

Insoo Hyun, Cynthia Griggins, Margaret Weiss, Dorothy Robbins, Allyson Robichaud, and Barbara Daly, "When Patients Do Not Have a Proxy: A Procedure for Medical Decision Making When There Is No One to Speak for the Patient," *The Journal of Clinical Ethics* 17, no. 4 (Winter 2006): 323-30.

## When Patients Do Not Have a Proxy: A Procedure for Medical Decision Making When There Is No One to Speak for the Patient

*Insoo Hyun, Cynthia Griggins, Margaret Weiss, Dorothy Robbins,  
Allyson Robichaud, and Barbara Daly*

**Insoo Hyun, PhD**, is an Assistant Professor in the Department of Bioethics, School of Medicine, Case Western Reserve University in Cleveland, Ohio, [insoo.hyun@case.edu](mailto:insoo.hyun@case.edu).

**Cynthia Griggins, PhD**, is Co-Director of the Clinical Ethics Service, University Hospitals Case Medical Center in Cleveland.

**Margaret Weiss, MSSA, LISW, ACSW, CCM**, is a Medical Social Worker at University Hospitals Case Medical Center.

**Dorothy Robbins, MA**, is a Community Member in the Clinical Ethics Service, University Hospitals Case Medical Center.

**Allyson Robichaud, PhD**, is an Associate Professor in the Department of Philosophy at Cleveland State University.

**Barbara Daly, PhD, RN, FAAN**, is Director of the Clinical Ethics Service, University Hospitals Case Medical Center, and is a Professor in the Schools of Nursing and Medicine at Case Western Reserve University. © 2006 by The Journal of Clinical Ethics. All rights reserved.

The case of Theresa ("Terri") Schiavo drew national attention to the problems that can arise when too many family members and others compete to speak on behalf of a decisionally incapable patient. Today, healthcare providers are more likely to encounter the opposite problem — namely, that of caring for a decisionally incapable patient when there are *no* family members or other surrogates to assist in the medical decision-making process. This challenge is made even more difficult when there is neither a written advance directive nor any other evidence of personal values that can help the medical staff employ a substituted-judgment standard for making decisions about treatment. Particularly problematic are situations in which treatment of a patient's disease may require a significant medical intervention for which consent is necessary, such as amputation, ventilator support for pneumonia, or the insertion of a percutaneous endoscopic gastrostomy (PEG) tube. What guidelines should medical staff follow when significant non-emergent medical decisions must be made on behalf of a decisionally incapable patient and there is not enough time, or it is not possible, to get judicial authorization for a court-appointed guardian?

Healthcare providers should tend to these circumstances very carefully, for the stakes are indeed high. On the one hand, some may feel pressure to employ all available treatments, fearing a charge of civil liability from a previously unknown relative who suddenly appears complaining that doctors did not do "everything possible." Others may decide to limit treatment, and choose instead to wait silently for the patient's condition to progress to an emergency, thereby obviating the need for someone to give informed consent for

treatment. In either case, the potential for harming patients is great in terms of added suffering, illness, and indignity.

We encourage hospitals and their ethics committees to pay serious attention to this issue. According to a 2003 report by the American Bar Association Commission on Law and Aging, caring for patients who are incapacitated and alone is a critical and escalating issue.<sup>1</sup> Most of these patients come to hospitals from nursing homes and institutions for the developmentally disabled. Although the exact number of patients without proxies in the U.S. today is not known, it is likely to be considerable. For instance, by extrapolating from a 1991 study of average-sized nursing homes, one commentator has conservatively estimated that there are more than 60,000 seniors who fall into this category.<sup>2</sup> Furthermore, recent demographic data suggest that the population of incapacitated patients who lack surrogates in the U.S. is becoming ever more sizable and diverse. Between 2010 and 2030, the number of decisionally incapable patients who will lack surrogates is expected to rise dramatically in the U.S. due to the aging Baby Boomer generation, the expanding population of elderly with dementia, and the growing number of seniors who live on their own.<sup>3</sup>

In light of these trends, we believe hospitals should now begin to formulate their own institutional policies for the ethical treatment of decisionally incapable patients who lack a surrogate, especially those for whom a timely decision must be made regarding a significant non-emergent medical intervention. Such policies should provide a readily available and consistent approach, with procedures that are open to critique. Although a handful of legislative mechanisms and local practices exist to help guide the medical care of these patients, we believe these avenues include disadvantages that are serious enough to warrant a search for alternatives.

We will first describe current approaches and their attendant difficulties, then we will offer our own recommendations for hospital policy. We suggest that our model policy can provide a template for other hospitals to formulate their own policies, although some institutional variation in implementation may be necessary.

## POTENTIAL APPROACHES

Presently there are two general approaches to caring for patients who do not have a proxy: one approach involves a single decision maker, the other uses a committee. Of these, the use of a single decision maker is more widespread. To date, 10 states have established statutory authorization for healthcare consent when no surrogate is available and when a full-fledged guardianship proceeding would be impractical.<sup>4</sup> Eight of these states have designated a single person to be the key decision maker, normally the attending physician or another employee of the hospital or institution where the patient resides.<sup>5</sup> In addition to these state statutes, some states will expedite judicial authorization for treatment or assign temporary guardians for medical treatment.<sup>6</sup> Intended to be far quicker than a normal guardianship proceeding, these judicial authorizations involve either a determination for medical treatment that is made by a judge or the designation of a temporary guardian whose role is limited to making a medical decision for a patient. Finally, it is worth acknowledging that in states where there are no legally codified mechanisms, or in situations when careproviders ignore or lack awareness of codified guidelines, it may be quite common for careproviders to "fly beneath the radar" by making their own treatment determinations or by obtaining a second physician's concurrence with their decisions.

While having a single decision maker may be expedient, we maintain that it is not the most ethically ideal. First, if the designated decision maker is an employee of the patient's hospital or institution, a danger lurks that the patient's medical decisions could be (or could appear to be) compromised by a third-party's interests or by financial incentives. This is especially worrisome when there is no guarantee of an external review of a surrogate's decision mandated in the state statute. Second, medical decision making should not be solely a matter of medical expertise and judgment; rather, it should involve a complex blend of careful medical and ethical reflection. For this reason, having a sole decision maker is not as desirable as an approach that utilizes the careful ethical deliberations and perspectives of more than one person. Indeed, some

designated decision makers — for example, some attending physicians — may be uncomfortable with their assigned roles and may prefer to have others involved in the decision-making process. Third, careproviders who choose to “fly below the radar” risk doing so without proper accountability and oversight, and might rely too heavily on their own biases. To summarize, using a single decision maker may not be ethically optimal due to possible conflicts of interest — real or perceived — and the missed benefits of having more than one deliberator involved in the decision-making process.

In contrast to having a single decision maker, the use of a committee might, by its very nature, avoid many of the difficulties just outlined. Unfortunately, the chief problem with this latter approach is that it is normally weighed down with practical difficulties. To illustrate, consider three versions in which committees are now utilized.

A few states have authorized external surrogate decision-making committees to make collective decisions for patients who are incapacitated and alone.<sup>7</sup> These committees are comprised of trained volunteers who focus primarily on caring for residents of institutions for the developmentally disabled. Some critics have doubted whether these kinds of committees can be adequately expanded to cover treatment decisions for all types of incapacitated patients.<sup>8</sup> Given the likely increase in the number of cases in the future as this population expands, it could be difficult to train and administratively manage an adequate pool of volunteers. A similar problem exists for localities that have public guardianship programs that are funded by the State or private organizations. These programs tend to be underfunded and understaffed.<sup>9</sup>

In light of these practical difficulties, one might suggest that a hospital ethics committee act as the primary participant in medical decision making for patients who do not have a proxy. Hospital ethics committees, however, are not authorized to make medical decisions. Furthermore, it is rarely feasible to assemble an ethics committee on short notice each time a significant treatment decision needs to be made for a patient, especially if the need for such decisions is frequent. While a hospital ethics committee may be useful to review controversial cases, it is an unwieldy instrument for use as the primary participant in making medical decisions for patients who lack a proxy.<sup>10</sup> Our conclusion is this: whether one is talking about state-authorized committees, public guardianship programs, or hospital ethics committees, the committee approach may be simply too overburdened, underfunded, and cumbersome to be of much practical use.

## RECOMMENDED GUIDELINES

In our state of Ohio, as in most states, there are no established judicial mechanisms that address the problem of how best to represent the interests of patients who do not have proxies and, at the same time, facilitate medical decision making. Furthermore, in our county, it can take three to six weeks — or longer — to obtain a court-appointed guardian. As a result of these limitations, we developed, and propose here, a modified version of the committee approach to care for patients without proxies. This collaborative decision-making process is comprised of the following series of recommendations.

### STEP 1

Members of the medical staff should contact the appropriate social worker and the ethics consultant on call when a non-emergent but significant medical decision must be made relatively soon for a patient who does not have a proxy.

### STEP 2A

The ethics consultant and social worker must ensure that a thorough and exhaustive search for possible surrogates has been made. They will contact the referral source and research the patient’s background to inform the medical team about the patient’s life-style and personal value system, if known. If no family members or friends can be found, the social worker shall consider initiating proceedings to obtain a court-appointed guardian for future decisions regarding medical care and discharge plans.

## **STEP 2B**

At the same time, the ethics consultant will convene a pre-established subcommittee of the hospital ethics committee. This subcommittee will be comprised of no fewer than two members of the hospital ethics committee (from a pool of several members) who are knowledgeable about the ethics of surrogate medical decision making and who are available for consultation on relatively short notice (less than 24 hours). Ideally, one member of the subcommittee should be a community member.

## **STEP 3**

Having consulted with the social worker, the subcommittee will deliberate with the attending physician about the patient's treatment alternatives — including the choice of no treatment — and will reach a consensus about an ethically appropriate course of action. The process of deliberation shall focus on considerations of the patient's quality of life, personal preferences, if known, and medical prognosis, so that the resulting treatment recommendation is based on a best-interests standard of care.

## **STEP 4**

If there is no clear consensus in step 3, the case will go immediately to the full hospital ethics committee. Together, the attending physician and the hospital ethics committee shall arrive at a consensus about an ethically appropriate course of action.

## **STEP 5**

If there is no clear consensus in step 4, the case will be brought immediately to the attention of the chief medical officer. The chief medical officer shall make a recommendation for resolution of the situation after considering the views of the attending physician and members of the hospital ethics committee.

Because the patient is not known by those who will decide his or her care, the process of deliberation must focus on determining the best interests of the patient. A sound basis for decision making in such cases must consider a number of factors. As with all decisions in medicine, the probable benefits and burdens of the various alternative courses of treatment must be discussed. Burdens include not only pain and discomfort, but also loss or absence of pleasurable experiences, such as eating, walking, interacting with others, or living in a familiar and desired environment. Benefits might include improvement in quality of life or return to a previous quality; a decrease in pain, discomfort, or other symptoms; or an increase in function. Under a best-interests standard, surrogate decision makers must seek the highest benefit among the available alternatives on behalf of the patient.

Following an evaluation of the benefits and burdens, the subcommittee must ask if there is any basis for judging the patient's value system with regard to these benefits and burdens. For example, was this a patient who willingly sought medical care and followed through with restrictive or burdensome treatments? Or was the patient someone who rejected medications and restrictions? Did the patient seem to enjoy some activities of daily living such as eating, interacting with others, or participating in activities? Or was the patient "a loner," who frequently voiced dissatisfaction with his or her quality of life?

Deliberations on the particular medical facts of the case are important, including the likelihood of success of each treatment. Careful review with the medical team is necessary. For example, if a PEG tube is being considered for a patient with advanced Alzheimer's disease, discussion must include a review of the research that has failed to show increased survival with artificial nutrition and hydration. It is especially important to discuss whether a proposed treatment may actually restore cognitive function to the patient.

If there is some information to suggest the patient's values or to hint at his or her wishes, then the deliberating group is obliged to take them into account. Obviously, any decision that is guided by the patient's definition of "the good" is to be preferred. If there is no indication at all of what the patient might want, then the subcommittee must rely on estimates of what the "average reasonable person" would consider to be a benefit or burden, in an attempt to treat the patient with respect. Determining this is, of course, difficult and

is subject to individual bias. This is why decision making by one individual or solely by medical personnel is undesirable.

Our proposed alternative is a modification of a common ethics consultation method. Ethics consultation programs sometimes consist of individual consultants who operate in much the same way as standard medical consultants do. That is, requests are made to an ethics service, and the individual who is on call responds and provides case review, advice, and assistance. An alternative structure is for consultation to be provided by duos or trios of ethics consultants. The proposed procedure is more easily and quickly implemented than calling together a full committee, yet it still reduces the likelihood that a single consultant may provide a biased or idiosyncratic recommendation. Although bias can never be completely eliminated, a small group trained in ethics consultation, operating on a best-interests standard, that has no vested interest in the decision to be made, can offer reasoned deliberation, while it still allows the vital exchange of views. In considering the problem of patients who do not have a proxy, it is particularly important to make every attempt to avoid the tendency to analyze situations solely from the perspective of typical medical and ethics staff — White, educated, middle- or upper-class, professionally trained, with loyalties to the organization and to the healthcare system itself; hence our recommendation that a nonmedical person from outside the institution be included. Many ethics committees have community members who meet these criteria.

## CASE EXEMPLARS

We instituted this procedure more than a year ago in our hospital, a large, academic, urban medical center. The procedure has been used more than a dozen times. We offer these two case illustrations of our policy in action.

### CASE 1

Mr. T was a 68-year-old male who had been a resident in a nursing home. He had a history of diabetes and several strokes, which resulted in aphasia and serious cognitive deficits. He was admitted to the hospital with new mental status changes and a fever. At the hospital, Mr. T was diagnosed with pneumonia and a urinary tract infection, and was treated with antibiotics. A speech evaluation, done early in the patient's hospitalization, noted generally poor nutrition, as well as a risk of aspiration. Therefore a PEG tube was recommended by the attending physician. Mr. T was taken to surgery for insertion of the PEG tube, but the GI [gastrointestinal] consultant noted that no consent had been signed. Because it was obvious that Mr. T could not consent by himself, and no proxy was available, he was sent back to the floor. It was at that point that an ethics consult was called. (This was on day 15 of Mr. T's hospitalization.) Efforts were made by a social worker to find family or friends who could serve as a proxy decision maker for Mr. T; however, he had no one — his spouse was deceased and they had no children. There were no other relatives or friends known by the nursing home.

The ethics consultant called together the ethics subcommittee. Two community members and the ethics consultant reviewed the patient's chart, including the medical team's and the consultant's recommendations. With the medical social worker, they also contacted the nursing home to learn more about Mr. T's history there and his quality of life.

They learned that Mr. T was extremely limited in his activities. He was not very verbal, and mostly watched TV. He enjoyed eating. He did not appear to be in any pain or to be suffering in any way. The subcommittee also interviewed Mr. T, who despite his limited ability to converse, communicated that he was hungry. He demonstrated that he could in fact feed himself. He also said that he liked the nursing home where he was residing and hoped to return there.

The subcommittee asked for another swallowing evaluation. Despite a small chance of aspiration while eating, the subcommittee weighed the benefits and burdens of inserting a PEG tube. They felt that eating was one of the very few pleasures that remained for Mr. T. They also felt that the benefits of a PEG tube in extending life or preventing aspiration in patients like Mr. T were not impressive. Therefore the subcommittee recommended that Mr. T not be given a PEG tube, but rather that he be allowed to eat. They also recommended that a DNR [do not resuscitate] order be put in place, and that Mr. T be discharged back to his nursing home. The medical team accepted this recommendation, and Mr. T was discharged.

## CASE 2

Mr. A was a 30-year-old ex-convict with AIDS. He resided in a nursing home after having been transferred from a halfway house for convicts. Mr. A was admitted to the hospital with a fever, possible urinary tract infection, and pneumonia. Mr. A had been on active HAART [highly active antiretroviral treatment] and had relatively few opportunistic infections, but did suffer from AIDS dementia. Mr. A's infection was successfully treated with antibiotics. However, due to his poor nutritional status, a PEG tube was recommended by the hospital staff.

Mr. A had no family members. The nursing home had made efforts in the past to locate a relative, without success. Nor did he have any friends who came to visit him. His only visitors were staff from the halfway house. Because Mr. A lacked capacity to consent to the PEG and had no proxy, an ethics consult was requested by the hospital staff.

The ethics subcommittee (two community members and the ethics consultant) reviewed Mr. A's medical situation and spoke with his treating team. With the help of a medical social worker, they also contacted the nursing home and learned that although Mr. A had not been there for long, he seemed to be adjusting well.

The subcommittee considered several issues. Mr. A was a young man. He had been committed to HAART, suggesting that he wanted to extend his life. He had relatively few opportunistic infections, indicating that the medication was working and that it had the potential to extend life. The subcommittee knew that PEG tubes were highly effective in providing nutritional support in the short-term. The subcommittee felt that Mr. A should receive a PEG tube to help improve his nutritional status, and that in all likelihood it could then be removed. They recommended that the PEG be placed.

## DISCUSSION

As these cases suggest, our ethics subcommittee approach is capable of producing timely yet carefully considered decisions based on the best interests of patients who do not have a proxy. Over the course of the past year, we have learned from our policy. First, we discovered that extensive research into a patient's background is absolutely essential and is frequently successful in finding a surrogate when there was thought to be none. In some instances, medical personnel and social workers, who are often overburdened, had not done a truly exhaustive search prior to calling for a consult. In more than half of the cases in which patients were initially thought to lack a proxy, our search did in fact identify a legal surrogate — an adult daughter who had moved, a sibling who had a different surname, or a relative in another state. In one of our cases, a close relative was found after the deliberation was completed, but prior to its implementation. This relative, who was ready and willing to participate in medical decision making for the patient, voiced his gratitude for the committee's efforts and agreed with their recommendations.

Second, we have found our policy to be relatively efficient and effective in generating clear recommendations that have been readily accepted by the medical staff at step 3. The subcommittee has been able to convene and offer recommendations within 24 hours, often less time than is typically spent questioning whether, in fact, the patient lacks a proxy. Members of the medical staff have, in all cases thus far, expressed satisfaction and gratitude to the subcommittee for its assistance.

Third, both the medical and nonmedical members of the subcommittee have uniformly found the process of jointly reviewing the case, interacting with the patient to the extent possible, and engaging in the expanded dialogue that is necessary when discussing issues among persons with diverse backgrounds, to be extremely effective in identifying and evaluating the nuances of values and alternatives. In following our procedure, we have sought to avoid the outside pressures noted earlier, which may influence difficult treatment decisions by the medical staff and possibly deflect the best interests of the patient. By engaging in a careful consideration of the available alternatives in light of the patient's best interests, the subcommittee has been able to provide a respectful voice for those who have no one to speak for them. In so doing, we have realized, insofar as it is possible, the ethical principles meant to guide medical decision making.

The situation of patients who lack a proxy requires us, ultimately, to reconsider the requirements of the canonical principle of respect for persons. In everyday clinical situations, this principle is applied in the usual requirements of autonomy — informed consent, veracity, confidentiality. When confronted with a

non-autonomous, ill individual, considerations of autonomy provide no direction, and we have had to consider the more foundational requirements of respect for persons.

Respect is a ubiquitous concept, having been applied to persons, non-autonomous human beings, fetuses, and nonhumans. It has come to connote the requirement to treat another with care, to recognize the inherent worth or value of the entity, including unique features and preferences, and to take care of or care for that valuable being.<sup>11</sup> We do not have access to the preferences of the proxy-less patient, and often have almost no information of those unique features that make the patient who he or she is. Thus, respect dictates that we be particularly cautious in relying on individual assessments of what is in the patient's "best interest." Requiring consultation from persons outside of the clinical team, from several consultants rather than one, and from at least one person who is not a hospital clinician is thus an attempt to respond to this aspect of the principle of respect.

This addresses the methodology of our guidelines, but the standards for decision making also must be grounded in the principle of respect. In meeting our obligation as health professionals and as ethics consultants to care for ill individuals, we are normally directed by beneficence and nonmaleficence, again relying on the patient's interpretation of his or her good. Absent this information, we rely on a shared understanding among the community of caregivers, again cognizant that we actually may be well outside a patient's community. Nevertheless, seeking consensus among members of a group who have a fiduciary responsibility, as members of an ethics committee, to act for the benefit of the patient, lends some validity to the judgments that are made. Absent permission or specification from the patient regarding what the patient constitutes as benefit, the principle of nonmaleficence must be given priority. Unlike beneficence, the duties of nonmaleficence entail an independent component of the knowledgeable professional's assessment of whether the harm of any proposed action is likely to be outweighed by the benefit. In other words, without informed consent, we lack permission to do acts we believe to be beneficial, but we retain the obligation to avoid doing what we believe to be harmful.<sup>12</sup> Clearly this prioritization of nonmaleficence does not escape subjective evaluation of benefits in our attempt to justify even small burdens of treatment, but we have relied on the relatively absolute principle of nonmaleficence in our practical reasoning about how to fulfill the obligation of respect.

There are still clear limitations of our process. No matter how carefully and thoughtfully the members of the subcommittee approach their task, they are still not actually representing the patient who is a stranger to them — the patient's true wishes are unknowable. Secondly, despite efforts to enroll community members in the process, the subcommittee still tends to lack true diversity, and so they may not be able to approximate the wishes of those who are members of minority groups. Until more diverse members can be recruited, our decisions will not be truly pluralistic. Finally, although ethics committee members are usually immune from liability because of their membership on the committee, there is no law that protects them from possible lawsuit should some party decide to challenge a recommendation.

Although there is no case law in our state that establishes precedent or legal support for this process, we believe, given the silence of the law on this issue, that this process is a reasoned response to a growing social issue. With the increasing nursing home population in our country and the frequency with which elderly persons and the aging developmentally disabled will require surrogate decision making, we have an obligation to find appropriate ways to make decisions in the best interests of these vulnerable individuals. It is important to include assurances that health professionals or other individuals will not be able to unilaterally impose their own values onto patients who cannot speak for themselves. The use of an ethics subcommittee with nonmedical representation is one such assurance.

## NOTES

1. N. Karp and E. Wood, *Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly* (Washington, D.C.: The American Bar Association Commission on Law and Aging, 2003).

Insoo Hyun, Cynthia Griggins, Margaret Weiss, Dorothy Robbins, Allyson Robichaud, and Barbara Daly, "When Patients Do Not Have a Proxy: A Procedure for Medical Decision Making When There Is No One to Speak for the Patient," *The Journal of Clinical Ethics* 17, no. 4 (Winter 2006): 323-30.

2. M.R. Gillick, "Medical Decision-Making for the Unbefriended Nursing Home Resident," *Journal of Ethics, Law, and Aging* 1, no. 2 (1995): 87-92.

3. See note 1 above, p. 14.

4. *Ibid.*, 19-22.

5. *Ibid.*, 20-1.

6. *Ibid.*, 29-31.

7. *Ibid.*, 22-7.

8. T.E. Miller, C.H. Coleman, and A.M. Cugliari, "Treatment Decisions For Patients Without Surrogates: Rethinking Policies For a Vulnerable Population," *Journal of the American Geriatrics Society* 45 (1997): 369-74.

9. See note 1 above, pp. 27-9.

10. See note 2 above, p. 90.

11. M.T. Lysaught, "Respect: Or, How Respect for Persons Became Respect for Autonomy," *Journal of Medicine and Philosophy* 29, no. 6 (2004): 665-80.

12. V.A. Sharpe, "Why 'Do No Harm'?" *Theoretical Medicine* 18 (1997): 197-215.