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. A recent poll had indicated that 60 percent of the population feared pain, indignity, and loss of control in the final days of life.

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"—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 identified 10 issues as, though poorly understood, essential to the care of the dying:
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." 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." 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. 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..."
Withholding treatment is not the same as withholding 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 withdrawing and withholding 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 Liilika 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.

**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 child-care 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.

\[\text{For more information, contact Karen Feller at 330-489-1307.}\]