BETTER CARE FOR THE DYING

Hawaii Healthcare System Develops a Manual For End-of-Life Care

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"Keep her alive," the senior resident physician barked. "We mustn't lose her. Her family and attending physician want everything necessary done."

The intern approached the bed and looked at the patient, an elderly woman who was unconscious and paralyzed from a stroke three weeks before. Afflicted with the failure of multiple organs, the woman already had many tubes attached to her body. Now one of her lungs had collapsed, and she would need a chest tube inserted to help her breathe.

The intern knew the woman would die without the chest tube. But even with it the prognosis was grim. At best, he knew, she had no more than six weeks to live.

During a previous hospital stay, the woman had apparently told a nurse that she wanted no "heroic measures" performed for her. But she had left no advance directive.

Why, the intern wondered, do we insist on keeping her alive?

In 1996, the leaders of St. Francis Healthcare System (SFHS), Honolulu, convened a brainstorming session for people concerned about end-of-life care issues. The leaders called the meeting because they knew that Americans were finding such issues increasingly worrisome. A recent study had shown that at least half of terminally ill patients suffered significant pain, their wishes concerning their care either unsolicited or ignored by caregivers.[1] A recent poll had indicated that 60 percent of the population feared pain, indignity, and loss of control in the final days of life.[2]

About 25 people—including physicians, nurses, managers, administrators, and parish and community representatives—attended SFHS's meeting. They identified 10 issues as, though poorly understood, essential to the care of the dying:

- Decision making
- Pain management and comfort care
- Pastoral and spiritual care
- Psychosocial care
- Hospice and home care
- Cardiopulmonary resuscitation
- Futility
- Withholding and withdrawing treatment
- Artificial nutrition and hydration
- Physician-assisted suicide and euthanasia

The meeting's participants decided to write an end-of-life care manual that would be a resource for staff throughout SFHS. The *Ethical and Religious Directives for Catholic Health Care Services* would serve as the manual's ethical foundation, the participants determined. Noting the directives' commitment to holistic healing—"Since a Catholic health care institution is a community of healing and compassion, the care offered is not limited to the treatment of a disease or bodily ailment but embraces the physical, psychological, social, and spiritual dimensions of the human person"[3]—they decided that the manual should take a holistic approach as well.

The participants decided that, before trying to improve SFHS's end-of-life care, they must first come to understand how it was then being provided. They formed themselves into 10 teams, each of which would study one of the 10 end-of-life issues and develop them into chapters for the manual.

The teams then spent six months conducting their studies. In the case of each issue, they collected and reviewed the relevant system policies and procedures and compared them with professional standards and various legal and ethical criteria. They also interviewed staff members about these policies and procedures, comparing the written versions with how they were actually practiced.

The teams soon learned that the delivery of services can be disjointed in acute care settings. Interviews with staff members revealed significant differences in the way that end-of-life care was delivered by the SFHS's many departments, units, and caregivers. There were even differences between the system's two acute care hospitals. When staff members were asked whether they ever withheld pain medication from dying patients, some said, "I'm not sure I know when someone is dying." Many maintained that certain aspects of care—psychosocial or spiritual assessment, for example—were the responsibility of staff members other than themselves.

It became clear to the teams that the manual would have to make difficult issues relevant and comprehensible to a staff trained in different disciplines and working in different environments.

WRITING THE MANUAL

The *Ethical and Religious Directives* state that "Catholic health care institutions offering care to persons in danger of death from illness, advanced age, or similar condition should provide them with appropriate opportunities to prepare for death."[4] In preparing SFHS's end-of-life manual, the teams devoted a chapter to each of the issues they had identified in their first session.

The teams initially found it difficult to determine where one end-of-life issue ended and another began, but through a process of continuous dialogue and reevaluation they were able to write a rough draft of each chapter. Once that was accomplished, a core committee made up of team representatives was assigned to weave the chapters together. Four physicians then reviewed the manuscript before turning it over to a professional editor for completion. The manual was published in June 1997.

In its final form, the manual refers the reader to various SFHS policies and procedures but does not list them. It does include an appendix containing relevant Hawaii statutes, including those concerning treatment decisions, informed consent, advance directives, and durable power of attorney.

THE MANUAL'S CHAPTERS

Each of the manual's chapters describes a particular end-of-life issue, offers a framework for resolving the ethical dilemmas involved, cites the relevant statutes and professional studies, and concludes with a question-and-answer section on practical matters. (In what follows, the chapter on spiritual and pastoral care is discussed with the one on psychosocial care, and the chapter on cardiopulmonary resuscitation is discussed with the one on futility.)

Decision Making This issue is the moral foundation of medical care for the dying. The *Ethical and Religious Directives* say that people facing death should be offered "the appropriate medical information that would make it possible to address the morally legitimate moral choices available to them."[5] This chapter discusses ways of assessing a patient's capacity to make decisions; the different types of surrogacy; and advance directives.

Spiritual, Pastoral, and Psychosocial Care These concerns are often considered secondary in acute care settings. The manual recognizes them as vital in the care of the dying because they help define the "whole person's" response to illness. These chapters emphasize the responsibility of all staff members to promote the emotional, financial, spiritual, and psychosocial comfort of patients and their families.

Pain Management and Comfort Care Research has shown that healthcare providers do not manage patients' pain well in many end-of-life cases.[6] As a result, people naturally perceive dying to be a highly painful process. This chapter clarifies the issue from the Catholic point of view, noting that the *Ethical and Religious Directives* say that "medicines capable of alleviating or suppressing pain may

Summary In early 1996, as it became clear that Americans were becoming increasingly concerned about end-of-life care, the leaders of St. Francis Healthcare System (SFHS), Honolulu, convened a meeting at which local people—community and parish representatives as well as healthcare professionals—discussed the matter.

The meeting's participants identified 10 issues as essential in end-of-life care: decision making, pain management and comfort care, pastoral and spiritual care, psychosocial care, hospice and home care, cardiopulmonary resuscitation, futility, withholding and withdrawing treatment, artificial nutrition and hydration, physician-assisted suicide and euthanasia.

The participants then divided themselves into 10 teams, each of which spent six months studying one of the identified essential issues. In each case, the team reviewed the relevant SFHS policies and procedures and compared them with national standards. The team also interviewed staff members about the policies and procedures, comparing the written versions with actual practices.

Each team then wrote a chapter on its assigned issue, after which a core committee wove the chapters into an end-of-life care manual for SFHS. The manual was published in June 1997. The system's leaders currently use the manual to educate staff members in good end-of-life care.

be given to a dying person, even if this therapy may indirectly shorten the person's life. . . ."[7] This passage supports using the "principle of double effect."

Withholding and Withdrawing Treatment Like the others, this chapter is based on the premise that a sound ethical framework and compassionate communication are necessary in arriving at decisions to initiate, withhold, or withdraw treatment. Withholding treatment, it makes clear, is not the same as withholding care.

Withholding treatment is not the same as withholding care.

Artificial Nutrition and Hydration Although the teams realized that withholding or withdrawing fluids and nutrition is ethically no different than withholding or withdrawing other kinds of treatment, they devoted a separate chapter to this issue. They recognized the special significance food and drink have in many cultures, including the cultures of medicine and nursing. Indeed, one of the chapter's purposes is to help staff members resist their normal impulses and instead consider how continued nutrition and hydration might be a burden rather than a blessing to a dying patient.

Cardiopulmonary Resuscitation and Futility From their interviews, the teams learned that staff members had a tendency to interpret do-not-resuscitate orders as calling for no further treatment of any kind—although dying patients may benefit from such therapies as antibiotics or intravenous fluids.

But even when the treating physician writes "Comfort measures only" on the chart of a patient who has asked not to be resuscitated, the order's meaning is not always clear to other staff. There is no standard definition of "comfort care" because different people define comfort in different ways.

The *Ethical and Religious Directives* say healthcare providers are morally obligated to preserve a patient's life, providing that the means used offer the patient "a reasonable hope of benefit and do not entail an excessive burden. . . ."[8] The directives do not endorse futile efforts. These chapters discuss "reasonable hope" and "excessive burden."

Hospice and Home Care Recognizing that most healthcare professionals work in an acute care setting and thus may not be knowledgeable about hospice and home care, the teams devoted a chapter to those settings. The chapter reminds caregivers that a patient need not face imminent death to profit from a discussion of end-of-life care.

Physician-Assisted Suicide This chapter explains why SFHS, which is dedicated to providing compassionate care for the dying, considers physician-assisted suicide and euthanasia to be unacceptable.

QUESTIONS AND ANSWERS

The teams found the question-and-answer sections of the manual the most challenging to write:

- The team assigned to work on the chapter on *decision making* had little difficulty defining "advance directives" and "guardianship." But it had to devote considerable thought to coming up with correct answers to the questions "Who is responsible for obtaining informed consent?" "What if the patient's wishes are not being followed?" and "What if the patient has no surrogate?"
- The team assigned to the chapter on *pain management and comfort care* discovered that, to answer the relevant questions, it had to interview bedside staff, especially nurses, who are trained to use a patient's vital signs as a gauge for treatment. The answer to the question "Should I stop pain medication if I see a patient going downhill?" addresses both withdrawing treatment and "double effect."
- As they were finally developed, the manual's chapters on *spiritual, pastoral, and psychosocial care* and *hospice and home care* raised questions such as "What if I am not a Catholic?" and "What if I have no health insurance?" These chapters not only answer the questions; they also direct staff to the appropriate resources.
- The answers to the questions "Are all patients with advance directives automatically 'no codes'?" and "Can patients who refuse cardiopulmonary resuscitation be cared for in an intensive care unit?" correct common misconceptions about those issues.
- The questions and answers concerning *cardiopulmonary resuscitation and futility* tie in well with those on *withholding and withdrawing treatment* and *artificial nutrition and hydration*; indeed, they constitute something of a step-by-step approach to those issues. The answers to the questions "Who decides if a treatment is futile?" and "Is it legal to withhold artificial nutrition and hydration?" address some of the issues that frequently result in ethical consultations. The answer to the question "If I want to

be put out of my misery, why can't I have that right?" helps staff respond to the legal and ethical issues involved in physician-assisted suicide.

IMPROVING END-OF-LIFE CARE

The current physician-assisted suicide debate in the United States is making healthcare providers more aware of the issues involved in end-of-life care. This is a good thing. Government should not have to legislate appropriate, high-quality care for dying patients. That responsibility lies with providers themselves.

SFHS is determined to make improved end-of-life care a high priority. Putting the manual on the shelf will not suffice, however. SFHS's leaders will not rest until such care is an integral part of the system's culture. They are currently considering ways to educate the system's staff. □

The End-of-Life Manual *is available for $20 from the St. Francis International Center for Healthcare Ethics, St. Francis Medical Center, 2230 Liliha St., Honolulu, HI 96817.*

NOTES

1. The SUPPORT Principal Investigators, "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)," *JAMA*, November 22-29, 1995, pp. 1,591-1,598.
2. Gallup Survey, "Knowledge and Attitudes Related to Hospice Care," *National Hospice Organization Newsline*, October 15, 1996, pp. 1, 3.
3. National Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, U.S. Catholic Conference, Washington, DC, 1995, p. 9.
4. National Conference of Catholic Bishops, p. 22.
5. National Conference of Catholic Bishops.
6. D. Weber, "Deathcare: Exploring the Troubled Frontier between Medical Technology and Human Mortality," *Healthcare Forum Journal*, March 1995, pp. 14-25; B. Rich, "Pain Management: Legal Risks and Ethical Responsibilities," *Journal of Pharmaceutical Care in Pain and Comfort Control*, May 1997, pp. 5-20; M. Buchan and S. Tolle, "Pain Relief for Dying Persons: Dealing with Physicians' Fears and Concerns," *Journal of Clinical Ethics*, June 1995, pp. 53-61.
7. National Conference of Catholic Bishops, p. 23.
8. National Conference of Catholic Bishops, p. 22.

BRIDGES

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keep up with the other employees. Working with the welfare department, we found her a more appropriate situation in another facility. Two other people left the program.

The participants in the first group, and a recently selected group of another eight, agree that beginning the program with others helped them make the adjustment to employment. We try to get the participants together regularly to discuss how things are progressing. The program coordinator is available to offer any assistance when participants are ready to become employees, as well as when there are any problems.

FACING THE CHALLENGES

As we continue to expand the Bridges program, we encounter many challenges. Some are the challenges that any human resources department faces in selecting people for entry-level positions. We have had to intercede with the welfare bureaucracy for some of the participants. We needed to allow one person extra time off when her childcare arrangements failed and she had to find a safe place for her children to stay while she was at work. It has been difficult for some participants to have to wait to be hired for a full-time position. But we have had many rewards. The look on a single mother's face when she signs the papers that say she is now a paid employee with benefits and a future here is a reward in itself.

When we kicked off the Bridges program, Mercy Medical Center hosted a breakfast for other human resource professionals and directors of social service agencies in our area. We challenged other businesses to join in the effort to assist people who need to get off welfare. We have sent representatives to several countywide focus groups on the effects of welfare reform on the people and businesses in our county. By utilizing all the available resources, we hope to be able to provide the support and guidance that our participants may need. □

☎ *For more information, contact Karen Feller at 330-489-1307.*