

Paul J. Ford, "Misjudging Needs: A Messy Spiral of Complexity," *The Journal of Clinical Ethics* 16, no. 3 (Fall 2005): 206-11.

Misjudging Needs: A Messy Spiral of Complexity

Paul J. Ford

Paul J. Ford, PhD, is an Associate Professional Staff Member of the Department of Bioethics at the Cleveland Clinic Foundation and is an Assistant Professor of Medicine at the Cleveland Clinic Lerner College of Medicine in Cleveland, Ohio, fordp@ccf.org. © 2005, *The Journal of Clinical Ethics*. All rights reserved.

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 nursing 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 retrospect, 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 healthcare 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 misunderstand 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, careproviders, 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 family 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 underestimated. 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.