.

4. See note 2 above.

5. *Ibid.*, 243.

Clinical Practice

Ethics First Aid: Reframing the Role of “Principlism” in Clinical Ethics Education and Practice

Daryl Pullman

INTRODUCTION

Just over a decade ago the eminent physician-ethicist Edmund Pellegrino published a short article in which he recounted briefly the history of medical ethics.¹ His primary focus was on recent developments, with a particular emphasis on the role of “principlism.” Principlism is the term that identifies the “four principles” approach to bioethical decision making (autonomy, beneficence, nonmaleficence, and justice) as it has been formulated and popularized in succeeding editions of Beauchamp’s and Childress’s widely read and highly popular *Principles of Biomedical Ethics*.² The four principles approach came to dominate bioethics throughout the 1980s. But by the time Pellegrino penned his article in 1993, principlism was under attack.³ Hence, Pellegrino dubbed the time in which he was writing the “period of anti-principlism,” and

suggested that medical ethics was about to enter a “period of crisis.” He wondered what direction medical ethics would take in succeeding years, as principlism appeared to be on the wane and absent any alternative unifying philosophy that would serve to underpin this nascent discipline. “It is clear,” stated Pellegrino, “that principlism in its present form is unlikely to survive unscathed through the next decade.”⁴

It is now more than a decade since Pellegrino anticipated the demise (or at least, the radical transformation) of principlism. In the intervening years, Beauchamp and Childress have published a fourth and then a fifth edition of their text, and have expanded the theoretical discussion in each subsequent edition in response to their critics. In this respect, it is true that principlism did not survive the decade unscathed. But although philosophers continue to debate the merits of principlism as a model for methodological case resolution in bioethics,⁵ and while Beauchamp and Childress and their defenders have continued to respond,⁶ this debate has been largely unnoticed by those who make ethical decisions at the bedside. For the most part, clinicians con-

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tinue to rely extensively on the four principles as a ready means by which to assess and address ethical problems, and they appear to be largely ignorant of or unconcerned by theoretical and methodological squabbles. On the front lines of clinical ethical decision making, principlism appears to have changed little in the intervening decade, as it continues to play a dominant role.

The purpose of the present article is not to review yet again the supposed merits and demerits of principlism. Rather, the intent is to assess some of the reasons for its resilience within clinical medicine despite ongoing theoretical and practical challenges. For while the debate regarding principlism has transpired in some of the mainstream journals in biomedical ethics, for the most part this debate has been ignored or has gone otherwise unnoticed by bedside clinical decision makers. This is not to say that the continuing debate about principlism is irrelevant to clinical bioethics. It is just that there are certain features of the form that principlism has taken from its inception that could guarantee its central role in clinical bioethics well into the future, irrespective of ongoing theoretical and methodological challenges. Thus it is important that those who invoke “the four principles,” both in the teaching and the practice of clinical bioethics, have some understanding of the appropriate role and function of principlism at the bedside.

The discussion to follow begins with a brief review of some reasons why principlism has assumed a central and dominant role in clinical bioethics. For the most part, the reasons canvassed have more to do with the form that principlism has taken, rather than with the content of the principles themselves. Put otherwise, there are certain structural and contextual features of the teaching and practice of clinical bioethics that make principlism an especially attractive approach to clinical ethical assessment and decision making. Given this reality, it is argued that the proper role of principlism in the teaching and application of clinical ethics should be that of a

preliminary assessment tool. That is, the four principles provide a ready means to assess some key ethical features of a given clinical situation. However, applying the four principles should not be confused with providing rigorous ethical analysis of an issue. Rather, invoking the four principles in clinical ethics training and bedside consultation should be understood as akin to providing ethics first aid.

THE RISE AND ENDURANCE OF PRINCIPLISM

The metamorphosis of bioethics to which Pellegrino alludes has been detailed admirably in Albert Jonsen’s *The Birth of Bioethics*.⁷ Jonsen recounts how rapid advances in medical technology throughout the 1960s and 1970s provided opportunities for philosophers and theologians who had long worked in the field of ethical theory to apply those theories to emerging ethical problems. However, these new opportunities presented additional theoretical and practical challenges. On the theoretical front, it was thought important for the emerging discipline of medical ethics to identify and describe a unifying theory. For practical purposes, it was necessary that philosophers be less arcane in their language and that theologians be less sectarian in their discussions if they hoped to affect physicians and researchers working in the field.

In many respects, attempts to address these twin challenges have worked at cross-purposes. That is, while theoretical debates have been ongoing throughout the life of the still relatively young discipline of medical ethics, attempts to refine the discussion have tended to drift increasingly toward the esoteric. Nowhere is this more evident than in the ongoing debate about the relative theoretical and practical merits of principlism itself. As a case in point, an article published in 2002 in defense of principlism purports to repudiate a widespread deductivist misinterpretation and to develop the fundamental meta-

ethical disagreement by outlining the deductivistic critique of principlism, and then restructuring the dispute between casuistry, deductivism, and principlism. This leads to the conclusion that “principlism is the most attractive position, if the perceptual model of weak intuitionism is made more explicit.”⁸ The point here is not to trivialize or otherwise dismiss what is undoubtedly an important theoretical and methodological debate, but to illustrate that those who engage in such discussions often speak a language that fails to resonate with those in clinical practice.

The genius of Beauchamp and Childress is that they managed early on to distill the central elements of some long-standing theoretical debates in moral philosophy down to four fundamental ethical principles. This is at least a partial explanation for the continuing popularity of their approach. Not only are the four principles easy to comprehend, but the emphasis on the principle of autonomy in particular resonated well with a general cultural movement toward greater individual freedom and with the concomitant distrust of authority that was so prominent in the post-Vietnam era. At the same time, beneficence and nonmaleficence comport well with the long-standing Hippocratic tradition in medicine. The principle of justice, in turn, speaks to the need to balance competing interests in the increasingly complex domain in which bioethical decisions must be made.

It is the very complexity of the field of bioethics, however, that has motivated some to resist what was perceived as oversimplification and reductionism on the part of Beauchamp and Childress. The criticisms of their detractors have not fallen on deaf ears. Although they continue to insist that the principles they present are not intended as a general moral theory,⁹ in each subsequent edition of *Principles of Biomedical Ethics* Beauchamp and Childress have expanded their discussion to address some of the ongoing theoretical and methodological challenges, and to include other elements of moral discourse as well. The most recent edition, for example, includes a

chapter on moral character, as well as extensive discussions of alternative moral theories, method, and moral justification.

The amendments Beauchamp and Childress have made to their model over the years have helped to clarify their position regarding the theoretical status of principlism, and have made their presentation more complete. But while such amendments may address some of the concerns of the more theoretically inclined, much of this discussion is wasted on clinicians who are charged with making ethical decisions at the bedside, and perhaps even, to some degree, for those whose task it is to educate clinicians regarding various approaches to ethical decision making. This is not because these amendments are irrelevant to clinicians and educators. Rather, the context in which clinicians are educated and practice is just not conducive to deep philosophical reflection and protracted discussion about theoretical completeness and methodological rigor. Indeed, the theoretical and methodological issues regarding principlism that have been raised over the years have never been much of a concern to bedside ethical decision makers, simply because those on the front line have neither the time nor the requisite background knowledge and training to engage in those debates.

The vast majority of medical students come to the study of medicine with little or no background or training in philosophical ethics. Their pre-clerkship years are dominated by courses in physiology, biochemistry, anatomy, and the like. Such courses are extremely demanding and consume a considerable amount of a student's time and effort. Students are often introduced to medical ethics at this early stage in their medical training. However, the students' lack of background and experience, coupled with the time constraints imposed by an overcrowded curriculum, result in limited time for instruction in the finer points of moral theory and ethical decision making.

Similar pressures are felt by those who are charged with the teaching of ethics to medi-

cal undergraduates. Limited class time makes it all but impossible to develop the theoretical models that are necessary to properly evaluate the relative strengths and weaknesses of various approaches to ethical decision making, let alone the complexities of the clinical cases encountered. Furthermore, the context of most undergraduate medical education is one in which a tremendous amount of information is dispensed in a relatively short period of time. Students are expected to assimilate this information quickly. There are few opportunities to reflect on broader conceptual themes, and relatively little patience for doing so. In an overcrowded curriculum in which mnemonic devices for committing vast quantities of information to memory are the norm, four principles for ethical decision making are especially attractive. However, unlike the majority of other courses to which medical undergraduates are exposed, ethics requires nuanced reflection with an understanding that, in most situations, there are better and worse responses, rather than right and wrong answers that can be tested on multiple-choice exams.

Principlism provides a quick introduction to ethics for the busy medical undergraduate and a ready compromise for the ethics educator. Faced with the continuing challenge to provide some useful tools to prospective practitioners that will assist them in navigating the complex moral terrain they are about to enter, the ethics educator can fall back on principlism. Not only do the four principles speak to a variety of key ethical considerations that surface in many clinical situations, but their origin in two of the long-standing ethical traditions (deontology and consequentialism) provides an opportunity for the instructor to make at least a passing reference to such theoretical considerations. Although it may be optimistic to believe that the majority of medical practitioners who have been educated in the West over the past two decades could recall the theoretical origins of principlism, it is probably not unreasonable to suggest that

most have a degree of familiarity with the four principles themselves.

The foregoing explains, to some extent, the reasons for principlism's ascendancy in clinical ethics education and practice, and for its continuing dominant role despite ongoing theoretical and methodological challenges. The short of it is that, given the context of medical education and practice, principlism works. It provides a quick and ready reference tool for medical practitioners and enables them to identify a number of key ethical considerations in a variety of clinical contexts.

For the reasons outlined above, we should expect that principlism will remain popular with frontline clinicians into the foreseeable future. In this respect, the period of crisis that Pellegrino anticipated a decade ago has never materialized on the front lines of clinical ethics. Indeed, it seems unlikely to materialize at this level anytime soon. We should anticipate a sixth and perhaps even a seventh edition of Beauchamp's and Childress's highly popular and useful text, and, given previous experience, we should expect that each subsequent edition will be an improvement. However, barring substantial structural changes in the manner in which medical students are recruited and educated, we should not expect that any additional theoretical and methodological fine tuning in which the authors might engage will have much direct impact on the front lines of clinical bioethics.

ETHICS FIRST AID

What principlism does not do, and what Beauchamp and Childress never intended it to do, is to provide a comprehensive understanding of moral complexity. While this latter observation may strike many as so obvious as to be trivial, it is important to emphasize the point. In the past two decades the medical literature has been littered with articles that purport to offer ethical analyses of any number of complex situations. Often such analysis consists simply of reciting the four

principles and providing a superficial application (often of the principle of autonomy) before moving on to other things. Based on personal observation and discussion with other clinical ethicists, I can attest that it is not uncommon to find that a similar level of ethical assessment occurs in complex clinical situations. Given principlism's anticipated continuing popularity, coupled with the constraints upon ethics education that can also be anticipated to continue for the foreseeable future, it is important that clinicians have a proper understanding of principlism's role in medical education and practice. To that end, it is suggested that, in the clinical context at least, principlism should be framed as an exercise in "ethics first aid."

I financed my post-secondary education 20 years ago by working as a subcontractor on reforestation projects in British Columbia and Alberta, Canada. Each summer I would take crews of 10 to 20 fellow students into remote northern regions where we would live and work for weeks on end. Generally the only access to a planting site was by off-road vehicle, and on occasion we were transported by helicopter. In most cases, the closest medical attention was several hours away over rugged logging roads. Labor regulations required that there be a qualified first aid attendant on site, so each year either I or one of my coworkers would complete an intense, two-week training course to earn an industrial first aid ticket.

Fortunately, over several years of tree planting, my first aid expertise was required mainly to attend to minor scrapes, bruises, and blisters, and the occasional twisted ankle. There was only one relatively serious incident when a planter fell while climbing over some fallen trees. He hit his head and lost consciousness temporarily and was impaled on a broken branch in the process. My first aid intervention required field dressing his wound and then monitoring the patient while he was in transit to a medical facility. As we made the three-hour drive, I checked his vital signs regularly. However, while I was fully aware that,

should I detect a problem in any area, I was pretty well at the outer limit of my ability to intervene. The only remaining option would be to drive faster.

I relate my experience as a first aid attendant because I think it illustrates nicely the manner in which principlism should be framed in the ethics training and practice of frontline clinicians. As a first aid attendant, I had a rudimentary understanding of the importance of blood pressure, temperature, pulse, and respiration, what might be described as "the four principles of clinical assessment." Detecting an abnormality in any one of these areas might indicate a deeper problem. Unlike a trained clinician, I lacked the requisite knowledge and training to examine the underlying causes of many of these symptoms. At best I could treat the symptoms by providing aspirin if a patient's body temperature was high, by providing oxygen if there were breathing difficulties or if I suspected the patient might be in shock, or any number of other superficial interventions, depending on the presenting problem. This is not to say that such interventions are trivial. To the contrary, many first aid interventions are absolutely vital to the ongoing care and potential recovery of the patient. It is just that they are, by definition, *first aid* interventions, which implies that additional aid by appropriate experts will be forthcoming when necessary.

Blood pressure, pulse, temperature, and respiration are preliminary assessment tools utilized by both the first aid attendant and the highly trained clinician. In many cases, the cause of the symptom is obvious, and the required intervention is relatively straightforward and can be managed adequately by a skilled first aid attendant. In other situations, however, the underlying problems are not at all obvious. While the first aid attendant can often manage symptoms temporarily, only a trained clinician has the requisite knowledge and expertise to examine and treat the underlying problem. In a similar vein, in the context of frontline clinical ethics, autonomy,

nonmaleficence, beneficence, and justice should be framed as preliminary assessment tools. These tools are utilized by both the ethics first aid attendant and by the expert bioethicist in doing preliminary assessments of the ethical aspects of various cases. In most day-to-day clinical situations, the ethical issues are relatively simple and straightforward. In keeping with the first aid analogy, these might be described as ethical scrapes, bumps, and bruises that the ethics first aid attendant can identify and manage simply by attending to the ethical symptoms highlighted when reviewing the four principles. In some cases, however, a deeper examination is required, and those with the requisite training and skill must be called upon to do their work. Just as the skilled first aid attendant in the clinical situation demonstrates that skill by recognizing situations beyond his or her level of expertise, the skilled ethics first aid attendant will do the same. In any complex situation, be it clinical, ethical, or otherwise, accessing appropriate expertise at the appropriate time can do much to ensure that a relatively minor problem does not escalate into a full-scale emergency.

CONCLUSION

Some 25 years ago, physician/ethicist Mark Siegler proposed a model for clinical ethics education that included close collaboration between ethicist-philosophers and skilled clinicians in providing medical trainees with adequate preparation for bedside ethical decision making.¹⁰ He recommended that, in the preclinical years, ethicist-philosophers should take the lead assisted by clinicians, while, in the clinical years, the emphasis should change, with physicians assuming the primary responsibility, assisted by clinically informed ethicist-philosophers. Siegler's model is still appropriate today. However, given the ever-increasing demands of an already crowded preclinical curriculum, and the equally vexing pressures of clinical prac-

tice, the role of the ethicist-philosopher is ever in danger of being usurped.

Beauchamp and Childress are highly respected philosopher-ethicists who have done much to advance the field of clinical bioethics. However, one unintended consequence of their ever-popular *Principles of Biomedical Ethics* is that they may have inadvertently contributed to a reduced role for the philosopher-ethicist in clinical bioethics. That is, in providing a tool by which to reduce the complexity of philosophical ethics to four easy to comprehend principles, they have made it possible to educate an entire generation of ethics first aid attendants. However, the ease by which the four principles can be taught and assimilated by busy educators and students respectively, may lead some to conclude falsely that they have mastered the essence of biomedical ethics and that the role of the philosopher-ethicist is thus redundant. This is on par with concluding that the lay person who can assess the relevance of pulse, respiration, blood pressure, and temperature has captured the essence of medicine.

Principlism is a valuable pedagogical and clinical tool that will continue to play an important role in medical education and clinical practice well into the foreseeable future. However, within such contexts, principlism is best understood and utilized as an assessment tool in ethics first aid. Availed of this tool, the skilled clinician is ready both to assess and manage the relatively minor ethical problems that arise in day-to-day practice, and to refer more complex issues to the appropriate level of expertise.

NOTES

1. E.D. Pellegrino, "The Metamorphosis of Medical Ethics," *Journal of the American Medical Association* 269, no. 9 (March 1993): 1158-62.

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

3. K.D. Clouser and B. Gert, "A Critique of Principlism," *Journal of Medicine and Philosophy* 15 (April 1990): 219-36; E.R. DuBose, R.P. Hamel, and L.J. O'Connell, *A Matter of Principles: Ferment in US Bioethics* (Valley Forge, Pa.: Trinity Press International, 1994).

4. See note 1 above, p. 1161.

5. H.S. Richardson, "Specifying, Balancing, and Interpreting Bioethical Principles," *Journal of Medicine and Philosophy* 25, no. 3 (2000): 285-307; B. Gert, C.M. Culver, and K.D. Clouser, "Common Morality Versus Specified Principlism: Reply to Richardson," *Journal of Medicine and Philosophy* 25, no. 3 (2000): 308-22; J. Harris, "In Praise of Unprincipled Ethics," *Journal of Medical Ethics* 29 (2003): 303-6.

6. R. Gillon, "Ethics Needs Principles — Four Can Encompass the Rest — And Respect for Autonomy Should Be 'First among Equals'," *Journal of Medical Ethics* 29 (2003): 307-12; T.L. Beauchamp, "Methods and Principles in Biomedical Ethics," *Journal of Medical Ethics* 29 (2003): 269-74.

7. A.R. Jonsen, *The Birth of Bioethics* (New York: Oxford University Press, 1988).

8. M. Quante and A. Vieth, "Defending Principlism Well Understood," *Journal of Medicine and Philosophy* 27, no. 6 (2002): 621-49.

9. Beauchamp, see note 6 above.

10. M. Siegler, "A Legacy of Osler: Teaching Clinical Ethics at the Bedside," *Journal of the American Medical Association* 239, no. 10 (March 1978): 951-6.

Confidence and Knowledge of Medical Ethics Among Interns Entering Residency in Different Specialties

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INTRODUCTION

Many observers have noted the importance of ethics education during the critical, formative years of residency training.¹ However, the education of house officers in ethics has received little attention compared with the education of medical students in ethics. In particular, little is known about how the challenges of training house officers in ethics

might differ among residencies in different specialties. In this study, we looked at the confidence and knowledge of the newest physicians (interns) in an attempt to assess their readiness and ability to tackle the ethical issues of contemporary clinical practice. Specifically, our objective for this study was to evaluate the ethical knowledge and confidence of interns who were beginning training in four different specialties: surgery, medicine, pediatrics, and combined medicine-pediatric residencies.

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METHODS

An anonymous questionnaire was used to assess interns' self-perceived confidence in addressing ethical issues and to test their knowledge of medical ethics. It was given to all interns entering surgery, internal medicine, pediatrics, or combined medicine-pediatrics programs at two northeastern U.S. academic medical centers: Georgetown University ($N = 64$) and St. Vincent's Hospital Manhattan ($N = 145$). The data from Georgetown were collected in the months of July and August in

1996. The St. Vincent's data were collected in the months of July and August between 1999 and 2001.

Interns' confidence levels and knowledge scores were obtained with two extensively used, previously validated, and reliable instruments.² The confidence scale, based on the work of Bandura and colleagues,³ was based on a 5-point Likert scale; 1 = very low confidence; 5 = very high confidence. Interns were asked to rate their confidence on six items regarding their ability to (1) recognize a genuine ethical problem, (2) reach a sound ethical decision, (3) support their ethical decisions, (4) obtain genuinely informed consent, (5) proceed when a patient is incompetent, and (6) ethically care for the terminally ill. The confidence scale had a Cronbach's *alpha* (measure of internal consistency) of 0.81 for this sample.

The knowledge score was obtained using a test consisting of 16 questions regarding

medical ethics. Question formats included case studies, ethics terminology, and local laws to assess both theoretical and practical knowledge of ethics. The test was based on consensus recommendations regarding medical ethics education⁴ and was reviewed by a panel of experts for face validity.

Hypothesis testing was performed using Pearson correlation, two-tailed *t*-tests, one-way analysis of variance (ANOVA), and linear regression models. Calculations were performed using SPSS statistical software.⁵

RESULTS

Of the 209 interns surveyed, 21 percent were in surgery programs, 65 percent were in internal medicine programs, 9 percent were in pediatrics programs, and 6 percent were in medicine-pediatric programs. The average age of an intern in our study group was 27 years old. Nearly 43 percent were women. Most (nearly 84 percent) reported having an ethics course in medical school. Regarding religious preferences, 29 percent described themselves as Roman Catholic, 21 percent as Protestant, 17 percent as Jewish, 16 percent as having other religious preferences, and 15 percent as having no preference (see table 1).

Overall, interns had somewhat low confidence in their medical ethics decision-making ability, with a mean confidence scale score of 3.30 (see table 2). Interns had the highest confidence in their ability to recognize an ethical problem and to obtain a genuinely informed consent (both with a mean confidence score of 3.59). Interns expressed the least confidence in their abilities to navigate the ethical issues involved in caring for patients who are incompetent (mean confidence = 2.79) and in caring for the terminally ill (mean confidence = 3.02).

Interns' knowledge scores were also low, with a mean knowledge score of 48.1 percent (see table 3). Interns scored the lowest on the question regarding the contents of the Hippocratic Oath, with only 10 percent answering correctly. Only 22 percent knew whether hos-

Table 1
Sample characteristics (N = 209)

Characteristic	Mean	No.	%
Age — years	27.2	--	--
Gender			
Female	--	89	42.6
Male	--	120	57.4
Medical school			
St. Vincent's	--	145	69.4
Georgetown	--	64	30.6
Ethics course in medical school	--	175	83.7
Type of residency			
Internal medicine	--	136	65.1
Pediatrics	--	18	8.6
Surgery	--	43	20.6
Medicine-pediatrics	--	12	5.7
Religious preference			
Jewish	--	36	17.2
Roman Catholic	--	60	28.7
Protestant	--	43	20.6
Other preference	--	34	16.3
No preference	--	32	15.3

pitals were required to have an ethics committee and only 22.5 percent knew whether the District of Columbia or the State of New York (as appropriate) had a living-will statute. Interns scored highest in knowing they had a legal duty to report impaired colleagues (82.3 percent). They also knew that the Netherlands is the European nation most tolerant of euthanasia. Roughly three-quarters of interns recognized the ethical issues involved in the *Tarasoff* case and could correctly answer regarding the provisions of the Patient Self-Determination Act.

In bivariate analyses, surgical interns had significantly higher confidence levels (3.54 v. 3.24, $p < .01$), yet had significantly lower knowledge scores (42.2 percent v. 49.6 percent; $p < .001$) compared with their nonsurgical colleagues. Jewish interns tended to have higher confidence (3.42 v. 3.28; $p = .21$) and had significantly higher knowledge scores (52.4 percent v. 47.1 percent; $p = .02$) compared with all other interns. Interns who rated their prior ethics training as excellent or better were significantly more confident (3.46 v. 3.21; $p < .01$) but not more knowledgeable (47.3 percent v. 48.8 percent; $p = .40$) than those who rated their prior training as only adequate or inadequate.

No significant associations were found between confidence or knowledge and age, gender, medical school, or medical school graduation year. Confidence and knowledge were uncorrelated.

In a linear regression model for confidence (see table 4), being a surgeon ($p = .01$) and rating prior ethics training better than adequate ($p = .02$) were independently associated with higher confidence.

In a linear regression model for knowledge (see table 5), being a surgeon was associated with lower scores ($p < .001$), while being Jew-

Table 3
Knowledge score

Item	% correct	S.d.
Definition of deontology	32.5	--
Legal hierarchy of surrogates	40.2	--
State/District has living will statute	22.5	--
Convictions for turning off ventilator	66.5	--
Moral hierarchy of surrogates	33.9	--
Euthanasia in the Netherlands	80.9	--
Contents of the Hippocratic Oath	10.1	--
Definition of utilitarianism	24.9	--
Issues in <i>Tarasoff</i> case	76.1	--
Minor Jehovah's Witnesses and the law	35.9	--
Natural Death Act	56.9	--
Reporting impaired colleagues	82.3	--
State/district law on ethics committees	22.0	--
Confidentiality and the <i>Tarasoff</i> case	68.4	--
Patient Self-Determination Act	75.1	--
Formal incompetency declarations	40.7	--
Mean total score	48.1	±12.6

Note: S.d. = standard deviation.

Table 2
Confidence scale

Item	Mean confidence	Standard deviation
Recognize a genuine ethical problem in medical management	3.59	±0.77
Reach a sound decision when facing a problem in clinical ethics	3.36	±0.75
Give reasons in support of ethical decisions	3.46	±0.82
Obtain genuinely informed consent	3.59	±0.88
Knowledge of how to proceed when a patient is incompetent	2.79	±0.87
Manage the ethical aspects of caring for the terminally ill	3.02	±0.85
Scale score	3.30	±0.59

ish was associated with higher knowledge scores ($p = .01$).

DISCUSSION

We are unaware of any previous studies comparing the knowledge and confidence in medical ethics of house officers from different specialty training programs. In this study, we found that confidence and knowledge of medical ethics were generally low among entering interns. However, we found that surgical interns had more confidence despite less knowledge. In addition, we found that Jewish interns were more knowledgeable and tended to be more confident than their colleagues. Finally, we found that the perceived quality of a previous ethics course in medical school was associated with interns' confidence, but not with their knowledge.

Our findings regarding the ethics knowledge and confidence of surgical interns have

not previously been reported, although one study did indicate more favorable psychosocial belief scores among graduating medical students who matched in primary care specialties compared with those who matched in surgical or support specialties.⁶ This suggests that these characteristics are actually a result of self-selection. Likewise, since we surveyed interns at the very beginning of residency, our findings are likely to reflect self-selecting features rather than the result of residency training itself. The ethics knowledge scores we report here are lower than those reported by Angelos and colleagues⁷ and Wenger and colleagues⁸ in their studies of surgical house officers, but the studies are not strictly comparable, and this probably only means that our test asked more difficult questions.

The finding of relatively high confidence regarding the ability to address ethical issues despite relatively low knowledge of ethics is not unique to surgical interns. We have previously noted that internal medicine faculty report higher confidence than medical house officers, despite knowledge scores that are just as poor.⁹ The belief that one can confidently address ethical issues without a solid fund of knowledge, whether on the part of house officers or the attendings who function as their role models, can represent a significant barrier to effective ethics education.¹⁰ The troubling fact that confidence can be high without adequate medical knowledge is not limited to ethics. Courses regarding invasive procedures have been shown to make house officers more confident without improving their knowledge.¹¹ Learning how to bridge the knowledge-confidence "gap" in medical education will require more research.

Our findings regarding religious preference and ethics knowledge and confidence corroborate findings from previous studies.¹² Perhaps the Talmudic tradition of ethical study has pervasive influence that generalizes beyond the tradition.

The finding that the quality of ethics education in medical school influences the confidence of incoming interns, but not their

Table 4
Confidence: Linear regression model

Parameter	Beta coefficient	P
Residency type		
Other v. surgery	0.183	.01
Perceived adequacy of previous ethics training*	0.165	.02

* Dichotomized as inadequate/barely adequate v. excellent/so good that no further training is needed.

Table 5
Knowledge: linear regression model

Parameter	Beta coefficient	P
Residency type		
Surgery v. other	- 0.248	< .001
Religious preference		
Non-Jewish v. Jewish	0.172	.01

knowledge, also corroborates earlier findings.¹³ While it is gratifying to know that medical school courses improve physicians' self-perceived efficacy regarding ethics, these findings suggest that more or better training may be needed to improve knowledge. This might include improvements in medical school ethics education, but the opportunities for ethics education during the critically important formative years of residency training might prove an even more fruitful time for ethics training.

Several studies have demonstrated that ethics education can be effective in improving residents' knowledge, confidence, and behavior.¹⁴ Attention to ethical issues is now mainstream among bodies accrediting residency programs. The Accreditation Council for Graduate Medical Education lists professionalism among its uniform requirements, but it is up to each specialty to delineate how professionalism will be cultivated and assessed.¹⁵

Our findings suggest that further research might explore whether such training could be appropriately tailored to meet interns' differing backgrounds and the self-selecting characteristics that are associated with residency training in different specialties.

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Medicine and Public Policy

In Defense of Tongue Splitting

Jacob M. Appel

State legislators across the United States have recently set their sights on severely curtailing, or even proscribing, an increasingly popular body-modification procedure known as tongue splitting or tongue forking. Illinois Governor Rod Blagojevich signed a law in August 2003 that limited performance of the procedure to physicians and dentists.¹ Pennsylvania, New York, and Delaware have since enacted nearly identical legislation.² Similar laws are being considered in Kentucky, Tennessee, and West Virginia.³ In September 2003, the State of Texas banned the procedure entirely.⁴ Public health officials in Massachusetts and Wisconsin have indicated that they believe the practice is illegal in their state unless performed by a surgeon.⁵ While Michigan's House of Representatives narrowly defeated a total prohibition in June 2002, with dissenting lawmakers expressing civil liberties concerns, since then the political momentum has shifted to opponents of tongue splitting.⁶ Both the Massachusetts Medical Society and the American Dental Association have

of late spoken out against the practice.⁷ The U.S. Air Force has given airmen with forked tongues the choice of either "corrective" surgery or expulsion, and at least one serviceman had his tongue reopened and sewn back together to avoid being kicked out of the military.⁸ Unfortunately, efforts to ban tongue splitting are, at best, premature and ill-considered — and, at worst, reflect an effort to misuse medicine in an attempt to curtail the liberties of an unpopular cultural subgroup.

According to Shannon Larratt, editor of the *Body Modification* e-zine (an electronic magazine), approximately 2,000 individuals in the western world have split tongues.⁹ Although the practice was an integral part of ancient Khechari Mudra yoga, it did not begin to appear in the U.S. or Europe until 1997.¹⁰ Most of those seeking the procedure belong to an extreme piercing and tattooing subculture; many are also interested in skin branding, tooth filing, and subdermal implant. In addition to a more reptilian appearance, individuals with split tongues report an ability to move each fork of the organ independently and claim enhanced pleasure in kissing and oral sex. Critics of the practice, including Illinois Representative David Miller, the dentist who sponsored his state's legislation, counter that tongue forking can cause speech impediments,

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massive tongue hemorrhages, edema, abscess formation, tetanus, and nerve damage.¹¹ The debate is complicated because the tongue can be split through four common methods, some of which are more hazardous than others. These include slicing with a scalpel, a heated cauterizing tool, a laser, or a tie-off method in which a string is looped through a tongue piercing and slowly tightened over time. The only published study on the consequences of tongue splitting, in the *Journal of the Canadian Dental Association*, concluded that the procedure “did not significantly effect” either “speech intelligibility” or “tongue motility.”¹²

State laws that limit the practice to doctors’ offices may have the effect of eliminating it entirely, because few if any physicians will slice tongues. Representative Miller predicted this very outcome when he sponsored his bill.¹³ Even willing physicians, if they can be found, will presumably bill much more than the \$250 to \$500 charged by most professional piercers. As a result, according to tattoo artist Rick Freuh, who heads the national advocacy group Church of Body Modification, reputable practitioners will “go underground,” and potential customers will do the procedure under dangerous conditions “in their kitchen or in their bathroom.”¹⁴ These back-alley tongue splits (the analogy to pre-*Roe* abortions is striking) will increase, rather than alleviate, the dangers to body modification seekers. Moreover, it is entirely unclear why tongue splitting is any less dangerous, or more medical, than tongue piercing — which appears to carry its own significant risks.¹⁵ Licensing and training professional piercing artists to perform tongue forking procedures safely seems to be the best method to improve public health, if the genuine goal of anti-splitting advocates is the welfare of those seeking to look like a lizard.

The real intent of at least some opponents of tongue splitting may be more pernicious. Representative John Van Sant of Delaware, that state’s sponsor of legislation curtailing the practice, told the Associated Press, “it’s bad enough with the nose and the ears” — suggesting that the health concerns might be a

cover for aesthetic objection.¹⁶ In fact, many of the politicians and physicians who crusade against tongue splitting appear to object to the entire body-modification subculture. (If the military encourages servicemen to undergo surgery to undo a split tongue, it suggests that its primary concern is appearance and not health.)

Much of the legislative debate surrounding the issue has been short on science and long on speculation and misinformation. For example, West Virginia House Majority Leader Rick Staton argued that his regulatory bill was necessary because, “That’s a new fad, like tongue piercing, and once it’s done it’s permanent. You can’t sew it back together.”¹⁷ The reality is that split tongues can be rejoined surgically and that many forks grow back together naturally over time.¹⁸ While a study of medical complications from tongue forking by nonphysicians might clarify the procedure’s actual risk, none has yet been undertaken; in the absence of such a study, or even individual case reports, declarations of this danger are mere conjecture. Far more dangerous is the potential for misusing medicine to condemn practices that are aesthetically outside the mainstream — curtailing autonomy simply because we find certain lifestyles personally objectionable. Massachusetts did exactly that in 1962 when it used the pretext of hepatitis risk to outlaw tattooing, while its actual goal was to drive off the sailors, bikers, bookies, drifters, and drunks who then, for the most part, seemed to comprise the body art community.¹⁹

Beyond these ethical considerations, the constitutionality of anti-splitting statutes is doubtful. Massachusetts’s anti-tattooing law was overturned in 2000 as a violation of the First Amendment protection of free expression.²⁰ Courts and state medical boards in at least seven other states have ruled piercing outside the practice of medicine — and thus not subject to the sort of licensing requirements that might protect anti-piercing statutes from constitutional challenge.²¹ While there are both ethical and legal grounds to prohibit “cosmetic” or elective procedures under cer-

tain circumstances, such as when a high potential exists for coercion (female genital cutting) or when the practice is routinely performed on those with little meaningful ability to object (tooth pulling among Dinka children), society has a duty to demonstrate the need for such limitations. It is not enough to lament, as does Thomas E. Sullivan, MD, president of the Massachusetts Medical Society, that people are "mutilating" themselves.²² Sane, stable individuals who are free from coercion and unreasonable familial/cultural pressures should have a right to mutilate themselves. Opponents of tongue splitting, at least for now, have failed to advance any convincing medical or moral arguments for why they should not.

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Cochlear Implants in Children: Ethics, Informed Consent, and Parental Decision Making

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The purpose of this article is to examine the process of informed consent surrounding the complex issues of ethics, advocacy, and audiology that arise as a consequence of state-mandated universal newborn hearing screening (UNHS)¹ and the technological progress that encourages increasingly earlier cochlear implantation (CI). Earlier identification of deafness² in infants compresses the decision-making process for parents and professionals. Most states have an “opt-out,” not an “opt-

in,” UNHS policy: although parents have the final say, states may structure the decision to encourage screening by requiring parents to sign a waiver of liability should they choose not to have their child screened. In this atmosphere, parents may feel an urgency to act. Thus, the process of informed consent and the content that it includes become even more important in sound decision making and make such sound decisions even more difficult to achieve. Who presents the information; what is told, how, when, and where it is presented, after the parents have been told the screening results, all affect the parents’ decision.²

The process of informed consent can provide a realistic and objective framework to make an informed decision about surgical intervention for a D/deaf child.³ That process acknowledges the bias of a medical setting as well as prevailing social policy, that is, a bias toward oralism.⁴ Within this process of informed consent, the personal and cultural values of the parent(s) are privileged,⁵ and the values and beliefs of medical professionals, while clearly affirmed, are weighed as one of many factors influencing the parents’ decision. Informed consent thus becomes a dy-

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namic and evolving process — a means of addressing all of the relevant (medical, educational, psychological, social, economic, and cultural) issues and resolving them in the best interest of that particular family.⁶

UNHS AND PARENTAL DECISION MAKING

With the advent of UNHS, data on the prevalence of newborn deafness is now more accurately collected. Early reporting estimates based on data collected at the state level indicate that the prevalence of newborn deafness is approximately two to three per 1,000 live births in the newborn nursery and two to five per 100 infants in the neonatal intensive care unit (NICU).⁷ It is estimated that each year approximately 5,000 infants born in the United States have permanent moderate-to-profound deafness and possibly an additional 7,000 infants are born with mild permanent deafness.⁸

UNHS has changed the trajectory of how parents learn of their child's deafness. Before UNHS, parents were often the first to suspect that their child was D/deaf. For some parents, being the first to suspect their child might be D/deaf helped them to feel they had some control, and, however stressful this was, it could be empowering. This knowledge of their child was important and useful — and this parental knowledge was validated by medical tests. This was not to negate the anger that existed when professionals had not been listening, but to emphasize the importance of the parent-child bond.

With UNHS, medical professionals are now the first to suspect deafness immediately after birth, which medicalizes the condition of a newborn and places expertise about the child in the hands of professionals.⁹ The disclosure of screening results occurs at a time when new parents are particularly vulnerable, and the disclosure takes place in a medical setting that quickly sets in motion a number of medically related activities: to confirm and evaluate the child's deafness and to begin educational therapy with early intervention (EI)

programs. This activity compresses the events of birth, the creation of a new family, and then the diagnosis — generally unexpected — and may create pressure to take action. This is not an environment that fosters deliberate and informed decision making. Realistically, a decision concerning CI need not be hurried at all. If the process of fully informing parents begins at birth, and parents are advised that they have much to learn but plenty of time to be educated, they can begin to sort out their priorities and values before weighing the benefits and burdens of CI.

If UNHS indicates a need for further assessment, parents are set on a course that can be completed within four to six months, but may take longer.¹⁰ The process of informed consent must begin and be ongoing during this assessment period and continue past diagnosis and prognosis.

The benefits of UNHS are clear. Before UNHS, the greatest burden was the time interval between parents' suspicion of the deafness and a diagnosis. In that interval, parents could have been learning more about deafness and communication options. Now children who are at risk of any degree of deafness are identified very early, and habilitation through amplification and EI programs is initiated at younger and younger ages, which results in better speech, language, and literacy outcomes.¹¹ Early intervention programs are of great value, in part because they encourage active, involved parenting from the outset. Amplification through hearing aids, assistive listening devices, or CI makes the auditory signal more accessible, and EI educates parents on how to adapt their play, trust their parental instincts, and emphasize their child's typical development in every other respect.

COCHLEAR IMPLANTS: RISKS, BURDENS, AND BENEFITS

CIs are surgically implanted devices that electrically stimulate auditory nerve fibers located in the cochlea, simulating hearing. They are recommended for use when a child

or adult has profound hearing loss or deafness and cannot benefit from conventional amplification (that is, hearing aids). The National Institute on Deafness and other Communication Disorders (NIDCD) reports that, as of the year 2002, nearly 10,000 children have been implanted.¹² As the use of CI has become more widespread, the criteria for use have broadened, including the extent to which the person with deafness can benefit from the use of hearing aids and still be a candidate for surgical implantation. Thus the use of CI in children is increasing.

The Food and Drug Administration (FDA) approved CI devices for children two years of age or older in 1990. In 1998, the FDA approved a CI device for children as young as 18 months. While the FDA has strict requirements for CI used in young children,¹³ changes can be expected as experience increases and technology advances. Recently, children as young as 12 months have been considered candidates, and some centers are testing protocols for infants as young as six months.¹⁴ As well, children with significant residual hearing are now receiving CIs.¹⁵

CIs are not without surgical and medical risk. An incision is made behind the ear and a mastoidectomy is performed. To thread the electrode array through the cochlea requires drilling into the temporal bone, located in the skull. The internally embedded electrodes are connected to an external speech processor, which converts the auditory signal into an electrical impulse and allows the brain to decode this impulse into the perception of speech.

Surgical complications include infection at the site of the wound and damage to the facial nerve. Damage is more likely to occur when anatomic abnormalities exist. Improper insertion of the electrode array, although rare, requires removal and replacement of the device and another surgical procedure. For children less than 12 months, risk for respiratory failure and bradycardia is increased¹⁶ as are the risks of anesthesia. Increased risk must be carefully weighed and balanced with the ad-

ditional benefits that earlier implantation may provide.¹⁷

In addition to these surgical risks, young children are prone to otitis media (OM), which, on occasion, will compromise the integrity of the CI device.¹⁸ Aggressive treatment of OM is now the standard of care for children with CI. The risk of OM in young children is that it can lead to meningitis, a life-threatening disease. As a result of reported cases of meningitis¹⁹ by the three CI manufacturers, the Centers for Disease Control and Prevention (CDC), the FDA, and the health departments of 36 states and three cities conducted a comprehensive study of 4,264 children implanted at under age six between 1997 and 2002. The study found that the incidence of meningitis in children who had a CI was "more than 30 times the incidence in a cohort of the same age in the general United States population."²⁰ While the incidence was highest among children who were implanted with models using a positioner no longer in use, children without that particular positioner were still at a significantly increased risk. Other findings are cause for concern: the incidence of meningitis increased over the six-year period studied, and younger children were at higher risk.²¹

CI technology, as is now applied, causes a permanent physiological change — destruction of any residual hearing — possibly precluding the application of future technologies. As professionals are well aware, the child becomes dependent on a prosthetic and its associated services, requiring both technological and extensive audiological follow up. Likewise, parents must understand that services to repair or correct complications of the device must be readily available to assure ongoing benefit to the child.

The benefits of implantation for children, despite these medical and technological risks and burdens, are considerable — some would argue overwhelming. Recent studies have shown that implantation before the age of five years has improved long-term speech perception, speech production, language, and lit-

eracy development, although the exact age for optimal efficacy in these areas is still being tested.²² For *oral* speech and language development, current research reports that CI by age two years is even more effective than by age five.²³

Efficacy, however, is variable, as the outcome is also dependent on factors such as IQ, socioeconomic status (SES), gender, family size, and educational program (that is, auditory-oral, auditory-verbal, total communication, or cued speech).²⁴ While auditory input, which CIs provide, is felt to be optimal as a precursor to oral language development, some researchers suggest that nonverbal communication, shared experiences, attention, and mutual understanding are equally, if not more, important to the development of speech and language.²⁵ Research indicates that children with all degrees of deafness who experienced high levels of family involvement and early enrollment in EI score most like their hearing peers on a variety of tests.²⁶

This evidence of benefit becomes even more compelling for hearing parents whose children are born with medically diagnosed deafness: 95 percent of D/deaf children are born to hearing parents.²⁷ For these hearing parents, the diagnosis of infant deafness often is coupled with the desire to “fix” what they see as a physiological defect that prevents their child from fully participating in their hearing family and culture. CI then is seen as the appropriate medical “fix.” Indeed, it may even be the parents themselves who introduce CI as a remedy.

To hearing parents the desire to “fix” the deafness of their infant may also lead to unrealistic expectations. Parents often interpret the benefits of a CI as “restoring” hearing or “curing” deafness, thus making their child “normal.”²⁸ The CI does not “cure” deafness, although it allows previously inaudible signals to be audible and increases speech production capabilities. While this may be an expected outcome for most D/deaf children, parents still need to make this decision based on a clear understanding of the multiple factors

involved in successful implantation. The pairing of a medical problem with a medical solution (that is, hearing can be repaired through surgery), however, can confound informed parental decision making.²⁹ Even when balanced information is offered, parents are often still grieving and may not “hear” the burdens of the intervention, only the benefits. In addition (and understandably), otolaryngologists, audiologists, and speech-language pathologists are immersed in the medical diagnosis, amelioration, and habilitation of deafness and advocate for CI — a bias that should be clearly stated, and is an added impetus for making certain that parents have contact with resources that are more neutral and represent other points of view.

CI AND DEAF CULTURE

Deafness is not only an inability to hear, but also considered a culture. The relationship between D/deaf children and D/deaf culture is an issue even for those not born into a D/deaf family. Many individuals who are D/deaf do not view deafness as a defect or disability, but as a difference.³⁰ They see themselves as belonging to a culture that has its own identity and its own language, American Sign Language (ASL). To this group, an inability to hear is of less significance than this shared culture and language.³¹ Much as hearing parents want their D/deaf child to belong to the hearing culture, some D/deaf parents are fearful that CI will exclude their D/deaf child from the D/deaf culture, and, if they never achieve “good speech,” will indeed make them feel marginalized and disabled in both the hearing and D/deaf worlds.³² Irrespective of which culture the child is born into, an understanding of both cultures is essential.

Embracing both cultures, however, requires overcoming a history of antagonism between the two, and a more recent history of conflict concerning CI, a technology that threatens ASL, a foundation of D/deaf culture. The initial hostility to CI felt by some in the

D/deaf community is perhaps best illustrated by the ASL sign for CI, which is the sign for a vampire (forefinger and middle finger) thrust at the back of the neck. To those parents and families concerned about maintaining and using the language and culture of the D/deaf, the current practice of foreclosing the option of ASL for the implanted child echoes historical bias and rekindles their anger toward oralism, which stems from the latter half of the nineteenth century, when Victorian culture saw silence as being “prey to the devil” and deafness as a sign of sickness that needed to be cured.³³ The forced oralism of Alexander Graham Bell and the oralist educators left a legacy of suspicion and distrust. Not to be minimized is the perception on the part of the D/deaf culture that oralism was inherently paternalistic: a decision made by the hearing and imposed on the D/deaf. This distrust extends to perceived pressure, this time using CI, to once again move D/deaf children from D/deaf culture into the oral hearing world.

The dilemma of the young implanted child who does not belong to the culture of either the D/deaf or of the hearing, who uses a device that does not “cure” deafness, is not as contentious as it once was. The National Association for the Deaf (NAD), probably the most influential advocacy group for the D/deaf, significantly moderated its vehemently anti-CI position, stated in 1991, in 2000. NAD now acknowledges the heterogeneity of the D/deaf and recognizes CI as an option.³⁴ Since 2000, Gallaudet University, a university for the D/deaf and hard of hearing as well as the hearing, and a learning environment with a commitment to sign communication, has had a CI Education Center that would have previously been unthinkable.

The perception, however, of deafness as purely a disability persists and needs to be addressed. Critics of D/deaf culture point to the seeming contradiction of accepting as an entitlement the disability benefit provided by Supplemental Security Income (SSI). These critics argue that if the D/deaf consider them-

selves a cultural group, they should not claim disability benefits.³⁵ But this challenge is difficult to sustain. While superficially it may appear that the D/deaf community’s continued claim to benefits may be paradoxical, this is hardly the first such instance. As with any other culture in this nation of racial, ethnic, and religious diversity, it is often necessary to provide additional means educationally or financially to enable a culture to work or to be otherwise productive in mainstream society. If the word “disability” were changed to “assistance” to achieve parity in the educational and/or job market, perceptions might change. Or perhaps this would be termed “affirmative action” for the D/deaf, a present-day “boost” to balance the inequities of the past, such as forced oralism in segregated residential schools for D/deaf children.

U.S. society often accepts such paradoxes, indeed it sometimes insists on them, choosing to provide assistance to certain groups who have been vulnerable, dependent, or historically were discriminated against, even when not all members of the group are of equal need or status. Consider that when U.S. citizens turn 65, they are eligible to receive Social Security payments, whether or not they continue to work. Victim assistance and compensation are often available to those who suffer from a particular crime or event, irrespective of their personal assets. These examples abound in American society, where we have learned to take advantage of whatever benefit is available. Finally, these are not issues that should in any way influence an individual decision on whether or not to consider a CI. A CI, in and of itself, does not indicate how an individual child or family identifies itself, which makes these contentions irrelevant. Changing perceptions of deafness as other than a disability remains a challenge, and there are those, including those who are D/deaf, who have argued that society should not support individuals who make decisions, such as rejecting CI for a child, that will impose an economic burden on others.³⁶

The role of ASL as a basis of not only communication among the D/deaf but also of D/deaf culture has been the focus of disagreement between the organized D/deaf community, and non-D/deaf medical and therapeutic professionals. Specifically, the practice of recommending that children who have been implanted prelingually (under the age of three) be exposed only to oral English contradicts the evidence that children can learn more than one language, as well as denying the language-learning value of ASL. If there is a strong language base in a home language, children will be able to gain fluency and literacy in a second language, whether it is introduced simultaneously or postlingually when the child enters school or preschool.³⁷ As Oliver Sacks maintains, “it is *language*, rather than any particular language, that kindles linguistic competence and, with this, intellectual competence too.”³⁸

What is not known is whether the language skills that are developed through ASL — which is a visual, not a spoken language — as a first language provides the same benefits as oral language. Hearing children of D/deaf parents, for example, are ordinarily fluent in both languages, even though they learn ASL before oral English. It should be noted, however, that these are *hearing* children. Evidence strongly supports the conclusion that D/deaf children in programs that expose them to more auditory stimuli have better speech perception/production abilities than children enrolled in programs that do not have this emphasis.³⁹ Thus, children exposed to ASL at home would need to be enrolled in auditory programs to gain greater access and fluency in oral language and hearing culture. Early implantation and learning ASL need not be mutually exclusive. Thus it would appear that inclusion of ASL in the decision to implant a young child, and the denial of ASL for D/deaf families who choose to implant a child, is a “red herring” that raises a “red flag.”

With the evidence of increasing benefits of CI, parents still must make decisions based on their own evaluation of the best interest of

their child. For hearing parents of D/deaf children, decisions about whether to expose their child to D/deaf culture and ASL are more difficult than for D/deaf parents, for this decision imposes an additional burden — learning ASL as another language.

INFORMED CONSENT IN THE BEST INTEREST OF THE CHILD

The decision to implant or not, and, if so, when, is complex. Successful CI requires not only expert medical and audiological services, but also intensive early intervention, appropriate educational placement, and a high level of family involvement. The age of implantation is important, but so are variables beyond the parents’ control: SES, IQ, the number of children in the family, and gender.⁴⁰

The ultimate effect of CI on a child as she or he reaches majority and seeks her or his own personal and cultural identity should also not be minimized. The first group of children to receive CI prelingually is now entering adolescence, a time of emerging autonomy and self-identity.⁴¹ Early evidence suggests that some of these children are turning off their CI, exploring and identifying with D/deaf culture, which is consistent with other adolescent searches for identity.⁴² Even past adolescence, D/deaf children with implants may find the need or the desire to use ASL in different circumstances, with D/deaf peers or when auditory signals are not clear.⁴³

Advocacy groups as well as individuals often contend that neither a careprovider nor a parent can ethically make a decision about implantation: they do not live with the condition of deafness, and thus cannot make a truly informed decision.⁴⁴ The child is the one who will be permanently tethered to a mechanism that requires repair, maintenance, replacement, and upgrading.⁴⁵ Reliance on reconstructive and reparative technologies can complicate a child’s life, creating a permanent dependence and anxiety that persists throughout life. This dependency is even greater if access to fluency in a signing language is de-

nied. In other words, the benefits and burdens can only be evaluated by the person who bears them.

In the case of CI, parents are urged to make irrevocable decisions when the child has no capacity to weigh-in on the decision. EI in the form of reconstruction can preclude later determination of identity by the individual. For example, intersex advocates argue that early surgical intervention that decides gender assignment are often at odds with the gender identification of the adult based on “the belief that the person with an intersex condition has the right to self-determination where his or her body is concerned. Doing ‘normalizing’ surgeries early without the individual’s consent interferes with that right.”⁴⁶ Similarly, many D/deaf culture advocates argue that early CI denies D/deaf children full appreciation of the richness of D/deaf language and culture.⁴⁷

The difficult question that this raises is whether a case can be made that the benefits of respecting future emerging autonomy regarding CI outweigh any harm or damage resulting from delayed intervention. Delay in implantation has the disadvantage of significantly impairing the acquisition of good oral language skills. Poor oral language skills then become a handicapping or marginalizing condition, an important negative factor to be considered in whether to delay the decision until the child is able to make the best decision for herself or himself when she or he achieves full autonomy and decision-making capacity. On the other hand, early “reparative” interventions may preclude later technological advances that may prove preferable.⁴⁸

AN INFORMED-CONSENT MODEL FOR CI IN YOUNG CHILDREN

Informed consent involves both content (what is delivered) and process (how, when, where, and who delivers information). On the content side, while parents feel the medical aspects of CI are well presented, the cultural/social aspects of deafness are rarely if ever

offered.⁴⁹ Second, the medical information that is given should include the current state of research, particularly the uncertainties of practice outcomes and possible future developments. For example, there is little research about whether ASL hinders oral language development. Another example noted by Hyde and Power is that little is known about whether children who have state-of-the-art hearing aids who are given the same intensity of support as children who have been implanted, do as well in oral language skills.⁵⁰ Parents are capable of understanding, weighing, and accepting uncertainties when these are presented in a clear and unbiased fashion.

The content of informed consent is also influenced by the process — in short, the how, when, where, and who. Information that is delivered in a medical setting by medical professionals is different than that delivered in a nonmedical environment. Parents who first learn about CI through the medical profession tend to use only medical information as their primary source.⁵¹ In contrast, parents who go to other parents with implanted children tend to use a wider range of both medical and non-medical sources for information, thus receiving a more balanced perspective.⁵² At the same time that EI is explained and initiated, typically within the hospital setting, parents must be urged to step outside the medical model and begin learning about deafness from other sources. This expansion of information and options allows for a more considered and nuanced decision.

Different models have been proposed for how parents should access the information. The typical model used in American practice is that professionals within the medical setting are responsible for linking parents to resources such as organizations for the D/deaf, D/deaf and hearing parents of D/deaf children, parent support groups, and literature that examines the social, economic, and cultural implications of deafness and CIs. An alternative model, and one recommended in Australia by Hyde and Power, proposes “that informed consent be conducted in a non-direc-

tional independent counselling context; that is, one that involves removing the service provider from the counselling/advice context.”⁵³ A third “compromise” model that may be more realistic for use in the U.S. is that of a patient advocate/educator who is a part of the medical team who can guide families to outside sources and resources and is available to ask and to answer questions.

The process necessarily includes timing. With screening and early diagnoses, medical professionals may feel the need for immediate action, but parents may not be ready to make such decisions. If decisions are forced, more harm than good can occur.⁵⁴ Rather, medical professionals, in collaboration with nonmedical professionals, can help parents start to think about decisions, actions, and their ramifications. Specifically, asking parents early in the diagnostic process what types of information would be most helpful demonstrates respect for their feelings, and a belief that parents are capable of making sound decisions based on their unique family.⁵⁵ Parents may request different types of information at different times and in different sequences. Thus, information or access to information can be delivered when a family is most likely to process it best.

As pediatric CI centers move toward earlier implantation, bilateral implantation, and implantation when residual hearing exists, decision making will become even more complicated. The decision may not be whether or not to implant, but rather when to implant, and how to encourage participation in D/deaf culture. For hearing parents with D/deaf children, introducing their child to D/deaf culture is an undertaking similar to parents who have adopted children of a different race, religion, or culture who actively pursue participation in that child’s race, religion, or culture.

CONCLUSION

The purpose of this discussion is not to discourage the use of CI, but rather to open and broaden the discourse so that parents,

professionals, and the public perceive deafness in a more textured context (see table 1). A rational, well-considered, and truly informed decision is complex: an ongoing process that begins at birth and explores all of the options with their concomitant benefits and burdens. It takes into account such diverse factors as home and community environments, cultural beliefs, EI options, parents’ ability to support and manage the technology, medical/audiological data, the additional attention required, and respect for the child’s future autonomy and individual choice.

The considerations of the hearing parent may differ decidedly from that of the D/deaf parent. What must be kept in mind is the course of action that will allow the child to

Table 1
Components of consent to CI

Parents who are asked to give consent for CI for their child should receive the following information:

- The medical/surgical procedure of CI, its risks and future implications for the child, including loss of residual hearing, possible complications of surgery, and need for access to technological maintenance.
 - The benefits and burdens of each of the options; that is: to consent to surgery, delay surgery or reject surgery, including the role of the parent as decision maker.
 - A description of the range of outcome possibilities, including the possibility of unsatisfactory result.
 - Evidence-based data on language and literacy skill development with or without CI, including data on variables that account for more effective language acquisition, and, in particular, the need for a high level of family involvement.
 - Communication options; that is: ASL, oralism, cued speech, or total communication, including options for “bilingualism” or “multilingualism.”
 - Cultural (D/deaf) identity sensitivity and a familiarity with the D/deaf community.
 - Child/adolescent identity development, including considerations of how the emerging autonomy of adolescents can raise questions about agency and the appropriateness of parents as decision makers.
-

most closely fit into her or his family unit, community, and, down the line, place in the larger society.⁵⁶ These concerns can only be addressed when professionals ask the right questions and listen intently to the responses they get. While a child is being assessed, the concerns of parents and quite possibly the child can and probably will change, and new questions and concerns will emerge. Thus, a recommendation of CI, with its risks and benefits, should be tempered by the values and needs of each family. While the ultimate decision may not be unique, the questions and how they are answered may be. The dynamic nature of the process of informed consent optimally allows the final decision to be made entirely by the parents.

NOTES

1. Currently 38 states and the District of Columbia mandate newborn hearing screening allowing for early identification and habilitation of infants with mild to profound deafness. American Speech-Language-Hearing Association, "Incidence and Prevalence of Hearing Loss and Hearing Aid Use in the United States — 2002 edition, <http://professional.asha.org/resources/factsheets/hearing.cfm>, accessed 25 June 2004.

2. Joint Committee on Infant Hearing (JCIH), American Academy of Audiology, American Academy of Pediatrics, American Speech-Language-Hearing Association, Directors Speech and Hearing Programs in State Health and Welfare Agencies, "Year 2000 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs," *Pediatrics* 106 (2000): 798-817; M. Cunningham, E.O. Cox, and the Committee on Practice and Ambulatory Medicine, the Section on Otolaryngology and Bronchoesophagology, "Hearing Assessment in Infants and Children: Recommendations Beyond Neonatal Screening," *Pediatrics* 111, no. 2 (2003): 436-40; T.N. Kluwin and D.A. Stewart, "Cochlear Implants for Younger Children: A Preliminary Description of the Parental Decision

Process and Outcomes," *American Annals of the Deaf* 145, no. 1 (2000): 26-32.

3. *D/deaf* is used as a means to include both those who identify with the D/deaf culture as well as those who do not. The term *deafness* is used to describe any degree of permanent limitation of hearing; modifiers such as "mild," "moderate," "severe," and "profound" are used where appropriate. *Hearing impairment* can be understood to be negative, suggesting an individual's deficit rather than a limited ability to hear. *Hearing loss* is used to mean exactly what the two words say, that is, hearing was lost, for whatever reason. *Prelingual* is used to refer to the convention of considering children under three years old to be "prelingual." It does not mean that children under three do not have language skills.

4. Oralism as used in this article refers to a philosophy in D/deaf education. This philosophy asserts that D/deaf children should be taught oral speech and language through techniques that primarily or exclusively utilize spoken language and speechreading. Oralism does not recognize the value or validity of a visually based or Sign language.

5. For purposes of this discussion, it is assumed that parents have the right to make decisions for their children. As Kopelman points out, "to override parental authority, the state must establish, often by clear and convincing proof, that the child has been harmed or is in danger of suffering serious harm." See L.M. Kopelman, "The Best-Interests Standard as Threshold, Ideal, and Standard of Reasonableness," *Journal of Medicine and Philosophy* 22 (1997): 271-89, p. 272.

6. M. Hyde and D. Power, "Informed Parental Consent for Cochlear Implantation of Young Deaf Children: Social and Other Considerations in the Use of the 'Bionic Ear'," *Australian Journal of Social Issues* 35, no. 2 (2000): 117-27, <http://search.epnet.com>, accessed 7 April 2005.

7. L. Dalzell et al., "New York State Universal Newborn Hearing Screening Demonstration Project: Ages of Hearing Loss Identification, Hearing Aid Fitting, and Enrollment

in Early Intervention," *Ear and Hearing* 21, no. 2 (2000): 118-30; National Center on Hearing Assessment and Management, <http://www.infanthearing.org>, accessed 25 June 2004; J.L. Northern and D. Hayes, "Universal Screening for Infant Hearing Impairment: Necessary, Beneficial, and Justifiable," *Audiology Today* 6 (1994): 10-13.

8. National Center on Hearing Assessment and Management, see note 7 above.

9. See note 6 above; G. Valentine and T. Skelton, "Living on the Edge: The Marginalisation and 'Resistance' of D/deaf Youth," *Environment and Planning A* 35 (2003): 301-21.

10. M. Harrison, J. Roush, and J. Wallace, "Trends in Age of Identification and Intervention in Infants with Hearing Loss," *Ear and Hearing* 24, no. 1 (2003): 89-95.

11. Dalzell et al, see note 7 above; *ibid.*; T.P. Nikolopoulos et al., "Development of Spoken Language Grammar Following Cochlear Implantation in Prelingually Deaf Children," *Archives of Otolaryngology/Head and Neck Surgery* 130, no. 5 (2004): 629-33; A.E. Geers, "Speech, Language, and Reading Skills After Early Cochlear Implantation," *Archives of Otolaryngology/Head and Neck Surgery* 130, no. 5 (2004): 634-8; A. Geers, J.G. Nicholas, and A.L. Sedey, "Language Skills of Children with Early Cochlear Implantation," *Ear and Hearing* 24, no. 1 (2003): 46S-58S; E.A. Tobey et al., "Factors Associated with Development of Speech Production Skills in Children Implanted By Age 5," *Ear and Hearing* 24, no. 1 (2003): 36S-45S; D.M. Houston et al., "Speech Perception Skills of Deaf Infants Following Cochlear Implantation," *A First Report: 2001-2002* (2002): 25.

12. National Institute on Deafness and other Communication Disorders, "Cochlear Implants," <http://www.nidcd.nih.gov/health/hearing/coch.asp>, accessed 25 June 2004.

13. At present all of the following criteria for children between 12 and 24 months of age must be met for a CI to be approved: bilateral profound deafness, minimal benefit from amplification, enrollment in EI or a program for children with deafness, and no medical

contraindications.

14. Houston et al., see note 11 above.

15. R.C. Dowell, R. Hollow, and E. Winton, "Outcomes for Cochlear Implant Users with Significant Residual Hearing: Implications for Selection Criteria in Children," *Archives of Otolaryngology/Head and Neck Surgery* 130, no. 5 (2004): 575-81; S.J. Dettman et al., "Cochlear Implants for Children with Significant Residual Hearing," *Archives of Otolaryngology/Head and Neck Surgery* 130, no. 5 (2004): 612-8.

16. R.L. Keenan et al., "Bradycardia during Anesthesia in Infants: An Epidemiologic Study," *Anesthesiology*, 80 (1994): 976-82; N.M. Young, "Infant Cochlear Implantation and Anesthesia Risk," *Annals of Otolaryngology and Rhinology* 111 (2002): 49-51.

17. Young, see note 16 above.

18. C.M. Discolo and K. Hirose, "Pediatric Cochlear Implants," *American Journal of Audiology* 11, no. 2 (2002): 114-8.

19. As of May 2003, there were 118 cases of meningitis due to CI reported worldwide; 55 in the U.S., with five fatalities. The majority of cases occurred in children five years of age or less. Symptoms of CI-implicated meningitis appeared as early as 24 hours and as late as six years post-surgery; 50 percent of the cases, however, were within one year of surgery. Children who are candidates for a CI should receive the *Haemophilus Influenzae Type B* and *Pneumococcal* vaccinations to offset and decrease their risk of meningitis. J. Reefhuis, M.A. Honein, and C.G. Whitney, "Risk of Bacterial Meningitis in Children with Cochlear Implants," *New England Journal of Medicine* 349, no. 5 (2003): 435-45.

20. *Ibid.*

21. *Ibid.*, 435.

22. Nikolopoulos et al., see note 11 above; A.E. Geers, "Speech, Language, and Reading Skills After Early Cochlear Implantation," see note 11 above; A.M. Robbins et al., "Effect of Age at Cochlear Implantation on Auditory Skill Development in Infants and Toddlers," *Archives of Otolaryngology/Head and Neck Surgery* 130, no. 5 (2004): 570-4.

23. A.E. Geers, "Speech, Language, and Reading Skills After Early Cochlear Implantation," see note 11 above; Robbins et al., see note 22 above.
24. J.S. Moog and A.E. Geers, "Epilogue: Major Findings, Conclusions and Implications for Deaf Education," *Ear and Hearing* 24, no. 1 (2003): 121S-125S.
25. D.C. Thompson et al., "Universal Newborn Hearing Screening: Summary of Evidence," *Journal of the American Medical Association* 286, no. 16 (2001): 2000-10.
26. R. Calderon and S. Naidu, "Further Support of the Benefits of Early Identification and Intervention with Children with Hearing Loss," *Volta Review* 100 (2000): 53-84; M.P. Moeller, "Early Intervention and Language Development in Children Who Are Deaf and Hard of Hearing," *Pediatrics* 106, no. 3 (2000).
27. See note 6 above.
28. Kluwin and Stewart, see note 3 above.
29. Ibid.
30. See note 6 above.
31. J.L. Cherney, "Deaf Culture and the Cochlear Implant Debate: Cyborg Politics and the Identity of People with Disabilities," *Arguments in Advocacy* 36, no. 1 (1999): 22-34; H. Lane and B. Bahan, "Ethics of Cochlear Implantation in Young Children: A Review and Reply from Deaf-World Perspective," *Otolaryngology/Head and Neck Surgery* 119, no. 4 (1998): 297-312.
32. See note 6 above.
33. O. Sacks, *Seeing Voices: A Journey into the Land of the Deaf* (New York: Vintage Books, 1989).
34. NAD Cochlear Implant Committee, NAD Position Statement on Cochlear Implants, <http://www.nad.org/infocenter/newsroom/positions/CochlearImplants.html>, accessed 2 October 2004.
35. B.P. Tucker, "Deaf Culture, Cochlear Implants, and Elective Disability," *Hastings Center Report* 28, no. 4 (1998): 6-14.
36. Ibid.
37. K. Hakuta, *Mirror of Language: The Debate on Bilingualism* (New York: Basic Books, Inc., 1986); V. Gutierrez-Clellen, "Language Choice in Intervention with Bilingual Children," *American Journal of Speech Language Pathology* 8, no. 3 (1999): 291-302.
38. See note 33 above, p. 94.
39. See note 24 above.
40. Ibid.
41. J.B. Christiansen and I.W. Leigh, *Cochlear Implants in Children: Ethics and Choices* (Washington, D.C.: Gallaudet University Press, 2002), 314; J.B. Christiansen and I.W. Leigh, "Children with Cochlear Implants," *Archives of Otolaryngology/Head and Neck Surgery* 130, no. 5 (2004): 673-7.
42. Christiansen and Leigh, *Cochlear Implants in Children: Ethics and Choices*, see note 41 above, pp. 290-314.
43. See note 6 above.
44. American Academy of Pediatrics Committee on Bioethics, "Informed Consent, Parental Permission, and Assent in Pediatric Practice," *Pediatrics* 95, no. 2 (1995): 314-7; National Institutes of Health 1995 Consensus Development Conference Statement, "Cochlear Implants in Adults and Children," <http://medhelp.org/lib/100coc.htm>, accessed 13 December 2004. Parental decisions concerning CI are typically made now when the child's assent is moot. Where the child has the capacity, however, to make a decision in her or his own interest, she or he should be allowed to at least weigh in on, if not make that decision. The argument made by Ross that a child's questionable ability to implement and/or adhere to decisions that she or he has made do not apply in this particular context. An adolescent with deafness is in a better position to determine what she or he would be most comfortable with. Moreover, whether or not she or he has CI surgery now or delays it is no longer time sensitive; whether or not she or he turns off the CI causes no serious harm. See L.F. Ross, "Pediatric Bioethics: Reintroducing the Parents," *The Responsive Community* 9, no. 3 (1999): 40-7.
45. Cherney, see note 31 above.
46. A. Dreger, "Shifting the Paradigm of Intersex Treatment," <http://www.isna.org/library/dreger-compare.html>, accessed 2 Octo-

ber 2004, p. 1.

47. See note 6 above.

48. A.E. Brusky, "Making Decisions for Deaf Children Regarding Cochlear Implants: The Legal Ramifications of Recognizing Deafness as a Culture Rather than a Disability," *Wisconsin Law Review* 195, no. 235 (1995); E.J. Sher, "Choosing for Children: Adjudicating Medical Care Disputes Between Parents and the State," *New York University Law Review* 58, no. 157 (1983); R.G. Hartman, "Coming of Age: Devising Legislation for Adolescent Medical Decision-Making," *American Journal of Law and Medicine* 28, no. 4 (2002): 409-53.

49. See note 6 above; Christiansen and Leigh, *Cochlear Implants in Children: Ethics and Choices*, see note 41 above, pp. 290-316; Christiansen and Leigh, "Children with Cochlear Implants," see note 41 above.

50. See note 6 above.

51. *Ibid.*; Kluwin and Stewart, see note 3 above.

52. Kluwin and Stewart, see note 2 above.

53. See note 6 above, p. 6.

54. K. English, R. Kooper, and G. Bratt, "Informing Parents of Their Child's Hearing Loss," *Audiology Today* 16, no. 2 (March/April 2004): 10-2.

55. *Ibid.*

56. Valentine and Skelton, see note 9 above.

Dying While Homeless: Is It a Concern When Life Itself Is Such a Struggle?

John Song, Edward R. Ratner, and Dianne M. Bartels

INTRODUCTION

Society focuses much deliberation and energy to provide good end-of-life care and a “good death.” We have sought to identify the elements of quality end-of-life care, to quantify its delivery, and to institute interventions to improve end-of-life experiences. However, most of our conceptions and interventions to improve dying focus on individuals who have loved ones, reliable access to medical care, and stable homes.

Much of the provision of good end-of-life care is based on some fundamental assumptions. We assume, for example, that basic needs for food, clothing, and shelter are being met. Thus, we have identified advance-care planning and dying at home as important to a good death.¹ We assume that loved ones exist — or are desired. We have identi-

fied strengthening relationships as important for a good death.² We assume that we have some choices within our system of healthcare to improve how we die. Thus, we have identified symptom and pain management as important for a good death.³

We have, for the most part, not considered the viewpoints of those who die without loved ones by their side, without regular medical care, or without safe and stable housing—for example, our large population of homeless individuals. Homeless persons lack the basic connections to others, to resources, and to society that we believe are essential to a good death, and it is necessary to ask whether some of our assumptions fail to account for the lives of homeless people, many of whom are estranged from loved ones or disenfranchised from institutions of care and support.

A complete discussion of end-of-life care and death in this country needs to include homeless people for many reasons. First, there are many homeless people: estimates of the number of homeless persons in the United States on any given night range from several hundred thousand to several million.⁴ There are indications that the problem is getting worse; for example, there was a 13 percent increase in overall shelter needs in 2001.⁵

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Homeless persons also suffer disproportionately from illness, having more medical diagnoses and morbidity than comparison groups.⁶ They suffer not only from common conditions, but also from conditions related to their exposure to the elements, violence, poor sanitation, and stress.⁷ It is no surprise then that homeless people die at higher rates than anyone else — more than three to four times the rate of age-matched controls.⁸ Many die of conditions that afflict all of us, but many also die of conditions directly related to the lack of shelter, such as violence and exposure.

Compounding this crisis is the fact that homeless people have poor access to medical care.⁹ The barriers to accessing care are many, and are both personal and institutional.¹⁰ Although there are no studies addressing end-of-life care for homeless persons, it can be presumed that the barriers that homeless people face in receiving general medical care would also function as barriers to receiving end-of-life care.

There are also many characteristics common to homeless populations that may create special needs and attention at the end of life. For example, substance abuse is very prevalent in the homeless population,¹¹ and the use of illicit substances may affect adherence to care plans as well as the efficacy of pain control.¹² The high prevalence of mental illness among homeless persons¹³ may also greatly influence their adherence to care plans, as well as their emotional and personal responses to dying.

Finally, there are additional concerns raised by the very different personal and cultural characteristics of homeless persons. Given the immediacy of basic human needs faced constantly by homeless people, their thoughts on issues beyond daily survival may be very different than those who do not need to worry about food or shelter. Thinking about, having preferences about, and planning for death are higher-order concerns, perhaps a luxury, if one worries about food, shelter, and safety on a daily basis. Many concerns that have been identified by experts and the public as essential to good end-of-life care or to a

good death — such as achieving a sense of control or strengthening relationships — are higher-order concerns. If one's life is a daily struggle for basic existence, how might that affect one's views on death? How does the impoverished and basic existence that marks homelessness affect the moral imagination? Homeless persons might not be able or willing to think or plan about death — or be interested — or they may conceptualize death in extremely concrete terms, not able to consider more abstract worries such as closure, reconciliation, or spiritual peace.

Poverty and disadvantage have not been completely ignored in the search for good end-of-life care. However, the existing work is inadequate to fully portray the concerns of our most disadvantaged citizens. Understanding the viewpoints of people who are homeless regarding end-of-life issues will affect care and policy in several ways. It will help us attend to the needs of a substantial proportion of the population who have not been accounted for in the past. Elucidating the barriers to good end-of-life care experienced by homeless people may show barriers that other disenfranchised persons face. Finally, this information may offer insights into the most basic needs and wishes of all of us.

This work represents a pilot project we conducted, which had three main objectives:

1. To explore whether homeless people have the desire to talk about and interest in end-of-life care, dying, and death;
2. To inform the development of a larger investigation into this issue, including the construction of an appropriate questionnaire;
3. To explore whether persons who experience homelessness have concerns about end-of-life care, dying, and death that are different from those that have been described in the literature.

We conducted three focus groups for this exploratory investigation: two groups included those who provide services to the homeless, and one group of homeless men. We hypothesized that homeless people are

interested in talking about end-of-life care, dying, and death, and that an investigation into the concerns of homeless persons about these issues would raise different domains of concern than traditional end-of-life studies.

METHODS

PARTICIPANTS AND RECRUITMENT

Social workers from two service organizations that serve the homeless population in Minneapolis were recruited for this project — Loaves and Fishes, a nonprofit organization that provides free meals, and Anishinabe Waikagun, an extended-stay facility that serves those with chronic alcoholism who are homeless. Homeless participants were recruited from St. Stephen's, a large homeless shelter in Minneapolis.

All participants were required to be at least 18 years old, speak English, and be able to give valid informed consent. Homeless participants were required to have been homeless for the last six months. We defined "homelessness" according to the language of the federal guidelines, which define a homeless person as one who

lacks a fixed, regular, and adequate nighttime residence and has a primary nighttime residency that is: (A) a supervised publicly or privately operated shelter designed to provide temporary living accommodations. . . . (B) An institution that provides a temporary residence for individuals intended to be institutionalized, or (C) A public or private place not designed for, or ordinarily used as, a regular sleeping accommodation for human beings.¹⁴

The focus groups represent a convenience sample recruited during a pre-arranged visit to the organizations that participated in the study. The directors of each of the organizations initially approached individuals who they felt would be most likely to agree to participate, and who met the study criteria. The investigators explained the project to the potential participants as a group, and then ob-

tained informed consent from each participant. Homeless participants were offered and paid \$20 for the session.

STUDY DESIGN AND MEASUREMENT

This project utilized a qualitative approach, which is ideal for exploring our hypotheses. Specifically, we employed the use of focus groups, which take advantage of group dynamics to elicit information that may not be obtained through individual interviews.¹⁵ The interviews were semi-structured, allowing participants to control the flow of discussion. This use of a qualitative approach is an attempt at a ground-up discovery; it is intended to allow the subjects to speak for themselves and not to have them respond simply to investigator-generated concerns.¹⁶ Domains of initial inquiry were derived from the literature on end-of-life care and dying. These domains included:

- Subjects' experiences with end-of-life care and dying (personal and other),
- The level of homeless persons' concern and willingness to talk about end-of-life issues,
- Subjects' conceptions of dying and a good death,
- Subjects' views on how investigators might best approach this issue in this population.

The University of Minnesota Human Subjects Committee approved all of the procedures in this project.

Interviews were conducted by the three investigators, all of whom were trained in qualitative methodology. The interviews were audiotaped and transcribed, and investigators took notes during the interviews to record nonverbal communication and other pertinent information.

DATA ANALYSIS

The transcripts were coded independently by the investigators through editing analysis, a process that involves close, repetitive readings of the transcripts for themes or domains.¹⁷ The investigators independently derived the

preliminary domains during their initial analysis and coded the transcripts according to the domains. The investigators convened to revise and reconcile the independently derived domains, and the transcripts were recoded, using the revised domains. Discrepancies were discussed with all investigators, a process that further refined the characterization of the domains. Passages of text were extracted mutually to best characterize each domain.

TRUSTWORTHINESS

We employed several measures to ensure trustworthiness. First, we independently generated preliminary domains, and then met as a group to refine and reconcile differences. Next, we compared domains from this project with the literature and existing taxonomies of end-of-life care and dying established by experts, professional organizations, and patients. Finally, we recruited a person who provided services to the homeless and a homeless individual who was not involved with this pilot project to further validate our findings.

RESULTS

A total of 20 participants in three focus groups participated in the pilot study (nine service providers and 11 individuals who identified themselves as homeless). Table 1 describes the various domains elicited through the interviews, as well as the various components of each domain. Components of each domain were found in each focus group, another assurance of the trustworthiness of the data. The domains that the investigators formulated through analysis were as follows. (All quotations were directly transcribed from the interviews.)

CONTEXT OF DEATH

There was much discussion about the context of death among this homeless population. Death appears to be ubiquitous — frequently on the minds of homeless people and a part of life living on the streets. Death was also characterized as sudden and often violent.

Homeless person: They're [homeless people are] kind of like buffalo. They're out in a herd back in the buffalo hunting days. There's this great big herd of buffalo and they're all standing there chewing on the grass and all of a sudden you hear a shot ring out and a buffalo standing right next to you goes "oh," hits the dirt because he's been shot. And the other buffalo look over there and turn back and keep on eating the grass. And then another shot rings out and the guy on the other side of you goes "oh."

Homeless person: You can be walking down the street . . . or you can see me walking down the street and all of a sudden, lights out.

CONCERNS AND FEARS ABOUT DYING AND DEATH

Homeless participants revealed many concerns and fears about dying and the circumstances of their deaths. As noted above, there was great concern about dying violently. There was also a great deal of concern about dying alone and dying on the streets.

Homeless person: If I was to die, and die here in Minnesota, I do think about death. I could see myself in that bed and nobody around, and to be that would be really sad.

There were many concerns expressed about what happens to the physical body after death and whether certain traditions were carried out.

Service provider: One of the guys that stayed at St. Stephen's for quite a few years came up to me one day and said, "What will happen to me when I die?" And I didn't know, I mean because he was smiling, and I said, "Well, you'll make a pose or something." I tried to make a joke of it. Then he said, "No, I mean what will happen to my body? Who will take care of me?" He said, "I want to be buried in my, you know, in my Native ways . . ."

BARRIERS TO CARE AND END-OF-LIFE CARE

Both service providers and homeless persons described many barriers to healthcare. Some of the most difficult barriers to overcome

are institutional or societal, and are strongly influenced by prejudice, discrimination, and poor attitudes on the part of service providers, while other barriers are personal, such as a mistrust of medical providers and the medical system.

Homeless person: With me — I've seen a couple of guys die since I've been here, and my main concern is that people know that they need help, and they ask for help, and they can't get it. . . . Two or three days later, people ask, "Where's what-you-call-him?" "Oh, he dropped dead." It's like they just kick you to the

Table 1
Concerns of Homeless Persons Regarding Death, Dying, and End-of-Life Care

Context of death:

- Death is sudden.
- Death is ubiquitous.
- Death is often violent.
- Suicide can be common.
- Many have experience with or first-hand knowledge of death.

Concerns and fears about dying and death:

- Don't want to die alone, but this is very possible.
- Don't want to die in pain.
- Afraid that death may be a violent one.

Concerns and desire for advance planning:

- Fear of inappropriate/prolonged medical "care."
- What will happen to me if no one can speak for me?
- Do not want nursing home or other institutional care.
- Don't want to lose freedom when dying.
- Fear that body will not be respected or taken care of.
- Fear that death rituals of one's culture may not occur.
- Fear that no one will be there to view body.

Barriers to care and end-of-life care:

- Prejudice and poor attitudes from physicians and other providers.
- Undocumented status or running from law.
- Personal barriers include mistrust and lack of knowledge of medical system.
- Resistance to change that might be beneficial.

Interpersonal relationships, models, and communication:

- Would like to talk about death and dying.
- Have poor familial relationships.
- Wish that family may show up during dire illness or death, but fear that they would not.
- Fear that family may not know wishes leading to poor surrogate decision making.
- Peers might help to a certain extent, but no assumptions of this help.
- Many without trusted peers .

Meaning of life and death:

- Freedom is essential.
- Acceptance of death.
- Fatalism.
- The will of God.
- In the face of certain death, one must still have hope.
- The importance of the afterlife.
- The importance of religion and God.

curb. You don't exist, basically, the way that some of the medical field looks at it. You walk into a hospital sometimes, and because you're not dressed right, you get shunned.

INTERPERSONAL RELATIONSHIPS, MODELS, AND COMMUNICATION

Participants repeatedly spoke about communication and the lack of meaningful dialogue. The interviews demonstrated willingness, eagerness, and need to talk about end-of-life care, dying, and death.

Service provider: I mean I've heard a million stories . . . it started me being very saddened, wondering. I have family. I will be cared for in a way that I request. And people that I sit with every day won't simply because they haven't money or family. . . . They don't have anyone to talk to about this stuff, but you can see how important it was for him to have something done when he died.

Despite this willingness and need to talk about these issues, there was much indication that individuals did not have the trusting relationships that are necessary for such discussion. Family relationships, for example, frequently were described as poor or nonexistent.

Homeless person: Right now, I have left my folks. They know where I'm at. I got a brother here and he just saw me down the way, but there's no love there. The part that scares me, even though I lived a longer life, and I didn't expect to live a long life, is growing up with nine sisters in my family and I got a half-brother, and that still separates me. But to leave this world, I've been here seven years, and have no family to come by and visit me. They won't even stop by. As I get older, I'm saying, "Wow, I might die." This dying bit, and I don't have no one. They'll be there when I'm dead and gone, but who wants to wait till you're dead to be around?

Peers were discussed as possible sources of comfort and support, if not as surrogates to make decisions. However, many persons experiencing homelessness appear to be isolated and lacked trusted peers or companions.

Homeless person: I know my junkie friends aren't going to come down to visit me, and my drinking friends.

THE MEANING OF LIFE AND DEATH

Participants focused a great deal of their thoughts and discussion around the meaning of life and death, or put the concerns discussed above into a spiritual context. One commonly occurring theme was the acceptance and inevitability of death. This inevitability of death was either the will of God or the result of fate.

Homeless person: Because I can't change it. I can't change why it's snowing right now, why it rains. I can't change it; I'm not God. I can't do nothing about it. If I were sick, I could take some medicine to try to live longer, but I can't do nothing about it. If the good Lord is ready for you, ain't nothing you can do about it.

Homeless person: It's just not your day. Even though you are surrounded by death and you manage to live through it, it just ain't your day. But you are born one day and you're going to die one day. I'm saying that it ain't my day. When I pass away, which I'm going to do, that's my day.

While death is certain, and one must accept this fate, one must, however, still have hope, manage risks, and prevent death, and live life as much as possible, according to the participants.

Homeless person: But if that time's gonna come, it's gonna come, so I'm going to enjoy my life the best way I can, and try to help other people enjoy theirs too. I'm not going to be ducking around, being afraid, because life is part of death and death is part of life.

Religion, God, and the afterlife were commonly expressed concerns and themes. Much of the discussion occurred in the context of religion and God, and the afterlife had particular importance. Many participants fear the afterlife and desire time to prepare for it.

Homeless person: I know I believe in the Creator and the bible, but I feel that I want more time to get

myself together and be ready because I feel that right now I'm going to be judged and I ain't ready.

DISCUSSION

Both experts and the public have sought to identify the elements of quality end-of-life care. A complete review of these efforts is beyond the scope of this article; however, a summary is useful to demonstrate how the perspectives of disadvantaged persons may not have been fully considered in previous conceptual and empirical work in this area. In reviewing what we know about care and dying and the end of life, it becomes apparent that there are gaps in our understanding, particularly when it comes to addressing persons of low socioeconomic status.

Singer and colleagues summarized the domains of quality end-of-life care from three expert perspectives.¹⁸ There is considerable overlap in a policy statement endorsed by a number of healthcare organizations and published by the *Journal of the American Geriatrics Society*, in an Institute of Medicine report, and in an article by leading ethicists, Emanuel and Emanuel (see table 2).

These and other experts¹⁹ have come to similar conclusions: advance planning and end-of-life care is important; patients desire control of physical and emotional symptoms; dying persons wish to have their autonomy and spiritual needs respected; patients and families expect quality care from providers; and dying persons find their social relationships and support essential. As valuable as these reports have been, they have focused on the needs of people who are like the individuals who serve on these panels — people with homes, families, and health insurance. These reports rarely address the end-of-life needs of those whose daily lives are tenuous and for whom the end of life is most uncertain.

Other studies have examined end-of-life care from patients' perspectives. Singer and colleagues analyzed data from interviews with three groups of Canadians,²⁰ and Steinhauer and colleagues analyzed transcripts from focus groups of health professionals, patients, and recently bereaved family members at a Veterans Administration hospital.²¹ The issues that were identified by patients as essential to good end-of-life care and a good death were similar to those issues identified by experts:

Table 2
Domains of Quality End-of-Life Care

<i>Journal of the American Geriatrics Society</i> ¹	Institute of Medicine ²	Emanuel and Emanuel ³
Physical and emotional symptoms	Overall quality of life	Physical symptoms
Support of function and autonomy	Physical well-being and functioning	Psychosocial and cognitive symptoms
Advance-care planning	Psychosocial well-being and functioning	Social relationship and support
Aggressive care near death	Spiritual well-being	Economic and caregiver needs
Patient and family satisfaction	Patient perception of care	Hopes and expectations
Global quality of life	Family well-being and perceptions	Spiritual and existential beliefs
Family burden	Survival time	Provider continuity, skill

Adapted from P.A. Singer, D.K. Martin, and M. Kelner, "Quality End-of-Life Care: Patients' Perspectives," *Journal of the American Medical Association* 28, no. 2 (13 January 1999): 163-8, which cited: "Measuring Quality of Care at the End of Life: A Statement of Principles," *Journal of the American Geriatrics Society* 45 (1997): 526-7; M.J. Field and C.K. Cassel, ed., for the Institute of Medicine, *Approaching Death: Improving Care at the End of Life* (Washington, D.C.: National Academy Press, 1997); and E.J. Emanuel and L.L. Emanuel, "The Promise of a Good Death," *Lancet* 35, suppl. 2 (1998): 21-9.

receiving adequate pain and symptom management; avoiding inappropriate prolongation of dying; achieving a sense of control; relieving burden; strengthening relationships; clear decision making; preparation for death; and affirmation of the whole person.

Another common theme found in empirical work is a preference among most people to die and receive end-of-life care at home. This preference has been cited in studies of patients after they were released from an intensive care unit, in those receiving home care, and among individuals with cancer.²² Widespread preference for dying at home was also confirmed in a 1996 Gallup poll.²³

Poverty and disadvantage have not been completely ignored in the search for good end-of-life care. Researchers, for example, have found associations between higher levels of education, socioeconomic status, and insurance status and greater completion rates of advance directives.²⁴ The few investigations that have addressed the effects of poverty on the quality of end-of-life care usually come to grim conclusions. For example, a study conducted in 1999 among people dying with HIV found that those most impoverished were more likely to die in the hospital and in pain.²⁵ Commentators have noted that uninsured persons probably do not have access to many of the services needed for a good death, while others have speculated that poorer individuals might opt more frequently for life-terminating measures because of financial concerns.

However, even these studies make fundamental assumptions about desirable end-of-life care and the conception of a good death. Given the very personal nature these concerns, and the effects that extreme poverty, alienation, fear, and exposure can have on a person's view of life, it is necessary to hear the actual voices and concerns of people experiencing this condition.

Our major finding in this study was how willing and eager homeless persons were to speak about end-of-life issues. The discussion with homeless individuals was involved, vigorous, and emotional. Discussants often spoke

above one another, and each spoke at length. As can be seen by the results, the discussants had either experienced the issues around the end of life firsthand, or through a friend or relative, and/or had thought about the issue at length. Many of their statements were well-developed and demonstrated past reflection. Recruitment to the study was aided by the compensation provided, but the ease of recruiting subjects also reflected, in our opinion, their interest in the subject and/or experience. The amount of personal experience with death; the depth of previous consideration of death, dying, and end-of-life issues; and the passion and interest demonstrated by the participants were surprising and unexpected from a population that is often characterized as focused on daily survival and wary of scrutiny. Even with this small exploratory sample, it is clear that homeless persons desire to discuss death, dying, and end-of-life care.

Another new finding was the identification of several domains of concern regarding dying that have not been described in previous studies of those in more comfortable and secure situations. Even in this preliminary investigation, participants voiced concerns that have not been previously reported. There was, for example, an often-repeated concern about the fate of their physical body — whether anyone would view and witness their passing; whether their body would be respected; and what would actually happen to their body should no one claim it. This is a chilling, but logical, concern that would be raised among those who are so alienated and disenfranchised from close personal relationships and society. It's assumed by most individuals that one's body will be respected and cared for after death, and the authors — all with experience in end-of-life care — were surprised that they had not considered this to be a concern in their previous work and experience.

There was also the view that death was a sudden and ubiquitous part of life, and not the result of prolonged illness — it is something for which one doesn't plan, but one that is sudden and inevitable, yet still unexpected.

One could, as the participant said, be “walking down the street and, all of a sudden, lights out.” This kind of death requires a very different approach to advance-care planning than the deaths most of us anticipate. Given these and other concerns in this pilot investigation, we believe that further exploration of death and dying issues in this population will yield more concerns that are not yet reported in the end-of-life literature, or, perhaps more importantly, have not been considered by those who deliver care at the end of life.

The major limitation of our work is that it is preliminary and only speaks for the experiences and concerns of a very small sample of homeless persons, who were men. The circumstances of homelessness and the people who experience it are as unique and as varied as the experiences of people who have homes. It would be illogical, incorrect, and a disservice to assume that the experiences and concerns that we have explored are common to all people living without a home. The number of participants was small, and any conclusions cannot be generalized — all findings are exploratory.

Another limitation is that our subjects represented a convenience sample of individuals who accessed particular service organizations. There is evidence that homeless persons who access service organizations have different demographics than those who do not, and may have different levels of trust in institutions and the healthcare system; as a result, our findings may not be applicable to homeless persons who do interact with institutions. The views of those alienated from institutions may be very different, and this also needs further exploration.

However, despite these limitations and the preliminary nature of this work, our study strongly suggests further follow-up work and even some interventions to improve the end of life in this population. This work needs to be validated in larger groups of people experiencing homelessness, with greater representation of all groups who constitute the “homeless population”; for example, women, parents, elderly, and various racial and ethnic

subgroups. Also, this work may need to be replicated in different locales, as the experience of living without secure shelter as well as the local culture differs greatly from place to place — living without a home in frosty Minnesota is a different experience than in Phoenix, for example, and may influence how one thinks of death. Finally, larger-scale survey studies would be needed to generalize and further validate any findings.

Despite the need for further investigation and the preliminary nature of our findings, several interventions to improve dying and death for homeless individuals are suggested from this work. Educational initiatives directed both toward providers and homeless clients may be extremely beneficial. These educational interventions would be directed toward social service providers, who need to understand the end-of-life concerns of their clients, and toward hospice and other end-of-life providers who need to understand the special concerns and needs of homeless individuals. Another possible intervention suggested by our work is the identification of proxies not only for medical decision making — as traditionally identified — but also for the witnessing and care of the body after death. As it was reported that death is sudden and often occurs in out-of-the-way places (for example, under bridges, on the street), having some form of identification card with simple directives or contacts may also serve to preserve the dignity and autonomy of homeless persons at the end of life. It is worth observing that many of the interventions that are suggested by this work are simple ones, perhaps reflecting that — as in life — in death, the initial needs of homeless persons are basic.

In summary, this preliminary exploration supports our hypothesis that homeless people have a desire and interest in talking about end-of-life care, dying, and death. Interviews with homeless individuals and their service providers revealed a number of end-of-life concerns not described in the literature. Further investigation is needed to validate these findings and discover new concerns with a larger

and broader sample of people experiencing homelessness. Homeless populations are extremely diverse and complex, and further research is needed to differentiate among those different subpopulations who live without safety and security. Finally, exploration is needed to identify possible interventions to improve the final days of those who live such desperate and difficult lives.

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Raging Against the Night: Dying Homeless and Alone

James J. O'Connell

On the first Friday of March, we gathered in the basement of St. Anthony's Shrine in the heart of downtown Boston to remember a 49-year-old Air Force veteran and high school hockey star whose stubborn charm enchanted and exasperated us during his two decades on the streets of our city. Three days after Christmas, in frigid and snowy weather, he was found on a cement bench two blocks from Massachusetts General Hospital (MGH) with a core body temperature of 78°. The cause of death remains uncertain; he likely suffered a myocardial infarction or a seizure in the hours before he was found. Heroic measures to "warm" him in the emergency room with heated saline and bilateral chest tubes failed to restore a heart rhythm.

The subterranean ceremony was evocative and profound: songs sung to piano, guitar, and trumpet; poems of loss and hope; readings from the Old Testament; tears punctuated by

peals of laughter as the many assembled shared stories. The wide circle of caregivers surprised all of us and included emergency room nurses and social workers, outreach street workers, therapists from the mental health community, and our own street team who provided his primary medical care. This ebullient man had logged legendary numbers of visits to the MGH emergency department, earning a virtually permanent gurney in the hallway while blowing kisses to nurses, never refusing meals, and never failing to offer profound thanks to each one who cared for him. He was one of the most frequent and outspoken utilizers of the emergency service team of the Department of Mental Health. The staff of Andrew House lamented the loss of a man who had tried literally hundreds of detoxifications in this dual diagnosis unit, but never managed to achieve more than a few weeks of sober time. We couldn't help but share a single observation: how surprised he would be to see how many persons remembered and cared for him.

His past was shrouded in mystery, although he once admitted he had been married and had lost contact with his two chil-

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dren. No family members have been located since his death, and his hulking body remains unclaimed in the city morgue.

The findings in the evocative study by Song and colleagues in this issue of *The Journal of Clinical Ethics* resonate dramatically for clinicians engaged in the care of homeless individuals and families. The experience of illness and suffering for persons living without homes in urban and rural America is complex and poorly understood. The literature is bereft of studies on palliative and end-of-life care for homeless persons, even though our best practices firmly place the home and family at the center of care for the dying. Our patient's story is a familiar one; most inner-city physicians and other clinicians have witnessed the lonely, desperate, and often painful deaths of homeless men and women in our hospitals. Song and his colleagues urge us to no longer ignore this hidden burden of human suffering and tragedy.

Death is commonplace on the streets and in the shelters, a constant — albeit erratic — companion for persons living in shelters and on the streets. Studies from Philadelphia, Boston, and Atlanta have found mortality rates in homeless adults to be three to four times greater than in their housed counterparts.¹ A study of homeless women in Toronto found a 10-fold increase in mortality when compared to other women in that city.²

The risk of dying increases dramatically for persons wandering the streets. The Boston Health Care for the Homeless Program (BHCHP) has followed a cohort of 119 persons living on the streets since 2000. Most have been homeless for more than a decade, and many for more than 20 years. The mean and median age is 47, with a range from 32 to 82 years. The demographics do not differ from the overall homeless population in Boston. Surprisingly, 80 percent are disabled and have health insurance. In the five years from 2000 through 2004, 33 (28 percent) died and another six (5 percent) are now in nursing homes. The causes of death were primarily chronic diseases such as cancer, cirrhosis, ob-

structive lung disease, and heart failure; only two persons died of hypothermia and exposure. Such morbidity and mortality is alarming and often preventable; such outcomes in any disadvantaged population represent astonishing healthcare disparities that constitute a public health emergency.

Behind the numbing statistics are the stories: people struggling against the oppressive odds of persistent poverty and homelessness. Stunning glimpses of these lives emerge in the interviews in Song's study. Fears candidly voiced include dying alone and in the streets, the disposition of one's body after death, and whether anyone will remember them. The ubiquity of death in the journey through homelessness seems to ease any reluctance to discuss dying and spirituality among those interviewed. While the group interviewed is small in number, their responses parallel our experiences during these past 20 years.

The call from the Medical Examiner's office to help identify a John or Jane Doe comes often. The fear of dying alone on the streets is prominent and palpable among homeless persons, and not without good reason. Many individuals in the city morgue remain unknown; more commonly, as with our patient above, we are able to identify the body but cannot find any next of kin. Unless we are able to find a generous funeral home director and a donated cemetery plot, those unfortunate individuals are cremated and buried in a paupers' field after six months. A 35-year-old man died of AIDS several years ago after months of suffering through repeated bouts of pneumonia and a profound wasting syndrome. He absconded from innumerable hospitals and nursing homes seeking independence on the streets, soon to be found gravely ill and brought to local emergency rooms. As happens frequently with our patients, we learned upon his death that the name he gave us was an alias. Despite caring for him intensively for over a decade, we never learned his true identity and have no idea whether any family members exist. A kind funeral director arranged a wake for him, a Mass was said in an

inner-city church where he often slept in the alcove, and he was buried in a plot alongside thousands of indigent citizens of our city. His grave is marked by a small bronze medallion with a number; the name associated with the number is kept in a ledger at Boston City Hall.

The loss of autonomy and the fear of losing control at the time of death are concerns with substantial validation. A patient of ours was apprehended for several misdemeanors and imprisoned in the county jail for several months. This 45-year-old man, combative and vituperative, won my begrudging respect for his fearlessness and noble insistence on being the protector of older folks on the streets. His approach to the world was explosive and confrontational, raging openly about the "lousy hand" he had been dealt in life. He belittled most of us in healthcare for "never listening," even though he frequently presented with a plethora of somatic complaints that resulted in exhaustive and futile evaluations. He wrote several letters from jail imploring our intercession, as his complaints of severe back pain were being ignored. I finally visited and found a pale, cachectic man unable to get out of the chair without severe pain. His complaints had gone unheeded, even though a chest x-ray upon incarceration four months earlier showed a suspicious lung mass and several collapsed vertebrae. After an immediate transfer to our hospital for treatment, he requested that "everything" possible be done. However, his condition rapidly deteriorated, and we began a nightly vigil in his room. An armed guard was constantly at his door, and his leg shackles remained in place because he was a prisoner of the county. He fought furiously for life, sitting up through the night gasping for breath while refusing oxygen. On the day before his death, he pleaded for the dignity of dying without the shackles on his legs. After many hours of calls and with the help of the hospital lawyers, we found a judge willing to release him to our custody. Once the shackles were removed, his anger and will to live both dissipated, and he died within hours.

The lack of stable housing exposes a critical shortcoming in the continuum of care offered by our country's healthcare system and raises substantial ethical and pragmatic issues, especially for palliative and end-of-life care. In 1985, to bridge this gap, Health Care for the Homeless programs in Boston and Washington, D.C., with funding from the Robert Wood Johnson Foundation, developed and implemented the concept of "respite care." Medical care and a safe place to heal were offered to homeless persons who have short-term illnesses, infections, and injuries, who would otherwise require prolonged hospitalizations or risk considerable harm on the streets.

In the interim, seismic changes in our healthcare system have shifted the focus of care from hospital to home for many critical services. Drastic reductions in hospital lengths of stay, the astonishing evolution of anesthesia and minimally invasive day surgery, and the shift in specialty services from hospital to outpatient clinic (for example, chemotherapy) have resulted in a dramatic increase not only in the demand for respite beds, but also in the acuity and the complexity of the medical needs of persons referred for respite care. In 1993, BHCHP moved its original respite care program of 25 beds, initially nestled in a local shelter, to the Barbara McInnis House, a free-standing former nursing home that has 90 beds with 24-hour medical and nursing care. This program offers acute, subacute, pre- and post-operative, recuperative, rehabilitative, palliative, and end-of-life care to homeless persons throughout Boston and the Commonwealth of Massachusetts. Referrals come from emergency departments, hospital in-patient units, primary care and specialty clinics, and directly from BHCHP staff in shelters and on the streets. The demand remains intense and overwhelming; the census at McInnis House has seldom fallen below 95 percent.

McInnis House has been the venue for the deaths of several of our patients, a difficult but enlightening body of experience that con-

firms much of what has been voiced by the cohort in Song's study. Several years ago we diagnosed an undocumented 42-year-old man from Central America with a leiomyosarcoma. A tireless worker at a local thoroughbred race-track, he lived in a barn on the backstretch and sent half of his meager wages to his impoverished family. With no place to go, he was admitted to McInnis House after his initial surgery and remained while he underwent monthly chemotherapy that left him frail and fatigued. His response to treatment was disappointingly brief, and his medical and nursing care became intense as he weakened, and we initiated a referral to a skilled nursing facility for hospice care. This taciturn man tearfully pleaded to stay in the place he felt safe and accepted. The staff of doctors and nurses had become family as well as caregivers, a situation we had not anticipated. Virtually everyone volunteered to take turns sitting with him at night to monitor pain, ease his fears of being alone, and help him to the commode. Hospice nurses came to McInnis House to assist with his care and to educate us in end-of-life care. He died peacefully and with minimal pain two months later.

The time spent and intensity of these efforts were exhausting and created considerable tension within an already beleaguered staff. Yet all were grateful for the opportunity. Perhaps most profoundly, the fears of our other patients were allayed with the realization that they also would not be abandoned at the time of death.

Each death has posed new challenges and unearthed new obstacles. A 50-year-old Vietnam veteran who spent 20 years living in Boston Commons developed head and neck cancer soon after celebrating a year of sobriety. His medical odyssey included a sequence of progressively more radical surgical procedures after he failed to respond to weeks of radiation therapy and two courses of chemotherapy. He eventually lost most of his mandible and his tongue. Time outside the hospital was spent in our respite care program, where he stubbornly managed his own tra-

cheostomy care while still smoking in the courtyard. His deepening depression, explosive outbursts over innocuous comments by other patients, and an escalating dependency on opiates for pain control became contentious and frightening, and he was eventually transferred to a nursing home for the last three months of his life. We would visit him regularly, although we endured venomous wrath if we missed a day or failed to bring cigarettes. Unable to muster even a nod of thanks through his disfigured face, he left a poem of hope and gratitude in his bedside drawer to be read at his funeral.

Respite care programs for homeless persons now exist in over 30 cities throughout the country. Studies are critically necessary to determine clinical outcomes, cost-effectiveness, and the ability of such programs to divert emergency department visits, avoid acute care hospitalizations, and shorten hospital lengths of stay. Respite care programs offer a stable venue for palliative and end-of-life care and the hope of a good death.

Homeless persons in this small study echo a familiar desire to be remembered after death. To mark the deaths of homeless persons and to stave off fears of oblivion on the part of the living, annual memorial services are conducted in most large cities across the country, often sponsored by the National Health Care for the Homeless Council, the National Coalition for the Homeless, the National Alliance to End Homelessness, and local advocacy or religious groups. These public gatherings are attended by large numbers of homeless persons, and the litany of those who die each year is read aloud. Some cities have public memorials prominently displayed throughout the year. Jim Withers, MD, and Operation Safety Net, who have provided care for street persons in Pittsburgh for over a decade, engrave small bronze plaques with the names of each deceased person and mount them on the abutment wall of a bridge. This breathtakingly simple monument is located in a busy downtown area well-traversed by the homeless community.

Palliative and end-of-life care in our society must continue to improve throughout our healthcare system, and this important article by Song and his colleagues begs us to not forget or ignore our homeless poor who die alone and forgotten in the long shadows cast by our hospitals and healthcare institutions.

NOTES

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Clinical Research Ethics

Ethical Dilemmas Encountered by Clinical Researchers

Gordon DuVal, Gary Gensler, and Marion Danis

INTRODUCTION

Recent research controversies, including those at Johns Hopkins,¹ the University of Pennsylvania,² the University of Oklahoma,³ and elsewhere have inspired strong responses from the United States Office of Human Research Protections⁴ and the broader research community.⁵ Criticism of these institutions and proposals for reform have focused primarily on investigators' conflicts of interest and the quality of review of impugned protocols by institutional review boards (IRBs). Commentators and regulators have asked: Should these research projects have been allowed to

proceed at all? That question is consistent with the academic literature on research ethics, which has focused almost exclusively on issues of research design and standards for review and approval by IRBs.

Yet ethical dilemmas arise in all stages of research involving human subjects. Subject recruitment, informed consent, protecting confidential research information, assessing ongoing risks to subjects, and other aspects of research commonly present difficult ethical challenges for investigators. While IRBs may be able to anticipate and make provision for some of these problems, difficulties often arise after the study design is finalized and approval from an IRB is obtained. We are aware of no systematic study of the kinds of ethical dilemmas encountered by clinical researchers, investigators' satisfaction with their resolution, or the utilization of ethics consultation in a research setting. To address these questions, we conducted a survey of physicians and nurses at the Clinical Center of the National Institutes of Health (NIH), a 267-bed hospital facility devoted exclusively to research.

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METHODS

STUDY POPULATION

A random sample of research physicians and nurses was selected from lists of credentialed staff of the Clinical Center at the NIH in Bethesda, Maryland. Respondents were eligible for this study if they reported that they had been in practice for at least one year and had spent at least 20 percent of their time in clinical research activities at NIH.

STUDY SITE

The Warren G. Magnuson Clinical Center annually enrolls approximately 9,500 subjects into 1,165 research protocols, including 516 clinical trials (2001-2002 figures). Its Bioethics Consultation Service is staffed 24 hours a day by a bioethicist and a fellow from the Department of Clinical Bioethics and members of the Clinical Center Ethics Committee, which includes physicians, nurses, staff with training in social work, chaplaincy, and community representatives. Any professional or nonprofessional staff, research subjects and their families, or anyone else connected with the Clinical Center may request a consultation. The service provides approximately 90 consultations per year, ranging from telephone consultations to full committee consultations.⁶

SURVEY DEVELOPMENT

A survey instrument was developed based on a review of the research ethics and ethics consultation literature. Except for minor alterations reflecting the different context, the survey instrument is identical to that used in a parallel study of internal medicine physicians published by the authors.⁷ The term "ethical dilemma" has a very specific meaning for philosophers, as a situation requiring a choice between what seem to be equally desirable or undesirable alternatives, each of which seems to be justified by a well-established moral rule or principle.⁸ We intentionally did not define ethical dilemmas for respondents, because we wanted to elicit ex-

amples of ethical problems as researchers themselves perceive them.

We report results of the survey for questions in three domains: (1) the types of ethics issues faced by clinical investigators, (2) respondents' perception of the need for and effectiveness of ethics consultation services, and (3) sociodemographic, training, and practice characteristics of the physician and nurse investigators. To measure respondents' satisfaction with the resolution of ethical dilemmas and usefulness of ethics consultation, we used an 11-point scale (with 0 being "not satisfied at all" and 10 being "extremely satisfied"). To measure the usefulness of ethics consultation in reaching better ethical decisions, a similar 11-point scale was used. The survey instrument is available from the authors upon request.⁹

SURVEY ADMINISTRATION

Computer-assisted telephone interviews, lasting an average of 26 minutes, were conducted by trained interviewers from the Center for Survey Research at the University of Massachusetts in Boston. Subjects were not paid to participate.

HUMAN SUBJECTS PROTECTION

Participation did not involve the collection of personally identifiable information. Because of its anonymity and minimal risk, the Office of Human Subjects Research at NIH reviewed the study and exempted it from review by an IRB.

ANALYSIS

Respondents were asked to give narrative responses to identify the types of ethical dilemmas they face. These responses were coded using a consensus process. The investigators reviewed a 20 percent random sample of responses to identify major themes and to establish a coding scheme. The coding scheme identified broad categories of dilemmas (described below), such as informed consent, recruitment, and termination of research par-

ticipation (see table 1). This coding scheme was used to identify: (1) the most difficult type of ethical problems encountered, (2) the most recent ethical problems encountered, and (3) the most recent ethical dilemma for which ethics consultation was sought. Two investigators assigned up to three codes to each response. Multiple codes were required when complex situations gave rise to different kinds of ethical issues. Three investigators discussed coding disagreements until consensus was reached.

We developed a seven-point index to measure respondents' training and experience with medical ethics. This training/experience index was scored as follows:

- Attendance at six or more bioethics rounds (1 point),
- Participation in a bioethics conference or bioethics course (1 point),
- Participation in an intensive bioethics course (1 point),
- Completion of a bioethics fellowship (1 point),
- A report of general confidence about knowledge of current standards of ethics (1 point),
- Past or current participation on a clinical ethics committee (2 points).

Possible scores ranged from 0 points for no experience to 7 points for the most experience.

Table 1
Categories of research ethics dilemmas

	Most difficult dilemma		Most recent dilemma		Dilemma leading to ethics consult	
	Physicians (n = 160) %	Nurses (n = 159) %	Physicians (n = 130) %	Nurses (n = 137) %	Physicians (n = 175) %	Nurses (n = 85) %
Dilemmas not directly related to research						
End-of-life care	18*	29*	18	26	19	25
Informed consent	4	9	5**	18**	15	24
Confidentiality/truth-telling	5	9	8	16	7	7
Religious or cultural difference	2	3	5	4	9*	1*
Beneficence	2	2	2	3	3	0
Dilemmas related to research						
Informed consent	31	29	37**	15**	31	18
Conflicting clinical obligations	15	12	11	15	1*	9*
Children in research	8	9	8	11	12	12
Study design	9	7	4	7	4	
Termination of research participation	4	8	7	10	47	
Justice and the uninsured	5	4	13	10	8	10
Professional conduct	3	4	12	10	5	2

Notes: The table presents the percentage of responses that were assigned to each code category. The results add up to more than 100 percent because up to three codes were assigned to each response. Responses of "don't know," "no," and uninterpretable responses were omitted.

* Indicates statistically significant difference in the responses of the groups of subjects at the .01 level.

** Indicates statistically significant difference in the responses of the groups of subjects at the .05 level.

Descriptive statistics were used to summarize the frequencies of responses. Univariate and multivariate logistic regression analyses were performed to determine factors associated with the likelihood of a researcher requesting an ethics consultation. Linear regression was performed to determine factors associated with physician satisfaction with their own efforts to resolve dilemmas and with ethics consultation.

RESULTS

STUDY PARTICIPANTS

Among 600 randomly selected physicians, 325 were ineligible, primarily because they spent less than 20 percent of their time in clinical activity at the Clinical Center. Among the 275 eligible physicians, 89 refused to participate and 19 could not be located or interviewed before the end of the field period; 167 completed an interview (61 percent response). Among the 260 randomly selected nurses, 58 were ineligible. Of 202 eligible nurses, 27 refused to participate and 12 could not be located or interviewed before the end of the field period; 163 nurses completed an interview (81 percent response). A larger number of physicians were sampled to ensure roughly equal numbers of eligible respondents.

The majority of physician respondents were male and White, and the majority of nurse respondents were female and White. The primary religious affiliation for both groups were Protestant and Roman Catholic (see table 2). Respondents had varied exposure to the field of bioethics: 25 percent reported attendance at six or more bioethics rounds, 51 percent reported attendance at a bioethics conference, and 4 percent had served on an ethics committee. The mean ethics training and experience score was 2.0 (out of 7.0) for physicians and 1.9 for nurses.

KINDS OF ETHICAL PROBLEMS

Researchers at the NIH reported ethical dilemmas that involved both research issues and clinical-care issues that arose indepen-

dently of the conduct of research, but which involved enrolled subjects. Of the respondents, 95 percent could identify their most difficult kind of ethical problem and 76 percent could recall a specific recent ethical dilemma (71 percent of physicians; 81 percent of nurses). The frequency of responses identifying each kind of ethical problem is reported in table 1. These classes of dilemmas are described below, with a brief description of a representative case.

NON-RESEARCH-RELATED DILEMMAS INVOLVING SUBJECTS

Investigators identified the following types of ethical dilemmas involving the care of patient/subjects, encountered in the research relationship but not directly related to study participation.

End-of-Life Care

These were issues involving decision making at the end of life, such as withdrawing and withholding treatment, do-not-resuscitate (DNR) orders, and palliative care. For example, one respondent described a pediatric patient/subject in a cancer trial who was given a bone marrow transplant. She became neutropenic and developed a fungal sinusitis. The family strongly urged that everything be done to keep her alive, but the research team felt there was very little hope that she could be saved and that continued treatment would be burdensome.

Informed Consent

These were ethical concerns about the validity of the informed consent obtained from a patient/subject or when decision-making capacity was questioned. The range of issues included those relating to advance directives and surrogate decision making. For example, one researcher described a 21-year-old seizure patient with developmental delay who was judged to require brain surgery that was not a part of the research protocol. Although the patient's mother was anxious for the surgery to proceed, the patient seemed hesitant, and

the team was unsure whether he understood the procedure and could give capable informed consent.

Table 2
Demographic characteristics

	% Physicians (n = 167)	% Nurses (n = 163)
Gender		
Male	71.9	7.4
Female	28.1	92.6
Race*		
White	74.3	81.0
Non-White	25.7	19.0
Religion		
Protestant	28.1	42.3
Roman Catholic	23.4	39.9
Jewish	18.0	3.7
Other	7.8	0.6
No affiliation	17.4	13.5
Country of birth		
U.S.	67.7	89.6
Other	32.3	10.4
Medical training outside U.S.		
None	61.1	84.1
All or part	24.6	7.4
Ethics training and experience**		
Low (0 - 1)	35.3	38.7
Medium (2 - 3)	55.7	50.9
High (4 - 7)	9.0	10.4
Years at NIH		
< 5	24.0	14.1
5 - 10	39.5	38.0
> 10	36.5	47.9

Note: % ≠ 100% because nonresponses were excluded.

* The categories reflect U.S. Census Bureau standards for reporting race/ethnicity; http://factfinder.census.gov/home/en/epss/race_ethnic.html, accessed 9 September 2005.

** On a 7-point scale, 1 point was given for attending 6 or more ethics rounds; 1 point for participating in a bioethics conference or course; 1 for feeling knowledgeable about current standards of ethics; 1 for taking an intensive bioethics course; 1 for completing a one-year bioethics fellowship; 2 for past or current participation in a clinical ethics committee.

Conflict between Parties

In these cases, there was a strong difference of opinion regarding the clinical management of a research subject. The conflict could be between research team members, patients, or family members. For example, a patient/subject insisted on continuing smoking despite advanced lung disease and the unsafe proximity to oxygen, which he needed. This created an ongoing conflict with staff who believed that his behavior created a danger to himself, to his family, and to others.

Confidentiality and Truth-Telling

Questions about whether to divulge information were identified as raising ethical problems for respondents. One respondent told of an adult subject in a brain radiation study who lacked decision-making capacity and who had unexplained bruising and other injuries. The research team was worried that there may have been an unsafe environment at home, and wondered whether it was ethically permissible or obligatory to report these injuries, and, if so, to whom.

Religious or Cultural Issues

Beliefs and attitudes of persons from different religious or cultural traditions gave rise to ethical dilemmas. One researcher described the mother of a 13-year-old boy from a Middle Eastern country who did not want the child to be informed of his diagnoses of HIV and cancer, because she considered it would be unnecessarily distressing to him. Some research team members felt it was incumbent upon them to disclose.

Beneficence

In these situations, the researcher was striving to determine what course of action would best promote the welfare of the patient/subject. For example, a subject was suffering from a painful but nonterminal illness, and the research team believed that giving adequate doses of pain medication would likely

result in addiction. The team was uncertain whether to moderate the medication to ensure adequate pain control without creating addiction.

RESEARCH-RELATED ETHICAL DILEMMAS

Respondents reported the following ethical dilemmas that were directly related to the conduct of research (see table 1).

Informed-Consent Issues

Physician and nurse researchers described situations in which the competence or voluntariness of an individual research participant's decision making, or the appropriateness of his or her informed consent to research participation, were in doubt. In one case, screening revealed that a proposed subject had a low IQ, was illiterate, and had a history of psychotic illness. The research team was uncertain whether she was capable of giving informed consent to participate in the study.

Conflicting Clinical Obligations

These were dilemmas in which the clinical well-being of subjects conflicted with the requirements of research. In one study, patients/subjects who were diagnosed with schizophrenia were to have their antipsychotic medication discontinued to test the efficacy of an experimental memory-enhancing drug. Because of this medication "washout," a member of the research team became concerned about the well-being of some of the subjects in this study.

Children in Research

The special problems attending the involvement of minor children in research were identified as creating a number of dilemmas. In one case, a young child was proposed for participation in a bone marrow transplant under a research protocol. The parents, who were divorced and had a very inharmonious relationship, disagreed on whether the child should be given the transplant.

Study Design Issues

Investigators identified ethical problems relating to study design. For example, in the early stages of a phase I trial of an experimental HIV medication, infected subjects were to receive a dose that was not expected to be effective in reducing infection, and some staff feared it could cause drug resistance.

Termination of Research Participation

Some respondents described cases in which they were unsure whether to discontinue a subject's participation in the study. In one, a patient/subject who received an investigational treatment was having difficulty complying with the requirements of the study protocol. The team was uncertain whether it would be ethical to discharge him from the study, since he had no medical coverage and might have no access to treatment as a result.

Justice in Research

In these cases, researchers were concerned about whether the social obligations of justice or equality were afforded to research subjects. For example, a patient/subject with an illness for which an effective standard treatment was available, but who could not afford the cost of the standard treatment and who was uninsured, sought to be enrolled in a study of an experimental drug. The team was frustrated that this person felt obliged to enter a risky study to obtain treatment for his condition.

Professional Conduct

These were cases in which the professional conduct of a member of the research team was called into question. One researcher described a minor child, who was not a good candidate for surgery and who was otherwise not appropriate for the study, on whom surgery was performed solely to give the appearance that "something was being done."

The profile of the ethical issues encountered by physicians differed somewhat from

those of the nurses. Nurses were more likely to identify dilemmas involving end-of-life care, and physicians were more likely to identify informed-consent issues. Informed-consent issues and those involving conflict between involved parties tended to be referred more often for ethics consultation, and issues involving conflicting clinical obligations tended to be referred less (see table 1).

On a scale of 1 to 10, with 10 the most satisfied with the decisions that got made in the most recent ethical dilemma, respondents gave a mean score of 6.9 (physicians 7.0; nurses 6.8). Gender was the only variable for which there was a statistically significant difference — male respondents were more satisfied (7.3 *v.* 6.6, $p < .05$).

USE AND EFFECTIVENESS OF ETHICS CONSULTATION

Of the research physicians and nurses who participated in the survey, 44 percent reported that they had personally initiated an ethics consultation. Overall, 68 percent of the respondents had participated in an ethics consult. Multivariate analysis of the likelihood of requesting a consult revealed no significant differences between male and female respondents, or between physicians and nurses. However, those researchers with greater knowledge in ethics, as indicated by a higher score on the ethics training/experience index, were more likely to request an ethics consultation compared with those who had less knowledge and experience (odds ratio = 4.73, 95 percent confidence interval = 1.98-11.30).

Respondents' satisfaction with their most recent ethics consultation averaged 8.0 on a scale of 10. Only those who reported participation in ethics consult were asked. The level of satisfaction was similar for physicians and nurses and for male and female respondents. No other statistically significant differences were found based on race, years of experience at NIH, or level of ethics training and experience; 23 percent reported that the consultation had changed the existing plan of treatment; 78 percent reported that they gained

something from the consultation that might prove helpful in a similar situation in the future; 93 percent claimed that they were somewhat or very likely to request another consultation in the future.

DISCUSSION

To our knowledge, this is the first survey to systematically examine the ethical dilemmas encountered by clinical researchers. Three implications of these findings are noted.

First, the majority of researchers report encountering ethical dilemmas in the conduct of research; 95 percent could identify their most difficult type of ethical problem and 76 percent could recall a recent ethical dilemma. These dilemmas arise at all stages of the research process, from design through all aspects of the conduct of clinical studies. They can arise either prior to or following the traditional protocol review process of the IRB, but most of the dilemmas described by respondents in this study arose after IRB approval, while subjects were being enrolled or cared for as part of a study. The spectrum of issues reported by the clinical investigators surveyed here differ from those reported by clinicians.¹⁰ At times the issues were exclusively focused on matters pertaining to research ethics, at times they related to clinical obligations, or to the competing demands of the two. While there are established bodies of literature on the ethics of the research in clinical domains, the resolution of ethical dilemmas at the intersection remains less well-explored and warrants further ethical analysis.

Second, nearly half of the clinical investigators in the study reported requesting an ethics consultation. Those who had used the service were generally satisfied, with a mean satisfaction score of 8.0 out of 10. This suggests that researchers value the presence of a resource to provide advice and consultation regarding ethical issues arising during human subjects research. It would be useful, then, for existing ethics support services to be sufficiently trained in research dilemmas to offer

this kind of more-flexible consultation. A resource of this kind would be a helpful complement to IRBs in addressing clinical research dilemmas that arise in the conduct of research.¹¹

Singer and colleagues have proposed a model of research ethics consultation for innovative therapies that involves collaboration between investigators and clinical ethicists.¹² At the NIH, the Bioethics Consultation Service functions in a similar way. For a number of reasons, this model has promise for use at other medical research centers. Ethics consultants generally have knowledge of ethics standards and expertise in facilitating the resolution of ethical problems. In addition, ethics consultants are in a position to respond promptly to ethics problems that require a relatively urgent response, such as the validity of informed consent, the release of information, the eligibility of a proposed research subject, or a request for advice on the completion of research advance directives.¹³ IRBs are generally not structured to respond in this way, and typically do not have adequate resources to do so.¹⁴ Consequently, an ethics consultation service may be better able than an IRB to handle the additional responsibility of consulting on research ethics issues. Another possibility would be for IRBs to establish consultation facilities to help investigators resolve difficult ethical dilemmas. Because of their more formalized committee structure and processes, IRBs may be more intimidating to research subjects and health professionals, especially nonphysicians, than a more informal ethics consultation service would be.

Since investigators commonly encounter the types of ethical dilemmas that are associated with providing regular clinical care, such as end-of-life issues, determinations of decision-making capacity, and cultural/religious differences, some of the fundamental bioethical values at stake are similar to those routinely addressed by clinicians and ethics consultants. This indicates that existing ethics consultation services, which offer consults by

individuals or committees, might already be reasonably well-equipped to provide advice and guidance with respect to research ethics dilemmas. The involvement of IRBs in such consultations may be desirable because of their particular expertise in issues regarding the human subjects of research, methods and regulations, and their obligation to ensure the protection of human subjects and to monitor ongoing research.¹⁵

Third, the extent of self-assessed training and experience in ethics plays some role in researchers' attitudes toward ethics consultation. Those respondents who have higher levels of training and experience were more likely to request an ethics consult, although they did not report higher levels of satisfaction with the consult they received than other respondents did. In light of the frequency with which clinical researchers encounter ethical dilemmas and address them on their own, it is important that institutions and their ethicists focus efforts on teaching ethics and training investigators to resolve ethical dilemmas.

This study is limited in that it reports the experiences of investigators from only one site, a site that only conducts research. It remains to examine whether the experiences of clinical researchers reported here are similar to that at other medical research facilities. Further, these data were collected through self-report. There was no validation of the reports, which may have differed from actual behavior. In particular, the frequency with which researchers reported requesting and participating in ethics consultations was not verified. While the response rate in the study is similar or better than that reported for other physician surveys, we cannot exclude the possibility of response bias.¹⁶ The exploratory nature of the analysis warrants conservative interpretation of its significance.

Although published and anecdotal data indicate that ethics consultation services do not typically provide consultation in the research context,¹⁷ this study was not designed to determine the extent to which IRBs do so. The IRB structure does not lend itself to an-

swering consultation requests, particularly those requiring a prompt response, nor do IRBs typically have the resources to do so effectively.¹⁸ While investigators sometimes approach IRB members informally with ethical problems, there is little evidence that IRBs generally address these problems in a systematic or formal way.

In summary, IRBs are mandated to decrease the risk of ethical transgression in clinical research. Results of this study indicate that there is a range of ethical issues in research that are logistically out of the scope of IRBs. These results suggest that an ethics consultation service could have a role at the side of IRBs in assisting researchers to conduct ethical research.

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DISCLAIMER

The opinions expressed here are those of the authors and do not necessarily reflect the policies of the National Institutes of Health or the U.S. Department of Health and Human Services.

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