

Caring for the Terminally Ill: Resolving Conflicting Objectives Between Patient, Physician, Family, and Institution

Robert D. Orr, MD, John J. Paris, SJ, PhD, and Mark Siegler, MD

Loma Linda, California; Boston, Massachusetts; and Chicago, Illinois

Conflicts about clinical management frequently occur between patients and physicians. These are made more complex when families and institutions claim positions in the dispute. We present a case that demonstrates multiple parties in conflict, and we give the clinical and ethical analyses that helped resolve the conflict. Finally, we reflect on the accuracy of the analyses in light of the outcome.

Case Report

A.H. was an 80-year-old female nursing home resident with advanced dementia and recurrent aspiration pneumonia. Following her third admission to the hospital, her physician recommended surgical placement of a gastrostomy tube, but her family refused to give consent. An ethics consultation was requested by the patient's daughter in an attempt to resolve the conflict.

Background

A.H. had been a bright, assertive university graduate who had successfully raised two children and maintained a career. After retirement she had worked as a volunteer for social and church organizations. She was a religious person and had a firm belief in a "better life hereafter."

When her husband was dying of cancer 18 years ago, she had tenderly nursed him at home. Together they had decided that she would learn how to give morphine injections so that he could stay at home rather than go to

the hospital for terminal care. This was a choice made specifically so that his death would not be encumbered with mechanical intrusions.

Nine years before the requested ethics consultation, the patient had developed the early symptoms of Alzheimer's disease. She had been able to remain in her apartment for 2 years, at first living alone with help and oversight from family and friends, and later with a live-in companion. Her daughter, who lived across town, and son, who lived out of state, were named joint guardians. As they observed further deterioration in their mother's condition, they decided she needed a more supervised living arrangement. Since they were unable to care for her in either of their own homes, they placed her in a carefully chosen nursing home operated by the patient's church. There she settled in quickly and participated in activities. She received excellent nursing care, and both she and her daughter soon considered the members of the staff as their friends.

Her Alzheimer's disease continued its relentless course. She had last recognized her daughter 3 years before her physician's disputed recommendation of a gastrostomy tube. Though her eyes remained closed, and she had not acknowledged anyone's presence for more than a year, she had continued to eat. Her daughter was glad about this because she was certain that her mother would consider a feeding tube to be an unwanted and unnatural intrusion.

The staff at the nursing home were proud of their ability to feed patients after others had given up and inserted feeding tubes. Several times the daughter had watched as patients returned from the hospital with feeding tubes in place, yet the staff had patiently continued to feed them by mouth with a syringe, spoon, or eye-dropper until the tubes were removed. The staff had promised the daughter that her mother would never have to suffer the indignity of a feeding tube.

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From the Department of Family Medicine and the Center for Christian Bioethics, Loma Linda University, California; Boston College, Massachusetts; and the Center for Clinical Medical Ethics, University of Chicago, Illinois. Requests for reprints should be addressed to Robert D. Orr, MD, Department of Family Medicine, Loma Linda University Medical Center, Loma Linda, CA 92354.

A few months before hospitalization and the requested ethics consultation, A.H. had begun to choke frequently while eating. She had suffered aspiration pneumonia three times and had required hospital admission twice before for intravenous antibiotics. Her daughter, who believed that her mother was slowly dying and would not want vigorous efforts to prolong the process, had opposed transfer to the hospital. Uncomfortable with oral administration of antibiotics, which they predicted would be ineffective, the nurses had been even more uncomfortable with the idea of leaving the pneumonia untreated. Each time they had prevailed on the attending physician to admit A.H. to the hospital. On each return to the nursing home, the staff had patiently fed A.H. using frequent suctioning when she choked.

When she became febrile again, the attending physician insisted on admitting the patient to the hospital so that he could look for a correctable cause of recurrent aspiration. None was found. He then insisted that oral feedings be discontinued and requested consent for surgical placement of a gastrostomy tube.

The daughter refused to give consent for the feeding tube and requested an ethics consultation, asking if it was ethically obligatory to artificially feed this patient.

Identifying Conflicting Perspectives

The ethics consultant examined the patient, reviewed her records, and talked with the attending physician, the patient's daughter, and the Director of Nursing and administrator at the nursing home. He also consulted with a geriatrician, a theologian of the same religious faith as the patient, and the hospital attorney, and he looked into the literature of terminal care.

On examination, the ethicist found the patient in bed with eyes closed and mouth open. She responded only to painful stimulation and did not seem to be aware of his presence. She was well nourished and well hydrated, and her skin was in excellent condition.

The Director of Nursing at the nursing home told the consultant that the staff believed the patient was not imminently dying, and that they felt morally obligated to give her adequate nutrition. Should A.H. develop pneumonia again, they believed it would be necessary to transfer her to the hospital for intravenous antibiotics. They understood that their position was "more conservative" on this matter than their church's, but they firmly stated, "We are comfortable with it."

Acknowledging that Alzheimer's disease is a fatal condition, the geriatrician said that the patient's loss of gag reflex was a sign of the end stages of brain degeneration. He further pointed out that placement of a gastrostomy tube would not necessarily resolve the problem

Table 1. Conflicting Perceptions of Those Involved in Deciding Whether an Elderly Woman with Advanced Dementia Should Have a Gastrostomy Tube Inserted

The patient (presumed)
1. Natural eating and swallowing is good.
2. Mechanical overriding of inability to eat and swallow in the dying process is bad.
The family
1. Going against the patient's presumed desire is bad.
2. Loving atmosphere of this nursing home is good.
3. Using comfort measures for this dying woman is good.
The attending physician
1. Tube feeding to prevent aspiration is good.
2. Treating recurrent pneumonia even in dying patient is good.
The nursing home
1. Giving adequate nutrition to prevent skin breakdown is good.
2. Giving adequate nutrition to this demented woman to extend her life is good.
3. Aggressive treatment of pneumonia is good.
4. Death by dehydration is bad.

of frequent aspiration, since 56% of patients with gastrostomy tubes still aspirate.¹

The theologian stated that his denomination believed human life is sacred, but is not an end in itself. Thus it is not morally imperative to use artificial fluids and nutrition in all cases.² When it is believed that the burdens of such therapy outweigh the benefits, and the intent of not using such interventions is to allow the disease to run its course, the withholding or withdrawal of artificial nutrition and hydration would not constitute euthanasia, rather it would be the acceptance of the human condition and the desire to avoid a remedy disproportionately burdensome to the patient.³

The hospital attorney reminded the consultant that in the state where this occurred (Illinois), a recent state supreme court ruling made it very difficult to remove a feeding tube from a patient.⁴ He thus advised careful deliberation before instituting long-term artificially administered fluids and nutrition.

Literature on terminal care states that, even in fully conscious patients, the provision of nutrition and fluids does not always produce a net benefit to the patient.⁵⁻⁷ Further, dehydration is asymptomatic if the patient's thirst is adequately addressed by giving frequent mouth care.⁸

The conflicting perceptions of what would have been good or bad for A.H. are summarized in Table 1.

The ethics consultant submitted the following report:

Assessment: This 80-year-old woman is dying of progressive dementia. Her recent loss of gag reflex is evidence of further brain stem deterioration which is irreversible. Because of recurrent aspiration it is medically appropriate to discontinue attempts at total nutrition by mouth. Her physical inability to take adequate oral fluids and nutrition might

be overcome by surgical placement of a feeding gastrostomy tube, but this would not be effective in preserving or restoring her health, and it might not even prevent aspiration.

Despite lack of a written advance directive, her previous life choices give indication that she would decline artificial feeding. It is ethically permissible to honor the request of her legal guardians to not use artificially administered fluids and nutrition, and thus change her treatment goal from postponing death to comfort measures. This should include continued good nursing care, good oral hygiene, and ice chips or sips of clear liquids with syringe or eye-dropper, as tolerated.¹⁹

Her primary physician is somewhat reluctant, and the nursing home where she has received excellent care for seven years is very reluctant to not give total nutrition and fluids. Their moral beliefs should be respected and they should not be forced to participate in the limited treatment plan requested by her family.¹¹⁰

Recommendations

1. It is ethically permissible to devise a limited treatment plan which should not only address feeding and mouth care as outlined above, but should also address resuscitation, antibiotics, transfer in case of fever, etc. The goal of the treatment plan should be compassionate terminal care.

2. If the physician is not comfortable with carrying out a limited treatment plan for this patient, he should assist the family in transferring her care to another physician.

3. If the nursing home is not comfortable with carrying out a limited treatment plan for this patient, an alternative long term care facility should be sought.

4. Because of the long-standing positive relationship between this patient, family and nursing home, if the family chooses to continue her care at the same facility, there is a medical alternative that could be considered; a tracheostomy could be done with a cuffed tube that could be inflated during feeding and deflated when the stomach was empty.

Resolution

After much deliberation, the patient's daughter and son reluctantly consented to the surgical placement of a gastrostomy tube. They wanted their mother to spend her last days in the care of those who had demonstrated love for her for so many years, and they were persuaded of the appropriateness of the decision when the nursing staff at the nursing home emphasized that their mother would die a painful death without proper nutrition, a death that included skin breakdown and infected skin ulcers. The nursing home was willing to alter its original position by agreeing to treat recurrent infections with oral medications rather than transfer the patient back to the hospital.

When the pneumonia had cleared and the patient had been afebrile for 10 days, she was taken to surgery for the implantation of a feeding gastrostomy tube. Within 24 hours she again spiked a fever and was found by chest radiograph to have developed a new infiltrate, presumably from an unrecognized episode of aspiration.

After this recurrence was cleared, she was transferred back to the nursing home. She lived for another 2 months, had frequent recurrent fevers, experienced skin breakdown, and died quietly.

Discussion

Much has been written about conflicting values between patients and their physicians. Some medical ethicists propose resolution using the autonomy model¹¹⁻¹³ in which they maintain that the patient's right to self-determination is supreme and nearly inviolable, and thus should be accepted by physicians. Others look to a paternalism model,^{14,15} taking the position that the patient's illness makes him or her unable to be objective about his or her situation so that the medical professional should be more directive in guiding patient choices, or might even limit choices available to some patients. Most writers attempt to reach some middle ground, such as the patient-physician accommodation¹⁶ or the patient-provider collaboration,¹⁷ which aims for joint decision-making, or the beneficence model,¹⁸ which urges physicians to use a virtue-based ethic that seeks the patient's good after adequate dialogue has elicited the patient's values.

After noting the limits and perils of both the autonomy and the paternalism models, Pellegrino and Thomasma¹⁸ emphasize that physicians must act "for the good of the patient":

Parties in a clinical decision may hold opposing views of ultimate and immediate good. Each participant is a moral agent and as such is bound to uphold and be accountable for his or her own conception of what is right and good. Making morally defensible decisions in the face of substantive differences in conceptions of patient good has therefore become one of the most urgent procedural problems in medical ethics.

Most theoretical and practical discussions of such conflicts involve resolving differences between patient and physician. Some cases are more complicated, however, because family members are acting as surrogate for an incompetent patient, thus adding a third party.¹⁹ The "procedural problems" become even more complex when institutional considerations add yet another voice that may be in conflict.^{10,20}

Conflict resolution in situations like this takes considerable time and requires excellent communication. Adequate data must be available from primary physicians and consultants. Second medical opinions and legal consultation may help to clarify the issues. In an increasing number of hospitals, consultation from an ethics committee or a clinical ethicist is available when these efforts do not bring consensus. Bedside ethics consultation can

help to identify, analyze, and resolve moral dilemmas in the care of individual patients.

Probably the most beneficial procedure in attempting to reach consensus is an unhurried meeting with all parties present. This would include the patient (when appropriate), family, primary physician, bedside nurses, social worker, spiritual, ethics, and legal advisors, and representatives of the institutions involved. When such management conferences are held, the first priority should be establishing the goals of therapy. If all parties can agree on the goal or goals that are in the patient's best interests, the conflictual tone can often be relieved. Further discussion to find the best methods to reach those goals then becomes easier. Persistent disagreement on treatment goals may require that the patient be transferred to the care of other physicians or institutions.

When the treatment goal is changed from life-prolongation to comfort care, even though the patient is still in the acute hospital setting, it is appropriate to adopt the hospice precept that all treatment decisions should be judged by whether they contribute to patient comfort. The hospice literature can be of considerable assistance with both symptom control²¹ and ethical discussion of terminal care.^{22,23} Consultation with a hospice organization for assistance with symptom control or for other terminal care services may be beneficial.

The United States Supreme Court's *Cruzan* opinion,²⁴ that Court's first ruling on the controversial right-to-die issue, recognized that competent patients have a constitutional right to refuse any and all potentially life-prolonging medical treatments including artificially provided nutrition and hydration. The Court also ruled that, provided patients meet state-established criteria for making their wishes known, the values and wishes of now incompetent patients with regard to treatment decisions are likewise constitutionally protected. Physicians should be reassured by this ruling that in most states the traditional mechanism of joint decision making by family and physician is still valid for incompetent patients. The Court did say it was not unconstitutional for the State of Missouri to set a higher standard of proof and require "clear and convincing" evidence of the incompetent patient's previously expressed desires. Missouri and New York have established this higher standard, and it is up to the courts in those states to determine what constitutes clear and convincing evidence.

When that ruling is combined with the recently enacted Patient Self-Determination Act²⁵ requiring all hospitals and nursing homes receiving federal Medicare or Medicaid funding to inform patients of their right to provide advanced directives (living wills or the appointment of a health care proxy by means of a so-called durable power of attorney), health care institutions will

find increasing demands for the limitation or termination of life-sustaining treatments.²⁶ Those requests may set off more conflicts between patients, physicians, families, and health care facilities.

Some regard the *Cruzan* opinion and the Patient Self-Determination Act as the highwater mark of patient autonomy, and predict increasing efforts to withdraw decision-making authority from individuals and place it in the hands of third party payers.²⁷ If this prediction is correct, the addition of payers to the conflicts will make resolution even more difficult.

This case study documents a conflict that occurred while both the Court and the Congress were formulating their positions. It provides an insight into how such conflicts arise and guidance on how they may be resolved.

Analysis

The parties involved in the care of A.H. had differing perceptions of what would be good or bad for her. The task of the ethics consultant was to identify the conflicting values and recommend the ethically permissible courses of action.

This case demonstrates the situation discussed by Pellegrino and Thomasma¹⁸ where each participating moral agent held his or her own, and opposing, view of the ultimate and immediate "good" for the patient. There was no single resolution that would satisfy all parties' perceptions of that "good." The option that seemed closest to this ideal would have been for A.H. to be admitted to another nursing home in order to carry out a limited-treatment hospice plan. The family's trust of the high-quality care given in this nursing home, however, led them to compromise another "good," that is, their deduction that the patient would not want a feeding tube. In exchange for this, the nursing home relented in its insistence on hospital transfer for aggressive treatment of recurrent pneumonias.

Retrospective medical analysis shows that the geriatrician's and family's perception that the patient was dying was, in fact, correct. Further, the gastrostomy tube did not prevent aspiration, and the patient still died of infection. While the use of a jejunostomy (vs gastrostomy) tube might have postponed the inevitable pneumonia somewhat longer, in the final pathophysiological analysis, death from progressive neurological deterioration is almost always mediated by some secondary (infectious or pulmonary) means.

Reflection on the ethical analysis would suggest that in this case the burdens of artificial fluids and nutrition outweighed the benefits to the patient. Prolonging her

dying process by using artificially administered fluids and nutrition was not morally imperative; allowing her terminal disease to overtake her life would have been ethically permissible. Although compromise is generally an acceptable goal when there is conflict among multiple parties, in this case compromise did not appear to result in achievement of the good of the patient.

Key words. Terminal care; ethics, medical; patient advocacy; quality of life.

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