Whose Death Is It, Anyway?

Timothy Gilligan, MD, and Thomas A. Raffin, MD

As medicine has increasingly gained the power to prolong life in the face of devastating illness, patients have increasingly become concerned about maintaining some control over how and when death arrives. Competent patients have the legal right to refuse treatment, but critically ill patients are frequently unable to participate in decision making. Advance directives were designed to help patients establish the level of care they would receive if they were to be rendered incompetent; yet, as the case discussed in this essay shows, even a valid advance directive does not guarantee that unwanted medical interventions will not be forced on us. The problem of physicians ignoring their patients' wishes goes beyond issues of communication and reflects an ongoing ambivalence about power and control in the physician–patient relationship. Unfortunately, many physicians find it easier to define success in terms of life and death than to try to determine what sort of existence is meaningful to an individual patient.

Ann Intern Med. 1996;125:137-141.

From Stanford University Center for Biomedical Ethics and Stanford University Medical Center, Stanford, California. For current author addresses, see end of text.

As medicine has increasingly gained the power to prolong life in the face of devastating illness and injury, physicians, patients, and patients' loved ones have had to confront the difficult and delicate question of when to stop trying to save a life. When is a dignified death the best achievable outcome? This problem is complicated by the fact that critically ill patients are frequently unable to communicate their wishes, forcing their physicians and family members to make decisions for them that are among the most personal decisions one can ever make. To protect the right of patients to choose the level of life support and medical care they would want if they were to become critically or terminally ill, all 50 states have adopted legally recognized ways for persons to leave written testimony of their wishes. These documents take the form of advance directives and include living wills and durable powers of attorney for health care. Unfortunately, as shown in the essay by Hansot in this issue (1), a durable power of attorney for health care is no guarantee that unwanted medical interventions will not be forced on us when we are at our most helpless.

We believe that the case of Ms. Hansot illuminates several difficult and important problems in medicine: patient autonomy, communication between physicians and patients, the need for emotional as well as physiologic care, and the role of death as a colleague. In addition, this case highlights the limitations of durable powers of attorney for health care.

Autonomy

Patient autonomy is, in principle, a cornerstone of the legitimacy of Western medicine. Legally, a person's right to control his or her body is sacrosanct, and forcing medical care on an unwilling patient is akin to battery. Although patients do not have the right to demand interventions that are clearly futile, physicians do not have the right to impose interventions, even if medically indicated, contrary to the patient's wishes. The legal history establishing a competent patient's right to refuse medical interventions has been well documented elsewhere (2). Although we appreciate the concern that Ms. Hansot's physicians showed for the preservation of life, the actions of these physicians violated the patient's right to decide for herself what quality of life was acceptable (1). The hospital was legally required to ascertain whether Ms. Hansot had completed an advance directive or similar document but failed to do so. Then, the physicians put a tube down the patient's throat, connected her to a mechanical ventilator, and placed her in physical restraints so that she could not emancipate herself. Despite clear evidence from the patient and the patient's legally designated agent that Ms. Hansot did not want her life prolonged in this manner, it took 5 days for the physicians to relent and bring their interventions into accord with the patient's desires. That these physicians acted with the best of intentions makes Ms. Hansot's experience no less painful.

Withholding and withdrawing life support from patients has gained widespread acceptance in the

See related article on pp 149-151.

medical community (3, 4) and the legal system (2), but we still see far too many patients trying desperately to cut short the process of dying, only to have their best efforts rebuffed by physicians. This unwanted medicine is an arrogant usurpation of patients' rights and serves neither the interests of the patient nor those of medicine as a profession. In ancient Greece, the Hippocratic Corpus stated that one of the primary roles of medicine was to refrain from treating hopelessly ill persons, lest physicians be thought of as charlatans (5). This caveat still applies today.

One of the major ways that patients exercise their autonomy is through consent. Physicians have an ethical and legal responsibility to ensure that the patient has consented to the treatment they are providing. This involves talking to the patient. For hospitalized patients, physicians should determine, at a minimum, whether the patients wish to be designated as do-not-resuscitate/do-not-intubate and whether the patients have provided an advance directive or durable power of attorney for health care. When patients cannot speak (because of intubation, for example), they may be able to communicate by nodding and shaking their heads. If a physician believes that meaningful communication is impossible, a patient's agent, designated by a durable power of attorney for health care, can speak and decide for the patient. Dr. Hansot's perception that her mother's physicians did not concern themselves with the wishes of their patient is disturbing.

In an emergency, patients who are not designated as do-not-resuscitate/do-not-intubate are presumed to have given consent for cardiopulmonary resuscitation. However, once a patient's condition has stabilized, consent for continuing treatment is mandatory. Admittedly, obtaining meaningful consent from critically ill, ventilator-dependent patients presents a difficult challenge and is often made impossible by the patient's mental state. Patients receiving mechanical ventilation often appear to become depressed and, if not heavily sedated, may become desperate in their desire to be extubated. Acutely ill, ventilator-dependent patients in intensive care units regularly demand to be extubated despite having an excellent chance of returning to an independent life. Assessing the competency of these patients is critical because, although physicians have no right to force unwanted care on patients, allowing a patient in an altered mental state to make grave medical decisions can clearly be wrong. In such circumstances, carefully evaluating the patient's mental status, consulting with the patient's family and loved ones, and waiting to see whether the patient's wishes remain stable over time can all help physicians determine whether a patient's requests are consistent with the patient's known values and goals. Such an assessment is generally easier to make when the physician has had a long-term relationship with the patient.

For Ms. Hansot, the best-case scenario was not a return to her former state but rather was a hemiparetic life in a nursing home. The physicians not only lacked Ms. Hansot's consent but had evidence, supplied by her legally designated agent, that she did not want to live the life for which they were saving her. In such a scenario, we do not understand what could give physicians the authority to force a patient to undergo undesired medical interventions.

Communication, Listening, and Caring

Communication and listening skills are prerequisites for good physician–patient relationships, and they give the physician a chance to learn what an illness means to the patient and the patient's family. Good communication skills make patients feel less lost in the hospital environment and more cared for by their physicians. Effective communication is particularly important in the intensive care unit, which is an alien environment for patients and their loved ones. It is filled with monitors and unfamiliar sounds, and the patients are often obscured by a sea of wires and tubing. Visitors may find themselves overwhelmed not only by the gravity of the patient's malady but also by the foreign stimuli. If the patient's loved ones must make life-and-death decisions on the patient's behalf, they will probably have feelings of grief, guilt, and confusion. Caring physicians who take the time to make emotional, human contact with patients and their families can greatly ease the burden that these persons feel at times of crisis (3, 6).

Reading Dr. Hansot's account of her mother's last days of life, we ask ourselves what happened to the humanistic aspect of medicine in this case. One of the roles of physicians is to give solace and support to patients' families during times of serious illness. That the pulmonologist accused Dr. Hansot of being an ageist preoccupied with abstract principles when she was trying to realize her mother's wishes is to us a double violation of the principle of nonmaleficence: The physician not only did harm to the patient by prolonging her suffering but did harm to the patient's daughter by gratuitously insulting her and causing her anguish. We believe that much of Dr. Hansot's and Ms. Hansot's distress could have been avoided if the physicians had made a greater effort to listen to their patient and her daughter.

As Dr. Hansot implies, there is a difference between taking care of a patient and simply maintaining a patient's vital signs. Providing emotional support, understanding, and empathy are important aspects of medical care. Dr. Hansot clearly felt that she and her mother had been abandoned by the team of physicians, a feeling that was only exacerbated by the absence of the physicians at the time of death.

Beyond Better Communication

Physicians' neglect of their patients' wishes about critical care and code status is disturbingly widespread. The recent, large, multicenter SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) trial (7) found that physicians largely ignored or were unaware of the desire of terminally ill patients to be designated as do-not-resuscitate/do-not-intubate. And although poor communication is a problem in itself, it is also a symptom of deeper problems in the culture and climate of hospital-based medicine that must be addressed. Indeed, the second phase of the SUPPORT study found that having nurses facilitate communication between physicians and patients improved neither physicians' awareness of patients' wishes about medical care nor the incidence or timing of written do-not-resuscitate orders. The deeper problems are related to physicians' attitudes toward life and death and toward medical interventions and technology. Physicians' daily work with advanced medical technology may engender a familiarity that makes it difficult for them to understand why patients often view ventilators and feeding tubes with anxiety and aversion. Similarly, medicine's focus on pathology and physiology, on vital signs and diagnostic tests, may obscure the human context of the illness. Correcting electrolyte imbalances may seem to be more urgent than discovering what the patient wants. This is especially true in the critical care setting, in which the patient may be intubated and sedated and in which the physician–patient relationship may be reduced to a daily 2-minute physical examination. This elevation of the science of medicine above the humanity of the patient is a serious problem that probably cannot be resolved without changes in the organization and culture of the hospital and the active support of hospital leaders (8).

The problem of poor communication also reflects ongoing ambivalence and uncertainties about power and control in the physician–patient relationship. As the physician has gradually taken on a less paternalistic role in Western medicine, more emphasis has been placed on patient autonomy. This shift in emphasis has moved the balance of power in the direction of the patient. Educating patients about their diseases and available therapeutic options empowers them to participate more fully in medical decision making, but it also may threaten the physician's sense of authority. Physicians may feel that they, with their greater medical knowledge and experience, are in a better position to make decisions about health care. Moreover, when it comes to difficult decisions about end-of-life care, physicians may believe that they can relieve the patient's family of guilt, regret, and confusion by making tough choices on their own. However, treatment decisions are influenced not only by outcome probabilities but also by physicians' personal values and priorities (9–11). Because it is the patient's life that is at stake, we believe that the patient's voice must be heard and the patient's values must be honored.

The case of Ms. Hansot raises an additional question about power: Was the physicians' disregard for their patient's wishes influenced by the fact that Ms. Hansot and her daughter were women? We will never know the answer, but it is an important question to ask. In the legal world, for example, a study of appellate court decisions in right-to-die cases found that the courts consistently portrayed female patients as less capable of rational decision making than male patients (12). And the issue is not just that men devalue women's voices; it is much more complicated. Feminist psychologists have observed that women are often more interested in the truths of relationships than in the dictates of abstract principles, in the knowledge derived from human connections rather than the knowledge derived from impersonal reasoning (13, 14). When Dr. Hansot confronted her mother's physicians, a series of power dynamics were put into play. Dr. Hansot was a non–medical person questioning medical professionals; she was a woman questioning men; and she was posing the facts of her relationship with her mother against the facts of medicine presented by the physicians. The pulmonologist accused Dr. Hansot of preoccupation with abstract principles, but it seems to us that just the opposite was true. It was the pulmonologist himself who was preoccupied with the general medical principle that life is good and death is bad. Dr. Hansot was preoccupied with the knowledge of her mother's wishes, which she had obtained through a close, lifelong relationship. We are arguing not that one perspective is superior to the other but that the power differential in the physician–patient relationship can represent a deeper problem that impedes communication and interferes with optimal medical care. If Dr. Hansot's sex, her nonphysician status, and her focus on her mother's wishes rather than on her mother's physiology combined to make it difficult for the physicians to listen to her, then we can only recommend that physicians practice taking off their white coats. To understand and empathize with those who are sick or dying, we physicians must learn to talk to patients and families as regular persons and must avoid raising the barrier of medical authority. The practice of medicine should not depend on overpowering patients and their families.

Other Obstacles to Communication

Physicians may also fail to communicate with patients or ignore their requests to limit care because of the stress and emotional discomfort associated with confronting death. Physicians may be uncomfortable with their own mortality and hence may avoid spending much time with dying patients. Moreover, having been trained to prolong life and overcome disease, they may feel like failures when they allow a patient to die if that patient's life could have been prolonged with life support. In this regard, withholding or withdrawing life-sustaining care can be one of the most difficult actions that a physician has to take. Physicians who feel that they are unable to take such action probably should not work in critical care.

Discomfort with death may also explain one of the more disturbing aspects of Ms. Hansot's case: the feelings of abandonment experienced by the patient and her daughter. Why did the physician of record leave it to Dr. Hansot to determine that it was indeed possible to communicate with the intubated patient? Why were none of Ms. Hansot's physicians present at the time of death? There is an unfortunate tendency in hospitals to avoid engaging the humanity of critically ill patients near the end of life. The focus of intensive-care–unit rounds can quickly turn from the patient to the flow sheet of vital signs and laboratory values. When this happens, the patient is denied some of the most important benefits that medicine has to offer, and the physicians are denied one of their most meaningful roles, that of bedside caregiver.

Finally, physicians may fear the legal ramifications of withholding or withdrawing life support. These ramifications are complicated and still evolving, and they vary from state to state; we cannot explore them in detail in this context. What is clear is that physicians have no legal right to provide health care contrary to the wishes of the legally competent patient. In the specific area of cardiopulmonary resuscitation, case law indicates that physicians face greater liability when they provide futile resuscitation than when they withhold resuscitation (15, 16). Withholding or withdrawing care from incompetent patients contrary to the wishes of the family is a more complicated area that is beyond the scope of this discussion. Dr. Hansot was the only family member involved in her mother's medical care, and she wanted life support to be withdrawn.

Death as a Colleague

The failure to determine and respect the end-of-life wishes of patients is an obstacle to improving the quality of medical care, an obstacle that will require doctors to come to terms with death and adjust their vision of their role in patients' lives. It was not so long ago that physicians accepted tending to and comforting the dying as one of their responsibilities. Even with all of our advanced technology today, a good death is sometimes the best we can offer. Sadly, modern medicine frequently does the opposite, denying patients a peaceful and dignified exit from this world.

Dr. Hansot's account of her interactions with her mother's pulmonologist suggests problems encountered all too often in medicine: It is easier to keep patients alive on ventilators than to grapple with withdrawing support, and it is easier to define success in terms of life and death than to try to determine the quality of life that is meaningful to an individual patient. To the physicians attending Ms. Hansot, sending a hemiparetic patient with a tracheostoma out of the hospital to live in a nursing home counted as success. Ms. Hansot, however, had indicated that she wanted to be allowed to die. The patient in this case recognized death as a friend; her physicians were unable to accept death as a colleague.

Conclusion

Dr. Hansot presents a troubling picture of medicine. She portrays physicians who are so preoccupied with the preservation of life that they can no longer see the broader human context of their work, physicians who have lost sight of one of the privileges and responsibilities of medicine: to offer some humanity at moments of suffering and loss. Most disturbing, the physicians felt that they had the right to force a sick, elderly woman to undergo the frightening and uncomfortable experience of mechanical ventilation when she clearly wished to be allowed to die.

Requests for Reprints: Thomas A. Raffin, MD, Division of Pulmonary and Critical Care Medicine, Stanford University Medical Center, MC 5236, 300 Pasteur Drive, Room H3151, Stanford, CA 94305-5236.

Current Author Addresses: Dr. Gilligan: Department of Internal Medicine, Brigham and Women's Hospital, 75 Francis Street, Boston, MA 02115.

Dr. Raffin: Division of Pulmonary and Critical Care Medicine, Stanford University Medical Center, MC 5236, 300 Pasteur Drive, Room H3151, Stanford, CA 94305-5236.

References

1. **Hansot E.** A letter from a patient's daughter. Ann Intern Med. 1996;125: 149-151.
2. **Ruark JE, Raffin TA.** Initiating and withdrawing life support. Principles and practice in adult medicine. N Engl J Med. 1988;318:25-30.
3. Consensus report on the ethics of foregoing life-sustaining treatments in the critically ill. Task Force on Ethics of the Society of Critical Care Medicine. Crit Care Med. 1990;18:1435-9.
4. **Reines HD.** Attitudes of critical care medicine professionals concerning forgoing life-sustaining treatments [Editorial]. Crit Care Med. 1992;20:320-6.
5. **Cowley LT, Young E, Raffin TA.** Care of the dying: an ethical and historical perspective. Crit Care Med. 1992; 20:1473-82.
6. **Gilligan T, Raffin TA.** Rapid withdrawal of life support. Chest. 1996;108: 1047-8.
7. A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). The SUPPORT Principal Investigators. JAMA. 1995; 274:1591-8.
8. **Lo B.** Improving care near the end of life. Why is it so hard? JAMA. 1995; 274:1634-6.
9. **Raffin TA.** Withdrawing life support. How is the decision made? [Editorial] JAMA. 1995;273:738-9.
10. **Cook DJ, Guyatt GH, Jaeschke R, Reeve J, Spanier A, King D, et al.** Determinants in Canadian health care workers of the decision to withdraw life support from the critically ill. Canadian Critical Care Trials Group. JAMA. 1995;273:703-8.
11. **Christakis NA, Asch DA.** Physician characteristics associated with decisions to withdraw life support. Am J Public Health. 1995;85:367-72.
12. **Miles SH, August A.** Courts, gender and the right to die. Law Med Health Care. 1990;18:85-95.
13. **Gilligan C.** In a Different Voice: Psychological Theory and Women's Development. Cambridge, MA: Harvard Univ Pr; 1982.
14. **Belenky MF, Clinchy BM, Goldberger NR, Tarule JM.** Women's Ways of Knowing: The Development of Self, Voice, and Mind. New York: Basic Books; 1986: 100-52.
15. **Marsh FA.** Physician authority for unilateral DNR orders. In: Wecht CH, ed. Legal Medicine 1993. Salem, NH: Butterworth Legal Publishers; 1994: 283-98.
16. **Paola FA, Anderson JA.** The process of dying. In: American College of Legal Medicine. Legal Medicine: Legal Dynamics of Medical Encounters. 3d ed. St. Louis: Mosby; 1995: 404-23.