ETHICS

Ethics Corner: Cases from the Hebrew Rehabilitation Center for Aged

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This article begins a new six-part series in the Journal of the American Medical Directors Association devoted to medical ethics. Each issue, a case will be presented from the Ethics committee at the Hebrew Rehabilitation Center for Aged (HRCA) in Boston, Massachusetts. Following 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.

Founded in 1905 as the Jewish Ladies Home for Aged, HRCA is now a 725-bed long-term care facility in Boston, Massachusetts. There is a 20-bed skilled nursing unit, with permanent residents occupying the remaining beds. The main campus also houses an outpatient clinic and adult day health program. The mean age of the inpatient population is 89 years old and the average length of stay for a permanent resident is 4 years. Medical care is provided by a closed medical staff. The HRCA is a major teaching site for the Harvard Geriatrics Fellowship Program and is home to the Research and Training Institute, whose members conduct clinical and social science research.

The 12-member ethics committee is composed of representatives from psychiatry, geriatric medicine, social services, nursing, hospital administration, dietary, and the therapies (eg, physical therapy, occupational therapy, recreation, creative arts). There is also a community representative. Training and experience of ethics committee members varies from member to member, and members are encouraged to read the medical ethics literature and attend relevant educational programs. Consult requests are referred to the ethics committee chairperson, who assigns the consult to two committee members. Any staff member at HRCA may request an ethics consult to address an ethical dilemma in the care of a resident. The ethics committee consultants’ findings are discussed with the requesting party, and a report is placed in the resident’s medical record. The ethics committee meets monthly, at which time the month’s consults are discussed. A journal article is distributed at each meeting for discussion the following month. Other activities of the ethics committee have included participation in staff education programs, quality assurance initiatives in areas such as documentation of advance directives, and development of institutional policies relating to areas such as the withdrawal and withholding of treatment.

WHEN A FAMILY WANTS LESS

Case Presentation

The ethics committee was asked to evaluate Doris L., a 97-year-old woman with advanced dementia, whose family was requesting withdrawal of all care, including medication, food, and fluid. Mrs. L. had been admitted to the HRCA 5 years ago, when progressive impairment from Alzheimer’s dementia prevented her from being able to live in the community. Her other medical problems included blindness secondary to glaucoma, coronary artery disease, congestive heart failure, and hypertension. She had initially lived on a unit for residents with moderate cognitive impairment but had moved to her current unit 1 year before the consultation because of progression of her dementia. The transfer entailed assignment to a new primary care physician. Mrs. L.’s daughter and grandchildren visited her frequently. In addition, Mrs. L.’s daughter had hired a private companion to assist Mrs. L. several hours each day since Mrs. L.’s admission to HRCA.

Mrs. L. was born in Russia, the youngest of 10 siblings. She immigrated to the United States at age 14 with her mother and unmarried siblings. Her father was killed during World War I. Mrs. L. finished high school and married at age 24. She had two daughters, one of whom died from cancer 10 years before Mrs. L.’s admission to HRCA. After her husband’s death, Mrs. L. worked in a department store in the Complaint Department. Mrs. L.’s chief source of emotional support has been her daughter. The daughter has described Mrs. L. as having always been someone who was fiercely independent and resisted help from others. However, she was also someone who derived comfort from the company of others and who would become very anxious when alone. She had a very difficult time coping with her blindness because of its effect on her ability to relate to people. In recent years, Mrs. L. had experienced delusional thinking and episodes of agitation as her dementia progressed. She had not been able to recognize family members for 2 years. An HRCA psychiatrist had seen Mrs. L., and her symptoms improved with anxiolytic and antipsychotic medication.

Two weeks before the ethics consult, Mrs. L.’s condition

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declined significantly. Mrs. L. began to refuse to attend groups and became less responsive to external stimuli such as touch. She intermittently rejected food, although she would usually chew and swallow food placed in her mouth. Mrs. L.’s daughter believed that her mother’s facial expressions and vocalizations were indications of increased distress. Mrs. L.’s daughter had previously made clear that comfort, not life prolongation, was the primary goal. Accordingly, a “do-not-hospitalize” order had been written, and the physician’s progress notes documented requests that no diagnostic tests be used, including phlebotomy. The daughter had made exceptions to this plan as recently as 1 month before the ethics consult. At that time, Mrs. L. was febrile, tachycardic, and hypotensive, and her daughter agreed to blood tests and oral antibiotics. The ethics consult was triggered by a request from Mrs. L.’s daughter that medical treatments (medications, oxygen, nebulizer treatments) be discontinued with the exception of morphine for comfort. She also requested that food and fluid no longer be offered her mother. Mrs. L.’s daughter brought to the team copies of advance directives supporting these decisions. Mrs. L.’s treatment team (physician, nurse, social worker) believed this approach was not in Mrs. L.’s best interest and that it violated their professional integrity.

In addition to having completed a Massachusetts Health Care Proxy form, designating her daughter as her proxy, Mrs. L. had completed a Living Will. Her directives stipulated that, were her condition terminal, she would not want her life prolonged by any means, even if this created a transient period of increased discomfort. In addition, Mrs. L. wrote that she wished to have food and fluid withdrawn in the event of loss of cognitive function with no significant likelihood of regaining it. Mrs. L. identified concerns with personal dignity and the emotional well-being of her family as motives behind her directives.

The ethics consultants met first with members of Mrs. L.’s treatment team. The team members present expressed the belief that Mrs. L. was not suffering. They disagreed that Mrs. L.’s affect indicated emotional distress, and they felt that her vocalizations were random and purposeless. The nurses present felt that Mrs. L. still derived some pleasure from eating and drinking, and they objected strongly to the idea of depleting her of her major sources of satisfaction. The team members also objected to discontinuing oxygen or medications, feeling that these interventions provided comfort. The team expressed the concern that Mrs. L.’s daughter’s own distress over seeing her mother so debilitated might be motivating her advocacy for withdrawal of treatment.

The ethics consultants also met with Mrs. L.’s daughter. Four of Mrs. L.’s grandchildren accompanied their mother to the meeting. All five family members argued for withdrawal of treatment, including withdrawal of food and water. They expressed the belief that Mrs. L. would not want to continue to exist in her current state and reiterated that her mother’s behavior indicated distress. Mrs. L.’s daughter expressed the wish that her mother could be given a lethal dose of morphine. Mrs. L.’s daughter also expressed her unhappiness with her mother’s current primary care physician. She felt that this physician had not been attentive during meetings with the family and did not have a good appreciation of her mother’s needs.

The ethics consultants visited Mrs. L. while her private companion was feeding her. Mrs. L. accepted food when it was offered to her by spoon and stated the food was “good” when asked. She did not respond to other questions. She appeared comfortable and her affect did not appear anxious or depressed. Her medications were: isosorbide dinitrate, lisinopril, levothyroxine sodium, lorazepam, quetiapine, sulfacetamide drops, and vitamin B12 injections.

Case Discussion

As is often the case with ethics consults, the origins of this crisis were multifactorial and not strictly limited to an ethical dilemma. The issues identified by the ethics consultants in the case of Mrs. L. included: (1) difficulties in the relationship between the treatment team and the resident’s family; (2) conflict between the daughter and the treatment team about whether Mrs. L. was suffering; (3) conflict between Mrs. L.’s previously expressed interests and current best interests; (4) concern that the proxy might have a conflict of interest; and (5) the belief on the part of the team that the withholding of treatment advocated by the proxy violated their professional integrity.

DIFFICULTIES IN THE RELATIONSHIP

Frequently, ethics consultants are summoned when there is a breakdown in the alliance between the clinician and the patient or family. In the case of Mrs. L., her daughter had developed trust in her mother’s first primary care physician, who treated Mrs. L. during her first 4 years at HRCA. The daughter had also worked with the same social worker during that time. The daughter had worked with the new primary care physician for less than a year, and she did not conceal her mistrust of this physician. The ethics consultants were aware that the two physicians had different interpersonal styles. The other members of the treatment team and their practice styles were also relatively new to the daughter. The treatment team was similarly unfamiliar with Mrs. L.’s daughter and mistrusted her motives towards her mother. The case highlights the importance of establishing and maintaining trust between family and caregivers. In many nursing homes, residents acquire a new physician upon admission to the facility; at the HRCA, the resident also changes physicians if she moves within the facility.

The ethics consultants also identified lack of awareness of Mrs. L.’s advance directives as another communication problem. Team members were unaware of the presence of Mrs. L.’s Living Will until her daughter requested withdrawal of treatment. Ideally, this document should have been presented at the time of the transfer of Mrs. L.’s care to her new team. A review of Mrs. L.’s very specific requests regarding withdrawal of care might have allowed the team to determine in advance whether her wishes conflicted with their values. A discussion with the daughter at this early juncture might have increased each party’s sensitivity to the other’s position and fostered a better working alliance from the start. Alternatively, irreconc-

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citable differences could have been identified and plans made to transfer Mrs. L. to a different unit.

CONFLICT BETWEEN DAUGHTER AND TEAM ABOUT WHETHER MRS. L. WAS SUFFERING

The ethics consultation team acknowledged the difficulty of assessing suffering in the setting of advanced dementia. They pointed out the dangers of interpreting behaviors as having greater significance than is justifiable. For example, many caregivers believe that when an individual with dementia pulls out a percutaneous endoscopic gastrostomy (PEG) tube or intravenous line, he is showing that he does not want artificial nutrition or hydration. In fact, the patient probably simply views the catheter as a foreign object to be manipulated and does not have the cognitive capacity to make a judgment about its use. Instruments have been developed to help assess pain in the nursing home resident with dementia.1

Offering to use a validated tool can help bridge the gap between the subjective assessments of clinicians and families.

CONFLICT BETWEEN PREVIOUSLY EXPRESSED INTERESTS AND CURRENT BEST INTERESTS

Western biomedical ethics views the concept of patient autonomy as central.2 When an individual is unable to indicate his wishes regarding treatment, the usual practice is to try to infer his wishes based on previous statements, ideally in the form of a living will or instructional directive or via a surrogate decision maker, ideally a formally designated health care proxy. This proxy is expected to make decisions based on substituted judgment. Many bioethicists have argued that individuals aspire to “narrative integrity” to their lives: they wish the final chapter to be consistent with their earlier lives in terms of such things as the food they eat, the approach to medical care, and honoring of their religious beliefs.3 Other ethicists have suggested that respecting the previous self needs to be tempered by current reality: as with Mrs. L., she may have previously stated that she did not wish her life sustained if she developed advanced dementia, but in her current demented condition, she appears to derive satisfaction from her surroundings.4 The ethics consultation team tried to balance the prior wishes and the contemporary best interests of Mrs. L. by suggesting acceding to limitations on medical treatment but not on supportive care.

CONCERN REGARDING POSSIBLE CONFLICT OF INTEREST

Biomedical ethics places a great deal of weight on surrogate decision-making in the incompetent patient. Although Mrs. L. had provided fairly extensive directions about her future care, it fell to her daughter to interpret her wishes.5 The caregiving team expressed concern that Mrs. L.’s daughter was acting based on her personal sense of discomfort at seeing how debilitated her mother had become, rather than exclusively on substituted judgment. Challenging a surrogate’s decision often creates further conflict and mistrust. Mediation by an outsider or, as in this case, by an ethics consultant, can be helpful, much as it can when families request what the physician regards as futile therapy.6 Only rarely is the authority of the proxy overruled by the courts, principally in cases of psychiatric disturbances or florid (financial) conflict of interest.

BELIEF THAT WITHHOLDING TREATMENT AS ADVOCATED BY THE PROXY VIOLATED PROFESSIONAL INTEGRITY

In the Quinlan case, one of the first cases addressing withholding and withdrawing life-sustaining treatment, the New Jersey Supreme Court weighed “the right of the physician to administer medical treatment according to his best judgment” against a patient’s right to refuse treatment. The more invasive the treatment and the less likely the benefit, in the Court’s view, the less weight could be accorded the “integrity of the medical profession.”7 In other situations, such as physician-assisted suicide, the integrity of the medical profession may be a compelling argument favoring physician refusal to go along with the wishes of patients or their families. In the case of Mrs. L., the team felt that failure to offer food and drink was inconsistent with their responsibilities. Guidelines have been established to help practitioners and families deal with advanced dementia: the Fairhill Guidelines affirm that Alzheimer’s Disease is a terminal illness, removing any doubt about the right of affected people to refuse treatment by advance directive. They also indicate the need for caution in assessing quality of life in dementia, but acknowledge that “there may come a point in the progression of dementia where quality of life is so severely compromised that many would justifiably wish to limit life-extending treatment.” Comfort care is then appropriate, but this means limiting medical interventions, not personal care.8 Many experts in the field of dementia care believe that a strictly palliative approach is appropriate in the care of individuals with advanced dementia.9 In fact, some have advocated a hospice approach to treatment of such patients.10 Nursing home personnel caring for such residents should be comfortable with implementing hospice-style treatment.

Mrs. L.’s family and the treatment team appraised the nature of Mrs. L.’s existence differently, which contributed to this conflict. The family focused on her disabilities and was painfully aware of how her current existence was one that Mrs. L. would not have wanted prolonged. The treatment team, on the other hand, focused on supporting Mrs. L.’s remaining personhood. There are conflicting views in the ethical literature about “personhood” in advanced dementia, with some philosophers espousing the view that patients with advanced dementia have lost all sense of self, and hence that there is no moral obligation to sustain them.11 Others argue that even those with endstage dementia are people whose behavior reflects their own disposition as well as their environment.12

ETHICS COMMITTEE RECOMMENDATIONS

The ethics consultants recommended that the treatment team honor Mrs. L.’s wishes, as communicated by her daughter, to withdrawal medical treatment. The consultants recommended that the treatment team meet with the daughter to discuss the details of a plan for withdrawing care and ensuring comfort. The consultants expressed concern over the success
of such a meeting, however, given the feelings of mutual mistrust existing between the team and the daughter. The consultants recommended, therefore, that the team’s social worker, with whom the daughter had a better relationship, work toward helping the daughter and the team develop a better understanding and respect for each other’s viewpoints. The ethics consultants also recommended that the team consider enlisting the help of Mrs. L.’s previous primary care physician as a trusted third party to assist with negotiations. The consultants advised that if the team and the daughter were unable to reach a mutually agreeable plan, that the daughter be offered the opportunity to transfer her mother to a different team within the facility.

In some instances, the only way to abide by the decision of a patient or health care proxy while respecting the moral integrity of the caregivers is to transfer the patient to another facility. This was done in the case of Paul Brophy, a Massachusetts firefighter who was in a persistent vegetative state after the rupture of a cerebral aneurysm and whose family successfully petitioned the Massachusetts Supreme Judicial Court to withdraw artificial nutrition and hydration. The Court held that that “the withdrawal of artificial feedings did not violate the ethical integrity of the medical profession as long as health care providers were not compelled to withhold artificial feedings.” 13 It ordered the hospital, which was not comfortable with discontinuing the feeding tube, to arrange transfer to another facility where the tube was removed and Mr. Brophy died. In general, institutions should accede to patient wishes to forgo life-sustaining treatment, but may choose to transfer a patient whose wishes violate the institution’s mission. In rare instances, the courts have required that institutions comply with a patient’s request to forgo treatment and have not authorized a transfer on the grounds of discomfort to the patient. 14

The ethics consultants supported the team in its objections to depriving Mrs. L. of food and fluid. In addition, the ethics consultants advised that the daughter may not compel the primary care physician to perform euthanasia by administering morphine with the express purpose of bringing about Mrs. L.’s death. Euthanasia is illegal throughout the United States. Physician-assisted-suicide, which is legal only in Oregon, requires a decision-capable patient. However, providing morphine to assure comfort, even if there is a risk that the morphine might hasten Mrs. L.’s death, did not violate the ethical principle of nonmaleficence.

OUTCOME

Mrs. L.’s physician and Mrs. L.’s daughter agreed that all of Mrs. L.’s medications would be discontinued with the exception of quetiapine. Mrs. L. would continue to receive oxygen, and the nursing staff would continue to offer her food and fluid. Morphine would be administered for any signs of agitation or discomfort. After 3 days, Mrs. L.’s daughter requested of the HRCA medical director that her mother be transferred to another unit. The daughter related that she continued to lack confidence in Mrs. L.’s treatment team. The medical director agreed to the transfer, and Mrs. L. transferred to another unit. Mrs. L. expired 5 days later.

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REFERENCES