Secondary and Tertiary Palliative Care in US Hospitals

Charles F. von Gunten, MD, PhD

THE PATIENT’S STORY
Reverend J was a 75-year-old former hospital chaplain who was well until he developed dyspepsia, anorexia, nausea, and vomiting 4 months prior to admission. Three months prior to admission he was admitted to Hospital A, a community hospital, and was diagnosed with widely metastatic adenocarcinoma involving the stomach, liver, and pancreas with biliary obstruction. A biliary stent was placed. At the time of diagnosis, his wife reports being told, “if he made it 2 months, it would be a miracle.”

One week prior to admission he had waxing and waning mental status and increased somnolence. With worsening symptoms and pain, his wife brought him to the emergency department of Hospital B, where he had been chaplain for many years, although his insurance plan did not include that hospital. Evaluation showed severe hyponatremia (sodium, 108 mg/dL) and jaundice (total bilirubin, 26 mg/dL [444.6 µmol/L]). He was treated with intravenous saline in the emergency department and transferred to Hospital C, the local university hospital, for comfort care.

Reverend J was admitted from Hospital C’s emergency department to the palliative care unit. Goals of care were established with the patient and wife. These included freedom from pain, nausea, and vomiting, as well as some time for the rest of the family to gather and to cope with his impending death. The patient was treated with intravenous saline in the emergency department and transferred to Hospital C, the local university hospital, for comfort care.

Palliative care services provide secondary and tertiary levels of palliative care, the interdisciplinary care of patients in which the goal is comfort and quality of life. Primary palliative care refers to the basic skills and competencies required of all physicians and other health care professionals. Secondary palliative care refers to the specialist clinicians and organizations that provide consultation and specialty care. Tertiary palliative care refers to the academic medical centers where specialist knowledge for the most complex cases is practiced, researched, and taught. The case of Reverend J, a man with advanced cancer admitted to an acute palliative care unit in a teaching hospital, illustrates the use of secondary and tertiary clinical palliative care services in hospitals and health care systems.

Mrs J: [After he was diagnosed at Hospital A] they said they was going to make him comfortable. [When they sent him home from the hospital] the doctor sent the bottle of morphine here and that was it. [On the day he was admitted to Hospital C] I said, “I’m desperate.” We drove up at 12:30 AM to the university hospital’s emergency room.

Dr A: Too many times we saw people that were dying in ways that we thought weren’t optimal and so many times found ourselves trying to jury-rig a good setup for families and patients. While we could provide the right kind of care, often . . . it was hard to get everybody in the right frame of mind. We thought if we had a palliative care unit and a palliative care team that it would make these transitions and this kind of care easier and more likely to happen.

A Perspectives editor interviewed Mrs J on May 1, 2001, 2 years after Mrs J’s husband had died. The 2 physicians,

See also Patient Page.
pharmacist, nurse manager, and chaplain are members of the palliative care team at the university hospital to which Reverend J was admitted. A Perspectives editor interviewed them about palliative care and the palliative care unit on May 7, 2001.

The Challenge

Patients like Reverend J and his wife present a challenging paradox for physicians, hospitals, and health systems. Physicians are trained, and the health care industry promotes itself, to provide care that will reverse disease and restore health. Yet patients with advanced illness in which the disease cannot be reversed and health cannot be restored, like Reverend J, present themselves for care. If Reverend J and Mrs J were asked, they would say they understood the diagnosis and prognosis. Still, they came to the hospital. When Mrs J was asked why she came to the hospital, she said, “It’s really my confidence in the staff. I just felt like I have nothing to worry about.”

Viewing physicians as agents of cure and the hospital as a preferred place for medical care are contemporary phenomena. Historically, physicians were sought for comfort as well as for cure. Hospitals were places of last resort, to be avoided if possible. Families who could afford it cared for their ill at home, with periodic visits from the doctor. People died quickly, usually from infectious diseases or trauma. The suffering associated with life-threatening illness and the associated burden on family was brief.

Now, most people are ill with a life-threatening diagnosis for months to years before they die. This profoundly affects patients and their families in terms of their physical, psychological, social, and spiritual suffering. Of Medicare beneficiaries who die, 98% are admitted to a hospital during the year prior to death; of these, 15% to 55% will have at least 1 stay in the intensive care unit (ICU) in the 6 months prior to death. By contrast, more than 90% of adults in the United States say that they would prefer to die at home, although more than two thirds die in institutions such as hospitals (52%) and nursing homes (24%).

Reverend J’s physicians at Hospital A identified his diagnosis and prognosis. However, they did not appear to demonstrate the skills to relieve his and his family’s suffering. When he was sent home with morphine, he and his wife had many remaining, unmet needs for the relief of their pain and suffering. This case illustrates how the relief of suffering associated with serious life-threatening illness in hospitals and health systems often needs to be improved. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) showed that more than 50% of people dying in hospitals suffered from uncontrolled pain, and that decisions were inappropriately timed. One way that patients and their families will get better care is to ensure that clinical services focusing on the relief of suffering are available in every hospital.

Reverend J and his wife found their way to physicians and a hospital that had implemented state-of-the-art approaches to the relief of suffering. This case illustrates how physicians can use this approach—secondary and tertiary levels of care—to improve palliative care.

Palliative Care: Relieving Suffering

During the past 60 years, strides in the understanding and treatment of disease have overtaken the ability to relieve suffering associated with illness. However, technological advances to relieve suffering and improve quality of life have been made over the past 20 years. As the 21st century begins, it behooves each physician to incorporate those advances into practice.

Palliative care is a generic term whose manifestation as a clinical service can carry many names (eg, hospice care, comfort care, supportive care, advanced care, pain and palliative care service). The term palliative care may be defined as the interdisciplinary care of patients and families focused on the relief of suffering and improving quality of life. Palliative medicine describes the physician’s role as but one part of the larger interdisciplinary field of palliative care.

Several models exist for the delivery of palliative care. This article focuses on acute hospital care. However, hospice organizations are the most widely known and highly developed model for the delivery of palliative care when it comprises the entire focus of care in the last weeks and months of a patient’s life. A comprehensive array of palliative services is provided under terms of the Medicare Hospice Benefit by Medicare-certified hospice programs. Like individual hospitals, individual hospice programs vary in the scope of their services but respond to a common set of federal regulatory standards. Some hospice programs work in partnership with hospitals to provide services to hospitalized patients earlier in the course of their illness, when palliative care may be combined with efforts to cure illness or prolong life. For example, a physician, nurse, and social worker may staff a hospital palliative care service as well as work with a local hospice program.

Clinical palliative care can be made available at 3 distinct levels, in parallel with current concepts of all medical care. Primary palliative care refers to the basic skills and competencies required of all physicians and other health care professionals. In this way it does not differ from the primary care skills and competencies needed in the variety of content areas germane to clinical care, such as cardiology, where there is also specialist care. Secondary palliative care refers to the specialist clinicians and organizations that provide consultation and specialty care. By analogy, while not all patients admitted to the hospital with heart disease require care in the coronary care unit, or by a cardiologist, some do. In palliative care, specially trained clinicians and care delivery models, such as hospice programs, provide care in a variety of settings: the patient’s home, nursing homes, outpatient clinics, and hospitals. Tertiary palliative care re-
fers to the academic medical centers where specialist knowledge for the most complex cases is practiced, researched, and taught. Reverend J was admitted to a tertiary palliative care unit.

As compared with “usual” hospital care at the end of life, secondary and tertiary hospital palliative care make clinical services routinely available to help the primary physician ensure that adequate assessment and management of symptoms, psychological distress, practical and financial issues, and spiritual concerns are incorporated into comprehensive care of the patient and family. The care of Reverend J and his wife and family illustrates one way that a specialty palliative care team and unit can affect the care of hospitalized patients and their families.

The Interdisciplinary Team

CHAPLAIN: Working with the palliative care group is really more like a basketball team or a football team, where every member of the team is absolutely essential for making it happen. No one person is the star, but there is this constant passing it back and forth, calling on different people at different times because that’s what the need is. It becomes much more driven by the needs of the patients and family as opposed to the needs of the staff. [This contrasts with the rest of the hospital, where the multidisciplinary team] is like a relay team . . . where one passes the baton to the next and they run and do their thing and then the next person picks it up.

DR M: [Palliative care contrasts with] the way physicians are trained [where the focus is on] working independently; being “the only doc in the hospital” is a common phrase, especially for residents.

A cardinal feature of palliative care is interdisciplinary expertise. The core disciplines are medicine, nursing, social work, and chaplaincy. Pharmacists, physical and occupational therapists, volunteers, bereavement counselors, psychologists, and those from other disciplines are also frequently included. In his commentary, the chaplain uses a sports analogy to illustrate how interdisciplinary teamwork is different from the sequential multidisciplinary care that frequently characterizes “usual” hospital care. Although not all patients require all disciplines all of the time, each discipline participates in the assessment and the planning of treatment.

Focus on Patient and Family

NURSE MANAGER: My role is . . . to move my nurses beyond skills and specialized assessment abilities to a realm of caring that could be described as the moral art of nursing . . . where nurses are able to step in and out of life narratives of patients and their families and support them in very untraditional ways—ways that would seem unacceptable perhaps on another unit . . . This includes any cultural end-of-life rituals or any personal rituals.

PHARMACIST: My role . . . is to be available to offer alternatives, drug therapy for symptom management, to explain to families what the medicines are for. I don’t think there’s another area that is quite so dramatic in terms of the difference that the right drug therapy can make. Just to see the change in a person when the pain is gone or when the symptoms are under control. Then that person has time to talk to his family and do the things that he has to do before he dies, or that he wants to do before he dies.

The patient and family together make up the object of palliative care. Some conceptualize the patient and family as part of the team. Others describe them as the center of a wheel around which the members of the interdisciplinary team are arrayed like spokes. In all cases, the patient and family have important participatory and decision-making roles. This was true in Reverend J’s case, where the care of his wife and family was as important as the treatment of his physical symptoms. Table 1 summarizes the roles and functions that physicians can expect from clinical palliative care services.

Table 1. Roles and Functions of Palliative Care Service Members

<table>
<thead>
<tr>
<th>Role</th>
<th>Function</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical care</td>
<td>Provide consultation and/or management of portions or all of a patient’s care by a physician, sometimes with a nurse practitioner or physician assistant</td>
</tr>
<tr>
<td>Nursing</td>
<td>Provide comprehensive assessment and implementation of treatments; contribute extensive experience and expertise</td>
</tr>
<tr>
<td>Psychosocial care</td>
<td>Provide psychosocial assessment and support to patient and family unit; contribute expertise in family systems theory</td>
</tr>
<tr>
<td>Spiritual care</td>
<td>Help patient and family find meaning and hope in the transcendent dimension; work with community pastors as indicated</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>Provide consultative expertise in drug therapy, drug interactions, and patient/family education</td>
</tr>
<tr>
<td>Administration</td>
<td>Ensure smooth functioning of the team and facilitate problem solving</td>
</tr>
<tr>
<td>Volunteers</td>
<td>Provide additional care and support to patient and family; contribute time, the most valuable commodity</td>
</tr>
<tr>
<td>Therapy (eg, physical, occupational, music, massage)</td>
<td>Provide adjunctive therapies designed to achieve the goals of care; treat both patients and families</td>
</tr>
</tbody>
</table>

Four Domains of Palliative Care

In observing a large series of patients with advanced cancer, Saunders originally described 4 broad domains of palliative care: physical (eg, pain, nausea, vomiting), psychological (eg, anxiety, stress, worry), social (eg, family systems, economic, practical issues), and spiritual (eg, the transcendent dimension of human experience). Many patients and their families experience perturbations in each of these domains when faced with life-threatening illness. Recent empirical data support Saunier’s model. Progress in palliative care has yielded a growing body of knowledge related to the satisfactory relief of suffering in these 4 domains.

©2002 American Medical Association. All rights reserved.
CLINICAL PALLIATIVE CARE

Reverend J and his family undoubtedly could have benefited from primary palliative care from the time of diagnosis, had it been available to them. Unfortunately, his physicians were neither trained nor competent in its provision. Furthermore, his medical care was hospital based and disease focused. When his physician could “do nothing else,” he sent him home with morphine. His wife described “trying to find hospice,” but wasn’t able to obtain a referral to such a secondary level of palliative care that would have helped to care for him at home.

Primary Palliative Care in the Hospital

Primary care physicians can themselves provide much of the palliative care their patients need. They can ensure that they acquire the knowledge, attitudes, and skills needed to provide palliative care to their patients. They can also advocate to ensure that their colleagues and other health care professionals in their hospital are similarly trained. For example, one hospital had its hospice organization teach all staff about palliative care, then rewrote policies and procedures and required all nurses to demonstrate palliative care competencies as part of their employment. The Education for Physicians on End-of-Life Care (EPEC) and the End-of-Life Nursing Education Consortium (ELNEC) projects aim to provide the resources to learn such primary palliative care.

Secondary Palliative Care in the Hospital

Physicians will want to have access to specialty care for their patients when needs exceed their skills and available time. Pan et al reported that about 400 hospitals out of 7000 surveyed have established palliative care programs to provide such care. Billings and Pantilat report that 26% of teaching hospitals have such programs. In most cases, the hospitals use the clinical expertise of hospice organizations to advise, teach, and, in some cases, provide the clinical services in the hospital through either consultation, inpatient units, or both.

Consultation Services

Consultation services can help deliver specialist palliative care in a manner similar to other consultation services. Their success in assisting physicians to deliver palliative care reflects the role that consultation plays in the continuing education of physicians. Physicians often learn about new developments through consultation. Palliative care consultation services provide the physician with advice and can participate in management of patients anywhere in the hospital, eg, surgical services, intensive care units, medical wards, and cancer centers. The American Board of Hospice and Palliative Medicine certifies subspecialist physicians in the field. The Hospice and Palliative Nurses Association certifies nurse specialists.

Palliative care consultation services are a way to bring specialist knowledge and expertise about the relief of suffering and the improvement of quality of life to bear in combination with other medical services in the hospital. Some centers have extended this consultation service to the outpatient setting in palliative care clinics where the team sees referred patients. In other settings, palliative care clinicians see patients in established geriatric, oncology, pulmonary, or cardiac clinics.

Palliative Care Unit

Dr A: [The palliative care unit occupies] 2 rooms on the medicine floor. They have a million-dollar view of the city. We remodeled the rooms so that we have linoleum that looks like hardwood floors; we have curtains that have a floral pattern to bring the outside leaves and trees into the room. We have artwork on the walls. We have standing lamps, a TV, a VCR, a CD player for music. We have a fold-out couch. We’ve taken all of the medical equipment and hidden it behind a cabinet and have a standing fountain so that you can hear the sound of water bubbling. And our rooms are in the exact same location in the hospital as the birthing suites several floors above. We think that there is a nice symmetry to that. Right next door is a common room that has couches, a refrigerator, a microwave, a sink, so that families can camp out there if they need to. Our families sleep there, they set up shop. They bring in pictures and food and port-a-cribs and musical instruments and spiritual objects of all kinds.

Mrs J: They [the staff] were on a high pitch, very jovial. “We’re gonna give you some more medicine, we’re gonna fix this up, we’re gonna do this for you and this for you.” They would talk to him about what they was going to do. I was in 2 worlds and I sort of moved from one to the other one and when people came in I was doing everything I had to do. I mean we’d start talking about things. And then, when I was alone, I guess I didn’t want to deal with it, so I would go sit in the back and eat some food. And that was a beautiful view. The view that you have when you’re in this state of mind takes you into a whole new world. The first morning he was there, first thing he said when he woke up is “Oh, look at this view.” The sun came through that window and came right on this side of the bed. The environment itself was conducive to phasing out. It’s the kind of climate I would want to be in.

Calm. You look outside and you see some of God’s creation and the sun comes in on you. It did not take on the atmosphere of a hospital room. The first thing I thought, when they said we were going to be on that particular floor, “Oh my God everybody up here about to die.” But this is much better. I calmed down myself. I was worried, thinking they gonna be running all day and all night from one room to the other but that was not the case. That was the real beauty of it—that you got special care. I think there were about 4 interns there. And so I knew they were there trying to learn and get everything they could get. As a result, I knew there was always somebody there.

These descriptions illustrate the character and expertise of palliative care units in hospitals. They differ in an important way. Dr A describes the physical characteristics of...
the unit that differentiate it from other units in the hospital. He describes characteristics of most palliative care units in hospitals. Mrs J describes her experience of the care on the unit. While both aspects are important, it is worth stressing that palliative care units are not only distinguished by their decor. It is the quality of the care delivered there that is the distinguishing factor. In a 12-bed acute palliative care unit with physical surroundings similar to those at this hospital, more than 200 family members surveyed focused on the care delivered.20

Physicians may admit patients to acute palliative care units in hospitals for a variety of reasons. Patients can be transferred from elsewhere in the hospital if that would enable better care. Patients can be admitted directly from home when evaluation in the emergency department or general ward of the hospital does not seem appropriate. Patients can also be admitted from the emergency department, as in Reverend J’s case, or from psychiatric units, the surgical recovery room, and the intensive care units. Because the environment and expertise is ideal for withdrawal of life-sustaining measures, physicians can admit patients on ventilators, pressors, or dialysis for the express purposes of withdrawing such support in a setting that can provide maximum palliative care expertise.

Physicians can expect to encounter palliative care units of various models depending on decisions made at a local level. Each model has advantages and disadvantages. TABLE 2 lists some aspects of variability that physicians are likely to encounter. Units vary in size from 1 to 40 beds, averaging about 12.21

Dr M: *The biggest element that is different about an [acute inpatient palliative care unit] from other palliative care settings is that the patients are acutely ill. These are patients who, by and large, were admitted to the hospital with the expectation that [their disease] would be controlled or managed or even cured. It makes it very, very challenging.*

Dr A: *Our patients are very sick and 75% die in our palliative care unit. But that means that 25% of them don’t, and they either go home [usually with hospice care], or to a skilled nursing facility [usually with hospice care], or to an inpatient hospice unit.*

One issue that is frequently raised about palliative care units in the hospital is the acuity of patients admitted. Some phy-

<table>
<thead>
<tr>
<th>Table 2. Aspects of Acute Inpatient Palliative Care Units Physicians Are Likely to Encounter</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Design Elements</strong></td>
</tr>
<tr>
<td>Location</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Admission policy</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Visiting</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Admissions</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Procedures, tests, therapies</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

©2002 American Medical Association. All rights reserved.
Physicians wonder if the care in a palliative care unit is just skilled nursing or custodial care rather than acute hospital care. In practice, palliative care, like other types of medical care, spreads along a continuum. There are acute palliative care units, such as the one used by Reverend J, and there are units for more long-term care in nursing homes or in inpatient settings. Some facilities are able to provide the full spectrum. Others require patients to move to a different setting when their needs change. Some hospice organizations have dedicated units to provide some or all of these services, others do not. All Medicare-certified hospice organizations must be able to provide services both in the patient’s home and in inpatient settings. Of note, 40% of patients are discharged alive from such units—the majority to their home with hospice care, but some to their home with health agency care and some to a nursing home with hospice care.  

Establishing units such as this requires, at a minimum, the support of key clinical constituencies and hospital leadership. The developmental steps are described in detail elsewhere.  

Outcomes of Palliative Care

Dr A: We’ve had referrals to our unit from every service in the hospital. And our services are widely used.

The outcomes of palliative care programs can be assessed in several ways. Most important are the evidence for improvement of care for patients and families. Of secondary importance is the evidence that health care resources are better utilized.

One of the most practical ways to evaluate the outcomes of palliative care services is to assess whether and how they are used. At Froedert Hospital, the primary teaching affiliate of the Medical College of Wisconsin, the palliative care service receives more consultations than the hematology/oncology service (D. Weissman, MD, oral communication, December 2001). The broad range of patients and diseases seen by a palliative care service reflects the needs of the particular hospital.  

At Detroit Receiving Hospital, where young trauma patients predominate, the palliative care service is most active in the intensive care unit. Another way to measure outcomes is patient and professional satisfaction. In one unit, when patients and families were surveyed, their satisfaction with the palliative care and home hospice program ranked second highest among 27 departments in the hospital (Northwestern Memorial Hospital, Chicago, Ill, unpublished data, May 1999). When surveyed, the 1000-member physician staff reported similar satisfaction (unpublished data, May 1999). Numerous survey instruments are available.

Satisfaction is also measured by financial donations, correlated with the financial resources of the patient populations. At Northwestern University Medical School and Northwestern Memorial Hospital, families served by the program have donated more than $50 million to the medical school and hospital (unpublished data, May 2001). At the Balm of Gilead Project at Cooper-Green Hospital in Birmingham, Ala, a public “safety net” hospital, patients and families have donated in amounts of $5 and $10. This is the first time in the history of the hospital that patients and families have donated money. (A. Bailey, MD, oral communication, December 2001).

Pain and symptom management scores indicate that palliative care is effective. While data are still being collected, early reports suggest that pain and symptom management scores are better when patients are served by a dedicated service. The push to make pain the “fifth vital sign” on bedside charting is but one example of these efforts.

Finally, palliative care services have a positive financial impact on hospitals. In all studies to date, palliative care services decrease hospital and intensive care unit length of stay, promote more appropriate use of high-technology therapies, and are associated with no increase in risk-adjusted mortality.

Teaching Palliative Care in the Hospital

Reverend J was admitted to a teaching palliative care unit. House staff working with and learning from an interdisciplinary team of palliative care experts cared for him and his family. Beyond the benefits of being cared for in an academic center where they “practice what they teach,” the residents are learning palliative care skills in the same way that they learn other important medical skills—by doing. They learn the value of working as part of an interdisciplinary team, the satisfaction of bringing difficult symptoms under control, the challenge of resolving contentious family dynamics, the intrigue of exploring values and determining goals of care, the professional gratification of experiencing the death of a patient as a completion of good medical care, rather than as failure, and the responsibility of counseling the family through acute bereavement support.

If physicians are to demonstrate palliative care skills as part of routine, good medical care, it must be integrated into the practice and curricula of academic medical centers. In Reverend J’s case, the medicine house staff admitted him to the palliative care unit in the same way that they admit and transfer patients into other units within the medical service. This models an important message. This is part of a physician’s job—as much a part of the job as caring for a patient in the general inpatient unit and the intensive care unit. Moreover, the skills learned are transferable. It is impossible to compartmentalize palliative care approaches just to the palliative care unit. In my experience, many feel these services and units in academic centers broadly affect practice in the institution—for the better. In fact, it could be argued that such services are a practical way to restore balance to the technological imperative of contemporary medical practice.

CONCLUSIONS

Palliative care consultation services and specialty units are a response to the shortcomings of the curative health model for patients for whom no cure exists. Physicians need to de-
velop their own knowledge of primary palliative care, but health systems that provide the full range of secondary and tertiary palliative care services as part of their continuum of care will permit better options and care for patients and families. Physicians and other health care professionals can be motivated to see these developments achieved, in part, by recognizing that those trained today will care for each one of us, and our families, in time.

Funding/Support: The Perspectives on Care at the Close of Life section is made possible by a grant from the Robert Wood Johnson Foundation.

Other Resources: For a list of relevant Web sites, books, and articles, see the JAMA Web site at http://jama.ama-assn.org/issues/v287/n7/abs/jelf10002.html.

Acknowledgment: I am deeply indebted to Archbishop Theodore J. Remmett, SGS, who first introduced me to hospice care and to Jeanne M. Martinez, RN, MPH, who first taught me about hospital-based palliative care. Also to my collaborators and colleagues at the Education for Physicians on End-of-life Care (EPEC) Project, the Center to Advance Palliative Care (CAPC), and the Center for Palliative Studies for their inspiration and support. Finally, I am grateful for grant support as a Faculty Scholar of the Project on Death in America, the Robert Wood Johnson Foundation, the Dickinson Foundation, the Dr Seuss Fund, and the National Cancer Institute.

REFERENCES

Resources

**How to Set Up Hospital-Based Palliative Care Programs**
Center to Advance Palliative Care
CAPC Manual: How to Establish a Palliative Care Program
http://www.capcmssm.org


**Palliative Care Education**
American Academy of Hospice and Palliative Medicine
AAHPM Primer in Palliative Care
Available for order at: http://www.aahpm.org/primer.htm

American Academy of Hospice and Palliative Medicine
AAHPM UNIPACs
http://www.aahpm.org/unipac's.htm

Americans for Better Care of the Dying
Advice to Clinicians to Improve Daily Practice
http://www.abcd-caring.org/tools/actionguides.htm#clinicians

Education for Physicians on End-of-life Care (EPEC)
http://www.epec.net

End-of-Life Nursing Education Consortium (ELNEC)
ELNEC Curriculum
http://www.aacn.nche.edu/elnec/curriculum.htm

Fast Facts and Concepts on End-of-life Care
http://www.mcw.edu/pallmed/html/about1.html

Ian Anderson Education Project
http://www.cme.utoronto.ca/endolife/
National Physician Residency Curriculum Project
http://www.mcw.edu/pallmed/html/about1.html

**Norms/Standards of Palliative Care Practice**
American Academy of Neurology
Palliative Care in Neurology (1996)

American Academy of Pain Medicine
Quality Care at the End of Life (1998)
http://www.painmed.org/productpub/statements/endolifestmt.html

American Geriatrics Society
Measuring the Quality of Care at the End of Life: a Statement of Principles (1997)
http://www.americangeriatrics.org/about/special_projects.shtml

American Medical Association
Position Statement on Do-Not-Resuscitate Orders
http://www.worldrtd.org/AMAdnrOrders.html

American Pain Society
Principles of Analgesic Use in the Treatment of Acute and Cancer Pain (4th ed)
Available for order at: http://www.ampainsoc.org/pub/principles.htm

American Thoracic Society
Withholding and Withdrawing Life-Sustaining Therapy (1991)
http://www.thoracic.org/adoobe/statements/withhold1-6.pdf

Canadian Palliative Care Association (Ottawa, Ontario, Canada)
CPCA Norms of Practice
http://www.cpca.net/educate/index.html

The Hastings Center
Guidelines on the Termination of Life-Sustaining Treatment and Care of the Dying (1987)
Available for order at: http://www.thehastingscenter.org/publications.htm

Institute of Medicine report
Approaching Death: Improving Care at the End of Life (1997)
http://www.nap.edu/readingroom/books/approaching/

Joint Commission for the Accreditation of Healthcare Organizations (Oakbrook, Ill)
Pain Standards for 2001
http://www.jcaho.org/standard/pm.html

Milbank Memorial Fund
Principles for Care of Patients at the End of Life: An Emerging Consensus Among the Specialties of Medicine (1999)
http://www.milbank.org/endolife/index.html

©2002 American Medical Association. All rights reserved.
National Hospice and Palliative Care Organization and the National Hospice Work Group
http://www.nhpco.org/public/articles/OCFFINALRPT.pdf

National Hospice and Palliative Care Organization
*A Pathway for Patients and Families Facing Terminal Illness* (1997)
Members of NHPCO may order a copy (document 216) at:
http://www.nhpco.org/public/articles/FOR.pdf

Palliative Care Australia
Standards for Palliative Care Provision

Toolkit of Instruments to Measure End-of-life Care (TIME) (Teno JM, et al.)
http://www.gwu.edu/~cicd/toolkit/toolkit.htm

Weissman D.
Improving End-of-life Care: a Resource Guide for Physician Education

World Health Organization
*Cancer Pain Relief and Palliative Care* (1989)
Available for order at: http://www.who.int/ncd/cancer/publications/books/cancer_pain_relief_and_palliative_care.html

Cherny NI, Coyle N, Foley KM. Guidelines in the care of the dying patient.

Council on Ethical and Judicial Affairs, American Medical Association.

Council on Scientific Affairs, American Medical Association.

Task Force on Ethics of the Society of Critical Care Medicine.