Ethics Corner: Cases from the Hebrew Rehabilitation Center for Aged—Problematic Proxies

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This article is the second of a six-part series in the Journal of the American Medical Directors Association devoted to medical ethics in the nursing home. In each issue, a case is presented from the Ethics Committee at the Hebrew Rehabilitation Center for Aged (HRCA) in Boston, Massachusetts. After a description of the case and a discussion of the ethical issues that the case raises, Dr. Steven Levenson will discuss the implications for medical directors.

CASE PRESENTATION

Esther M. is an 80-year-old woman who was transferred to HRCA after a hospitalization for dehydration, pneumonia, and hyperglycemia. Her medical problems include diabetes mellitus, peripheral vascular disease, and urinary and fecal incontinence.

Mrs. M. was the youngest of three children born and raised in Boston. She completed high school and worked as a bookkeeper until marrying in her early 20s. Mrs. M. then stayed at home and raised two children. Mrs. M.’s husband died of heart disease 15 years before her admission. Until moving to HRCA, she had lived in the same house for 50 years. Recently, Mrs. M.’s daughter had been stopping by her mother’s house for 3 to 4 hours each day to help out. Three years before her admission, Mrs. M. designated her daughter as her health care proxy. Her son lives out of state.

Following her arrival at HRCA, Mrs. M. intermittently refused medications, food, and assistance with personal hygiene. She expressed paranoid delusions and appeared terrified by spiders that she saw all over her room. At one point, she fell while attempting to brush some of the “spiders” off her bedside table. Mrs. M. was started on a low dose of antipsychotic medication, and her paranoia and hallucinations improved slightly. A consulting psychiatrist diagnosed probable Alzheimer’s disease with psychosis and recommended an increase in antipsychotic medication. Mrs. M.’s daughter refused, requested that the current antipsychotic medication be discontinued in the near future and threatened legal action if these wishes were not respected. She did not believe Mrs. M.’s behavior was different than her baseline and believed that other interventions, such as more staff contact and improved diet, would suffice to treat her symptoms. Since Mrs. M.’s admission, her daughter visited her mother almost daily. She also sent e-mail and fax messages to team members almost daily with observations and recommendations about various aspects of her mother’s care.

Mrs. M.’s treatment team first consulted the Ethics Committee 1 month after Mrs. M.’s admission because of concerns that Mrs. M.’s daughter’s conduct as a health care proxy was inappropriate.

The ethics consultants observed in their report that Mrs. M.’s daughter did not believe her mother had dementia. They recommended that the team make efforts to educate Mrs. M.’s daughter about the signs and symptoms of dementia and try to determine the basis of daughter’s objections to antipsychotic medication. The consultants recommended that the above issues be discussed at a family meeting scheduled so that Mrs. M.’s son could attend and act as an intermediary. Finally, the ethics consultants told the team that it could request that the daughter transfer her mother to another facility if the team felt that it could not practice within the constraints she was imposing.

Over the next 2 months, the team had little success implementing the Ethics Committee’s recommendations. Mrs. M.’s daughter refused to allow the team to meet with her brother because of disagreements between her brother and her over their mother’s estate. Instead, a meeting with the daughter was held with a representative from the state Ombudsman Department. At that time, Mrs. M.’s daughter and the treatment team were unable to reach agreement on the management of her psychiatric symptoms. The team remained concerned that Mrs. M.’s psychiatric symptoms were both causing her direct suffering and also interfering with her medical care. Consequently, Mrs. M.’s son informed the team that he would seek to have his sister replaced as health care proxy by a nonfamily legal guardian. The treatment team assisted Mrs.
M.'s son by preparing a medical affidavit, while Mrs. M.'s daughter retained an attorney to contest the guardianship petition. Three months after her admission to HRCA, the state probate court removed Mrs. M.'s daughter as health care proxy and assigned Mrs. M. an attorney as guardian.

For the following 2.5 years, Mrs. M.'s medical and psychiatric conditions were relatively stable. The treatment team's attempts to taper her antipsychotic medication resulted in relapses of her psychotic symptoms: Mrs. M. would complain that her food had been poisoned, she would stop eating, and she would lose weight. Neuroleptics were then reinstated. Mrs. M.'s daughter continued to visit her mother daily and continued to make frequent recommendations about her mother's care. She hired a private companion to spend 3 hours with her mother several days per week, and she hired a masseuse to give her mother a weekly massage.

Three years into her stay at HRCA, Mrs. M. began to worsen. She frequently refused food and fluids, which made management of her already brittle diabetes even more difficult. Mrs. M. often resisted fingerstick glucose monitoring and also resisted efforts to treat her dehydration with intravenous fluids or clysis. Mrs. M.'s nurses became increasingly uncomfortable forcing these procedures on her and conveyed their discomfort to Mrs. M.'s guardian. The team presented the guardian with other possible options. Placement of a feeding tube would assure Mrs. M. a stable intake of fluid and calories and would spare her the discomfort of clysis. Alternatively, the team could discontinue fingerstick monitoring and parenteral hydration, which might result in hyperglycemia, dehydration, and death. In her advance directive, Mrs. M. had stipulated that she wanted tube feeding "if it is to be for a short period of time only." Mrs. M.'s guardian was uncertain whether the court would allow him to make a decision to withdraw treatment. He requested an ethics consultation followed by a family meeting with Mrs. M.'s children to discuss the options before going to court.

The ethics consultants affirmed the appropriateness of the treatment options the team had presented to Mrs. M.'s guardian and urged that a meeting be held with Mrs. M.'s children and her guardian to explore whether the children had had an opportunity to discuss her preferences for care with their mother while she was cognitively intact. The ethics consultants met with Mrs. M. on several occasions. They observed that her temperament changed over the course of the day: early in the day, Mrs. M.’s affect was brighter and she accepted fingerstick testing without objection, while in the evening she appeared withdrawn and resistant. The ethics consultants therefore recommended reconsideration by Psychiatry for treatment of possible ongoing depression and/or psychosis.

Mrs. M.'s psychiatrist found that psychotic symptoms were likely contributing to her refusal of food (she refused to eat because she believed there were snakes in her mouth) and recommended an increase in her dose of antipsychotic medication. He commented that the maximum dose he could give her as stipulated by the court-approved treatment plan was probably subtherapeutic. He also recommended that Mrs. M. begin taking an antidepressant medication.

The treatment team convened a meeting attended by Mrs. M.'s children and guardian. Mrs. M.'s children agreed that Mrs. M. would not want a feeding tube. However, Mrs. M.'s daughter advocated continued use of fingersticks and clysis, even if her mother resisted, while Mrs. M.'s son favored a palliative approach. Mrs. M.'s guardian felt obligated to present the dilemma to a judge. While awaiting a legal decision, the team continued to attempt clysis when medically indicated but would desist when Mrs. M. resisted. Surprisingly, Mrs. M.'s intake improved and stabilized to the point that fingerstick glucose monitoring was needed only rarely. Gradually, Mrs. M. stopped resisting clysis. Consequently, Mrs. M.'s guardian deferred a legal hearing and, with the help of the treatment team, composed a care plan for Mrs. M. that provided for fingerstick monitoring and clysis at the discretion of the treatment team.

**CASE DISCUSSION**

Mrs. M.'s case provides examples of issues that may confront clinicians and ethics consultants in working with surrogates. Some of these issues include the following: (1) Who may be a surrogate decision-maker for an incapacitated patient? (2) How is decision-making authority transferred from the patient to the surrogate? (3) What are the responsibilities of a proxy decision-maker? And (4) what options are available to the clinician who believes a proxy decision-maker is not meeting her obligations?

**Evolution of the Use of Proxies**

The past 3 decades have seen a flurry of activity in medical, philosophical, legal, and legislative arenas in the area of surrogate decision-making for incapacitated patients. The increase in attention to this topic parallels the evolution of biomedical ethics in general during this period and has been tied both to advances in medical technology and to cultural developments such as the civil-rights movement and feminism. A few landmark legal cases brought to the attention of the public and legislators the risk for clashes between advances in life-sustaining treatments and patients' rights of autonomy.

The first nationally prominent legal case to set a precedent for decision-making by next of kin was the case of Karen Ann Quinlan. Quinlan was a 22-year-old woman in a persistent vegetative state. She was thought by her physicians to be ventilator dependent. Her father, who was also her legal guardian, requested removal of the ventilator. The medical staff involved felt this would violate medical practice and went to court. The New Jersey Supreme Court ruled that Karen Ann had a right to privacy, which implied she could decline medical treatment. Moreover, the court held that her father and other members of her family should be allowed to “render their best judgment” as to whether she would want to discontinue treatment. A second important case that further clarified the role of families in medical decision-making was that of Clarence Herbert. Herbert was a 55-year-old man who had a cardiac arrest after surgery and never regained consciousness. His wife and eight children requested discontinuation of life-prolonging ventilation and later intravenous therapy. The case went...
to court because a nurse sought out the district attorney, who pressed criminal charges. Not only were all the charges dismissed, but the California court upheld the right of the family to act as surrogate decision-makers.3

The issue of the family’s authority in making medical decisions for the decision-incapable reached the United States Supreme Court in the Nancy Beth Cruzan case.4 Cruzan was a young woman in a persistent vegetative state whose family petitioned for the removal of the feeding tube that was sustaining her life. The Missouri court rejected the request, and the case was appealed to the Supreme Court, which held that there is a constitutional liberty right, protected by the 14th amendment, to refuse medical treatment. In the case of decisionally incapacitated patients, families may act on their behalf to refuse treatment. However, the Court also held that individual states have the right to enact legislation establishing procedural safeguards to protect the incapacitated. In fact, only Missouri and New York have enacted such standards. In those states, clear and convincing evidence standards prevail for allowing proxies to authorize withholding or withdrawing life-sustaining treatment.

In addition to judicial precedents, legislation also affects surrogate decision-making. At a federal level, the Patient Self-Determination Act (PSDA), which went into effect in 1991, requires health facilities receiving federal funds to advise patients of their right to execute an advance directive.5 The PSDA has had a significant effect on the use of advance directives in the nursing home, with usage rising from 4.7% before the PSDA to 34.7% after implementation of the federal law.6 On a state level, every state now has legislation providing for surrogate decision-making.7 Some states have separate living will legislation. Other states, such as Massachusetts, where Mrs. M. lives, only have proxy legislation. Many states also have health care surrogate laws, which specify who is legally designated as the decision-maker if the patient is incapacitated and has not appointed a health care proxy.8

Activating the Proxy

One matter about which Mrs. M.’s treatment team and her daughter did not disagree was Mrs. M.’s decision-making capacity. Nevertheless, determining the patient’s incapacity is a necessary first step to activating a patient’s surrogate decision-maker and deserves brief comment. The US Uniform Probate Code’s definition of incompetence provides little guidance: “a mentally incompetent person is one who is so affected mentally as to be deprived of sane and normal action, or who lacks sufficient capacity to understand in a reasonable manner the nature and effect of the act he is performing.”9 State legislatures have arrived at a variety of definitions of incompetence. The absence of clear guidelines in this area was remarked upon by the President’s Commission on Ethical Problems in Medicine, which recommended that health care professionals themselves work toward establishing clear policies.10 In response, a comprehensive body of literature now exists to assist clinicians in assessing whether or not a patient has decision-making capacity. In addition, Grisso and colleagues11 developed a structured interview that may eventually have clinical utility. Physicians who undertake such assessments should have familiarity with the tenets of this literature as well as with procedural and documentation requirements specific to their state. In Mrs. M.’s state, the Massachusetts Health Care Proxy Act requires the physician to make a written determination in the patient’s medical record that the patient is incapable of making or communicating health care decisions and also requires that oral and written notice be given to the patient of this determination.12

Responsibilities of the Proxy

As described earlier, landmark legal cases and health care proxy legislation have legitimized a tradition of deferring to an incapacitated patient’s next of kin for surrogate medical decision-making. The advantages of such a system over a system relying on legal guardians include the following: (1) compared with an outsider, a family member is more likely to be familiar with the patient’s values and expressed wishes, and (2) the courts are spared a potential log jamb of guardianship cases. The chief advantage of a health care proxy over a living will is that the proxy can respond to situations that may not have been foreseen at the time the living will was drafted. In addition, many living wills are applicable only in the case of terminal illness and imminent death and refer generally to withholding “extraordinary” treatment. What standards exist to guide the health care proxy in fulfilling her obligations appropriately?

Legal cases provide some direction. A review of the principal decisions relating to standards for decision-making by guardians is beyond the scope of this article. From these cases, however, two basic standards of surrogate decision-making have emerged, the “substituted judgment” standard and the “best interests” standard. The substituted judgment standard directs the proxy to make a medical decision based on what the patient would have decided herself, were she capable of making the decision. The best interests standard requires that the proxy make decisions based on what she believes is in the best interest of the patient.

The majority of courts follow the substituted judgment standard.13 In a case described previously, In Re Quinlan, the New Jersey Supreme Court held that Karen Quinlan’s father had the right to order withdrawal of the ventilator if, in his judgment, his daughter would have made the same decision. The applicability of the substituted judgment standard is questionable in cases of patients who were never decision-capable and thus could not previously have expressed a preference about care. Nonetheless, this standard has been invoked in some legal cases, such as the case of Joseph Saikewicz, a retarded man with leukemia, whose family’s right to authorize withholding of chemotherapy was upheld on the grounds that the patient would not have wanted treatment.14

The best interests standard has been used by some courts based on the belief that weighing of the benefits and burdens of the proposed treatment should be the basis for decision-making. In the Conroy case, for example, the court upheld the right to withdraw a feeding tube from an elderly, demented, nursing home resident but arrived at this conclusion by reasoning that the desirability of being “free of medical interven-
tion” outweighed any benefit of artificial nutrition. These courts have been skeptical about the ability of a surrogate, however knowledgeable about the patient and however well-intentioned, to infer the wishes of a decision-incapable patient.

One would assume that the next of kin would be well-positioned to make decisions using the substituted judgment standard, given her close relationship to the patient. Unfortunately, research on proxy decision-making casts doubt on this assumption. As reviewed by Emanuel, empirical studies have shown that proxies and patients only rarely discuss advance directives, that family members are unreliable at assessing a patient’s quality of life, and that proxies cannot accurately predict patients’ preferences for life-sustaining interventions. Furthermore, unlike outsider surrogate decision-makers, family members are uniquely positioned to have conflicts of interest that might distort their ability to make decisions based solely on what the patient would want. Drawbacks inherent in the best interests approach include difficulty defining objectively what is in a person’s best interest as well as the risk of overriding the patient’s idiosyncratic yet strongly held beliefs.

Most recently, a California Court of Appeals implicitly endorsed a combination substituted judgment/best interests standard. In the Wendland case, family members of a patient who was severely cognitively impaired following a motor vehicle accident challenged the right of the patient’s spouse, who was the court-appointed conservator, to authorize withdrawal of artificial nutrition. The Appeals Court held that the surrogate should base her decision on “medical advice, after considering the patient’s prior wishes and best interests.” Parenthetically, the Appeals Court held that the trial court should not itself decide on the best interests of an incompetent patient, nor should the court demand that the surrogate be held to a clear and convincing evidence standard. Rather, the role of the Court was to assure that the surrogate was acting in good faith.

**APPLYING THEORY TO THE CASE**

In the case of Esther M., the initial ethics consultation can be viewed as having been prompted by the treatment team’s disapproval of the manner in which Mrs. M.’s daughter was fulfilling her responsibilities as her mother’s proxy. The daughter’s conduct did not seem to be justified by a substituted judgment standard: the team had no evidence that Mrs. M. was opposed to antipsychotic medication or that she would have chosen to live with paranoid delusions and frightening hallucinations. In addition, the team and the daughter had different opinions about what was in Mrs. M.’s best interest. The team felt that the risk of side effects from antipsychotic medications was an acceptable risk in the interest of improving her psychotic symptoms, while the daughter held a contrary view.

The second ethics consultation was generated by the guardian’s discomfort, as an outsider, over making a substituted judgment decision about life-sustaining treatment. His desire to include Mrs. M.’s children in this decision was in keeping with the notion that the patient’s next of kin are best situated to represent the patient’s wishes. That the two children disagreed on major aspects of the care plan illustrates the imprecision of this approach and would seem to lend credence to the statement by Appelbaum and Gutheil that proxy decision-making, “far from having scientific accuracy and objectivity, in most cases represents a complicated form of guesswork, suffused by the decision-maker’s biases.”

**APPROACH TO THE PROBLEMATIC PROXY**

It is not uncommon for health care professionals who work frequently with surrogate decision-makers to encounter problems similar to those described in the case of Mrs. M. Rarely, however, does the conflict require removal of the health care proxy. In some situations, proxy problems arise because of the proxy’s lack of understanding about the appropriate standard for decision-making. In other situations, a proxy may have false assumptions about life-sustaining medical interventions. In most cases, the proxy has had no background in proxy decision-making before having been handed responsibility for making life or death decisions for a loved one. Sensitivity by health care professionals to the intimidating nature of this task and a willingness to provide education are approaches that may help prevent proxy problems down the road. Ethics committees can also be helpful in this regard.

More serious proxy problems may arise when a proxy has an obvious conflict of interest or when the treatment team questions the decision-making capacity of the proxy. In these situations, an ethics committee consultation may provide a helpful “second opinion” in addition to facilitating transfer of decision-making authority to a suitable alternate. Mediation by other professionals not directly involved in the patient’s case, such as a facility social worker or psychiatrist, may prove useful.

In rare instances, conflicts between the surrogate and the caregiving team may necessitate transfer of care to other providers. If the clash is between the surrogate and the primary physician, it may be possible to transfer the care to another physician within the same institution. Occasionally, it may be necessary to move the patient to a different institution. The courts were sympathetic to this approach in the case of Paul Brophy, a 49-year-old Massachusetts fireman who never regained consciousness after surgery for a ruptured cerebral aneurysm. His wife requested withdrawal of artificial nutrition and hydration. Brophy’s physicians and the hospital administration refused and went to court. The Massachusetts Supreme Judicial Court ruled that the feeding tube could be removed but added that the hospital could not be forced to withhold artificial feedings. The court ordered Brophy transferred to a nearby hospital, where supportive care was instituted, and Brophy died 8 days later. In the Requina case, however, a trial court refused to support the transfer of a 57-year-old woman to another nursing home after the patient requested removal of her feeding tube and was told she would need to move to another facility if she wished to remove. The judge argued that Requina had lived in the same nursing home for years and that relocation would be excessively burdensome to her.

The case of Esther M. followed the steps advocated by the
Council on Ethical and Judicial Affairs when patients or proxies and caregivers disagree on what constitutes reasonable therapy. The first step is an attempted negotiated understanding among proxy and physician; if agreement cannot be reached, mediation by a consultant or an ethics committee should be used. The next step, which was not needed but was considered in Mrs. M.’s case, is transfer to another physician or another institution. Finally, if transfer is not possible—because no physician or facility can be found that are willing to provide care on the terms specified by the proxy—and if the desired treatment is considered offensive to medical ethics and professional standards, then the caregiving team may opt to override the proxy’s wishes.21

Serving as a surrogate decision-maker is a difficult and painful responsibility for many individuals. In the nursing home setting, where multiple medical decisions typically are made over an extended period of time, there is the opportunity to develop trusting relationships between caregivers and proxies that can facilitate decision-making. However, even in an environment with low staff turnover and a closed medical staff such as the HRCA, the ideal of shared decision-making may be difficult to achieve. Development of institutional policies within the long-term care facility that restrict the scope of treatment decisions made by proxies may be useful. Such policies would delineate upper and lower bounds of acceptable care for residents of the facility, and proxy decision-making would take place within those bounds. This approach would protect patients, would help shoulder the burden for proxies, and would support caregivers.22

REFERENCES