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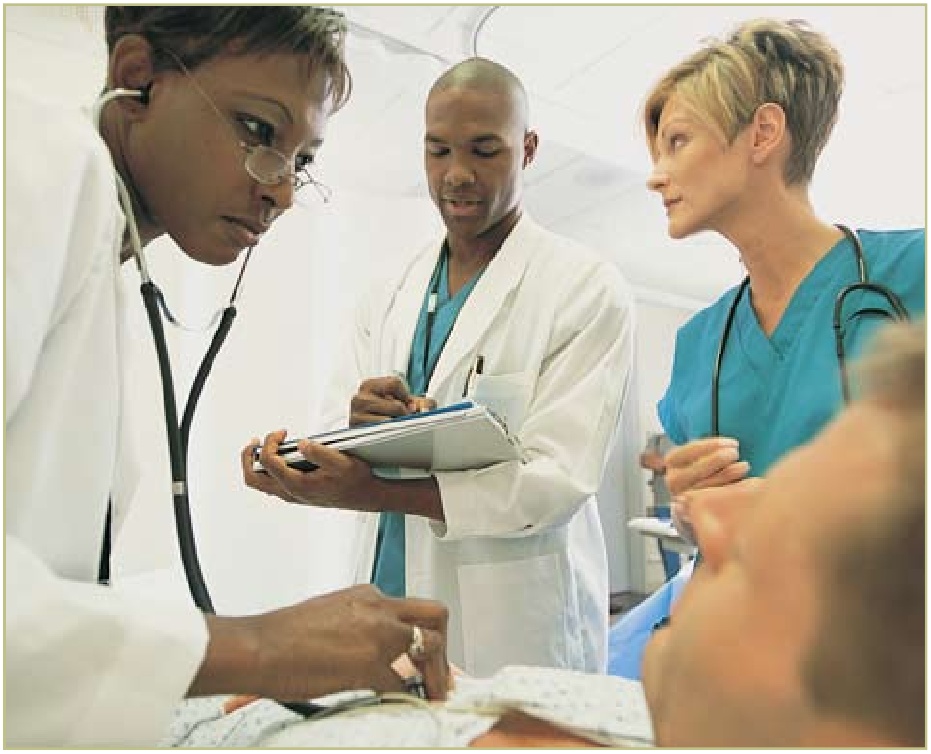

Palliative Care in California:
Fundamentals of Hospital-Based Programs

May 2007

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Fundamentals of Hospital-Based Programs

Prepared for
CALIFORNIA HEALTHCARE FOUNDATION

by
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About the Foundation

The **California HealthCare Foundation,** based in Oakland, is an independent philanthropy committed to improving California's health care delivery and financing systems. Formed in 1996, our goal is to ensure that all Californians have access to affordable, quality health care. For more information about CHCF, visit us online at www.chcf.org.

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I. Introduction

The California HealthCare Foundation has commissioned *Palliative Care in California* to alert, educate, and advise health care administrators, and in particular hospital executives and their boards of trustees, about the fundamentals of palliative care and the operational requirements for launching a hospital-based palliative care program. The project is intended as an important step toward increasing the number of hospital-based palliative care programs and thereby improving the overall quality of care for seriously ill Californians. The authors, members of the Palliative Care Program at the University of California, San Francisco and nationally recognized leaders in palliative care training and education, have created a series of reports, each dedicated to a different aspect of the substance and structure of palliative care programs.

This first report in the series introduces the concept of palliative care and differentiates it from hospice and other forms of end-of-life care. It then explains the structures of hospital-based palliative care services, and discusses challenges to the implementation and sustaining of such services. The two other reports in this series describe the business case for hospital-based palliative care, as well as provide an overview of innovative programs in the field in California and the nation. Both reports are available at www.chcf.org.

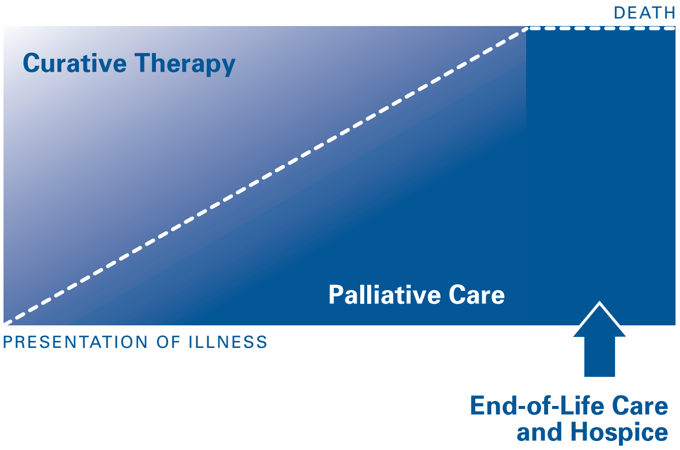
II. Fundamentals of Palliative Care

Basic Elements of Palliative Care

Palliative care is medical care, provided across inpatient and outpatient settings, that focuses on relief of suffering. It provides comfort to patients and their loved ones without respect to disease, prognosis, or other goals of care. It is provided concurrently with all other appropriate medical treatments. As the Institute of Medicine defines it: "Palliative care seeks to prevent, relieve, reduce, or soothe the symptoms of disease or disorder… Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs… It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them."[1]

The goals of palliative care—to improve quality of life and help manage distressing symptoms—do not exclude other clinical care goals, such as prolonging life. Palliative care may be offered concurrently with curative therapy and can begin as early as the diagnosis of any illness that causes symptoms and impacts quality of life. Toward the end of life, the relative balance of palliative and curative care may shift, and palliative care often comprises the entire plan of care, focusing completely on patient comfort and quality of life. The relationship between palliative and curative care is depicted in Figure 1.

Figure 1. Palliative and Curative Care



Source: Source: *A New Vision Of Palliative Care* NHWG; Adapted from the Canadian Palliative Care Association & Frank Ferris, M.D.

Quality palliative care is continuous and integrated, crossing all care settings, including home, hospital, nursing homes, and hospices. Palliative care can continue beyond the death of the patient, providing support to the family during bereavement.

The History of Palliative Care

In the early development of medical care, palliative care was one of the few effective services physicians could provide. Physicians were unable to offer cures for most life-threatening illnesses but worked instead, within the long tradition of "healers," to provide solace and comfort to the ill. With the emergence of medicines and technologies that enabled physicians to postpone death of many patients, the focus of medical care shifted to curative attempts. More recently, the realization that for some there may be "fates worse than death" (that is, prolonged unrelieved suffering, overly aggressive technological intervention, and loss of dignity at the end of life) has led to the modern hospice movement. Palliative care is a further development of this idea, recognizing that an either/or choice between curative care and hospice care is neither necessary nor desirable for most people.

Using a "bio-psycho-socio-spiritual" approach, palliative care seeks to attend to all domains of personhood, summarized in the following box produced by the National Consensus Project [2]—a collaboration of national hospice and palliative care organizations.

Domains of Quality Palliative Care [3]

1. Structure and Process of Care (Interdisciplinary Care Team with Integrated Patient and Family-Focused Care)
2. Physical Aspects of Care
3. Psychological and Psychiatric Aspects of Care
4. Social Aspects of Care
5. Spiritual, Religious, and Existential Aspects of Care
6. Cultural Aspects of Care
7. Care of the Imminently Dying Patient
8. Ethical and Legal Aspects of Care

Integral to palliative care is a focus on patient-centered communication. Palliative care empowers patients to participate actively in decision making regarding the course of their care. It works to facilitate identification and clarification of patients' goals of care, and within this context encourages patients to plan proactively for contingencies, as their illnesses progress, in a way that is consistent with their values. This aspect of the process is called "advance care planning," and includes, but is not limited to, completing an advance directive document. By offering alternatives to continued invasive medical interventions, palliative care offers patients care options that may better reflect their goals of care. Because many patients who are faced with life-threatening or terminal illness, when offered alternatives, choose care that is less invasive, palliative care can improve efficiency in the utilization of hospital resources (see *Palliative Care in California: The Business Case for Hospital-Based Programs,* at www.chcf.org).

Health Care Advance Directives

Advance directives document patients' wishes for care in the event that they become unable to express those wishes. These may include their choices regarding the use of cardiopulmonary resuscitation and advanced cardiac life support, and the identification of a surrogate decisionmaker.

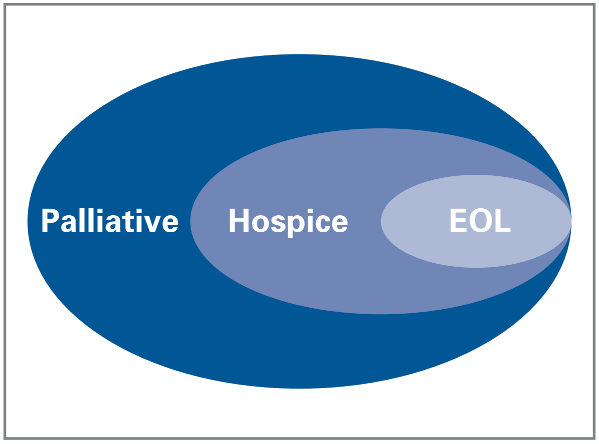
The Relationship of Palliative, Hospice, and End-of-Life Care

Currently in California, and in the United States, palliative care is most often provided by hospice programs, though hospital-based palliative care is becoming increasingly common. Although many people conflate palliative care with hospice care, the two are distinct in important ways. Hospice care in the United States describes a particular service and system of care in which palliative care is provided as the only goal of care for patients who are expected to die within six months. To receive hospice care, patients typically must agree to forgo any further attempts at prolonging life, curing, or modifying their disease. Palliative care, on the other hand, is a more general term for any care focused on improving symptom management and quality of life. Most significantly when compared with hospice care, palliative care can be offered to patients at any stage of illness, not just to those who are approaching death. Some hospices have demonstration projects that are providing expanded services to patients are still pursuing life-prolonging treatments.

End-of-life care refers to a specific subset of palliative care. End-of-life care is provided to patients in the last days, weeks, and months of life. The terminology refers to a focus of care but does not necessarily describe a particular system or mode of financing. End-of-life care focuses entirely on palliation and can be provided both by hospice programs and by non-hospice care, across all medical settings, including in the hospital, at home, and in nursing facilities.

The relationship among palliative, hospice, and end-of-life care is illustrated in Figure 2.

Figure 2. Palliative, Hospice, and End-of-life Care



A summary of the nature and extent of hospice utilization in California illustrates why the broader services of palliative care, if widely offered, might fill a critical gap in care for many patients. Typically, hospice care is provided to patients at home by family caregivers, with intermittent support from hospice nurses, physicians, social workers, chaplains, home health aides, and other staff, as dictated by the patients' conditions. There are also a limited number of residential inpatient hospice units for patients unable to be cared for at home. In addition, hospice patients cared for at home may be able to receive short-term care in hospitals or acute hospice units in order to provide respite to family caregivers, or to manage symptoms that are not controllable except in inpatient settings.

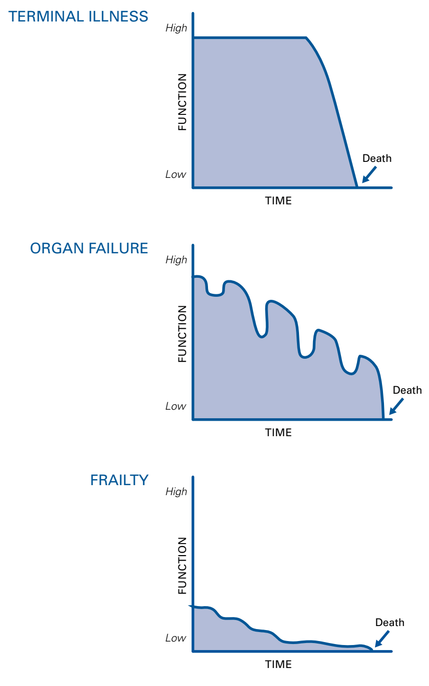
Hospice Financing

Since 1982, Medicare has paid for hospice care for patients who otherwise qualify for Medicare. Since 2002 in California, Medi-Cal and all commercial insurance companies have been required to provide hospice benefits equivalent to those provided by Medicare.

But even with the potential to enroll in hospice half a year prior to expected death, most patients are referred for hospice care only in the few weeks before they die[4]; in California, 64 percent of hospice patients began hospice 30 days or less before death.[5] Moreover, total utilization of hospice remains very low: of the 239,000 people who died in California during 2003, slightly more than one-quarter were referred for hospice care.[6]

There are several reasons for this low level of hospice use, some of which are addressed by palliative care. In the first instance, it is difficult for many patients to receive care at home. Although patients who cannot receive hospice at home will also likely be unable to receive palliative care there, the availability of palliative care in all care settings helps address this issue. The barriers to hospice use also include the challenge for physicians to make an accurate prognosis of a patient's life expectancy; hospice requires physicians to document a six-month prognosis. The fact that some diseases, such as cancer, have a more predictable trajectory of illness contributes to the fact that up to 50 percent of all terminal cancer patients eventually are referred for hospice care (Figure 3). However, other common causes of death, such as advanced congestive heart failure, are not widely regarded as "terminal," even when they carry a similar prognosis to cancer, due to a less predictable course of illness. Other increasingly common causes of death (such as advanced frailty, dementia, and stroke) are typified by a slow decline where death is likely but its timing is uncertain.[7] Even in situations where physicians can reasonably arrive at a six-month prognosis, some physicians have difficulty communicating this to patients. Within palliative care, clinicians still discuss prognosis with patients, but can do so in more general terms without having to document a specific prognosis in order for patients to receive palliative care services. Finally, physicians are trained to cure illness and fight disease and many patients are loath to give up on such treatment when there is even a slight chance of cure or improvement. Because it is available concurrently with curative treatment at any stage of illness, palliative care obviates the need for either the physician or the patient to make this difficult choice.

Figure 3. Three Trajectories of Dying



Source: Adapted and used by permission of *JAMA.*

The Interdisciplinary Palliative Care Team

Because palliative care strives to relieve physical, emotional, and spiritual suffering, no single individual has the expertise required to address the varied and complex needs of the patient. Rather, caregivers from multiple disciplines work together, integrating their skills and knowledge to offer comprehensive care.

At the core of a typical palliative care team are a physician, nurse, nurse practitioner or advance practice nurse, and social worker, each contributing his or her specific expertise in physical and emotional symptom management, and patient and family communication. Other team members may include a pharmacist as well as providers of spiritual care services such as chaplains, whose particular skills may become central for some patients. Others who may participate include psychologists, music thanatologists, art therapists, physical/occupational/ rehabilitation therapists, nursing assistants, and lay volunteers.

That no single clinician can do the work undertaken by a hospital-based palliative care team is made manifest by the summary of team members and their varied responsibilities presented in Table 1.

Table 1. Members of an Interdisciplinary Palliative Care Team

TEAM MEMBER	RESPONSIBILITY WITHIN THE TEAM
Physician	• Conducts frequent assessments and recommends therapies for managing uncomfortable symptoms • Participates in family meetings to discuss care plans • Educates patients and families on the typical course of illness and what they might expect • May coordinate the activities of the other palliative care team members • Communicates palliative care team recommendations and actions to primary (attending) physicians • May assume responsibility for a particular feature of patient care, typically pain or symptom management, if requested by primary physician
Nurse	• Typically registered nurse, nurse practitioner, or advance practice nurse who specializes in pain management and symptom control, particularly for end-stage disease • Provides bedside care, assists in assessing patient needs and helps provide support to patient families and significant others • Participates in family meetings where care plans are developed • May assume many responsibilities of the palliative care team physician and may serve as the clinical leader of the team
Social Worker	• Assists patients and families with emotional concerns, including bereavement • Helps arrange access to supportive community resources, including financial assistance where appropriate • Helps arrange admission to skilled nursing facility or institutional hospice, or for provision of home health or home hospice services • May serve as the clinical leader of the team
Pharmacist	• Recommends and manages, with other team members, drug therapies needed to control pain and other symptoms during the hospital stay • Recommends therapies to be used after discharge • Educates patients and families on purpose of medications, their proper use, and access to medications after discharge • Works to ensure that patients can receive needed medications after discharge
Chaplain/Spiritual Care Services	• Serves people of all faiths, or of no religious faith, providing spiritual and emotional care, comfort, and support • Is available to discuss ethics, values, and issues of meaning and relationship with patients and families • Facilitates contacts with community clergy

III. Imperatives for Hospital-Based Palliative Care in California

There are a number of imperatives for establishing more hospital-based palliative care programs in California. The first is the epidemiological imperative: Making hospital-based palliative care available for all Californians is necessary because nearly half of Californians die in hospitals. The second imperative is clinical: Too frequently patients suffer needlessly during the last stages of life. Third is the legal/regulatory imperative: Appropriate symptom control and adherence to patients' goals of care are now the standard of medical care, both professionally and legally, and hospital-based palliative care services directly address that standard. The last imperative is financial: Increased efficiencies of care with appropriate hospital-based palliative care provide a significant economic impetus to establish and sustain these services. (Further discussion of these sets of imperatives can be found in publications available from the Center to Advance Palliative Care [CAPC].[8])

The Epidemiological Imperative

Despite most patients expressing a wish to die at home, and some shifts in the epidemiology over time, nearly half of all Californians die in the hospital (Table 2). [9, 10]

Table 2. Percentage of Deaths Occurring at Various Sites of Care in California*[11]

YEAR	HOME	NURSING HOME	HOSPITAL
1989	13.2%	21.6%	57.6%
1997	25.5%	23.7%	47.0%
2001	26.7%	20.9%	47.4%

*Adjusted for age and gender

Given these findings, hospitals must provide palliative care services because that is where most patients die. Moreover, hospitals are a point of contact for the vast majority of patients during the year prior to death. For example, nearly all patients who die with Medicare insurance spend at least some time in a hospital in the year prior to their death.[12] Hospitals are therefore uniquely situated to provide palliative care to patients when and where they are most likely to need it.

The Clinical Imperative

Reliable data reveal that hospitalized patients suffer during the last days of life. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) included more than 9,000 seriously ill patients in five medical centers (including one in California) and demonstrated that in the last three days of life 40 percent of patients experienced moderate to severe pain regardless of diagnosis.[13] Much other research has demonstrated that distressing symptoms such as pain are common in patients with cancer and other serious chronic illnesses (Figure 4).

Hospital-based palliative care is a strategy to improve the quality of patient care in the face of these arresting statistics. Palliative care attends to urgent patient needs by addressing patient pain and suffering.[15] There is ample evidence to demonstrate that palliative care works: Palliative care provides hospitalized patients with improved physical symptoms, improved patient and family satisfaction, and decreased caregiver burden.[16–20]

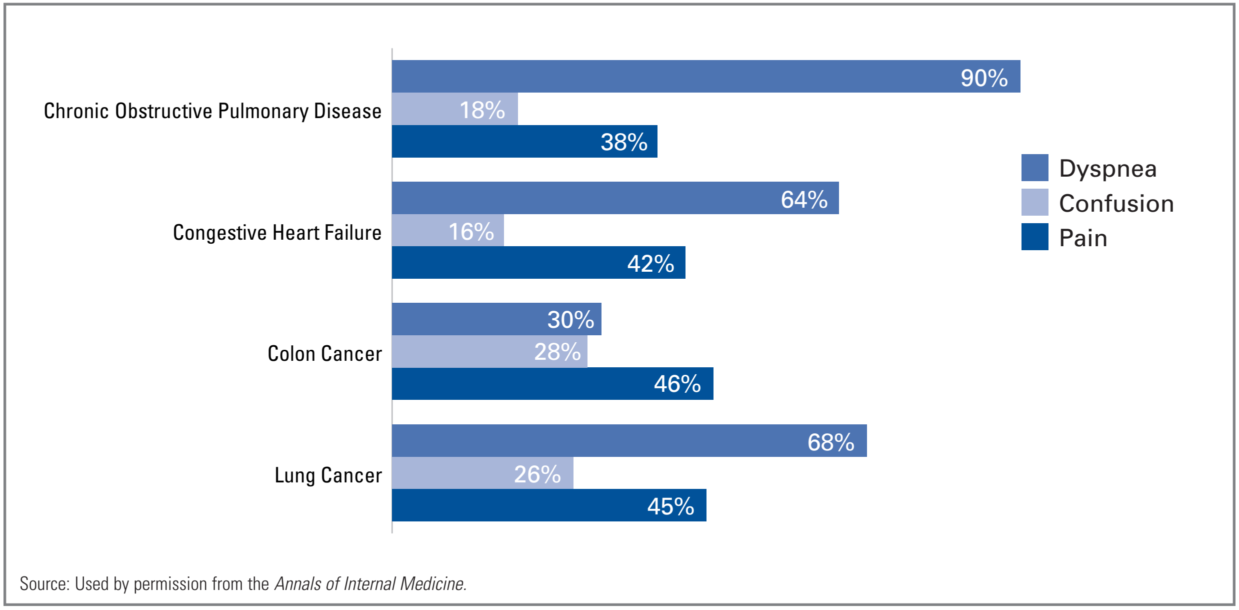
The Legal/Regulatory Imperative

Clinical competency in palliative care, including the skills of pain management and end-of-life care, are increasingly required of medical students and physicians at all levels of training by medical regulatory and licensing organizations. The Liaison Committee on Medical Education of the Association of American Medical Colleges includes end-of-life care as a requirement for medical student education. Similarly, specialty boards are increasingly requiring these skills of resident physicians.[21]

California law also mandates some palliative care training for its physicians. The state requires that all physicians (except radiologists and pathologists) participate in at least 12 hours of continuing medical education in pain management and palliative care to maintain their California medical license.[22] The Medical Board of California recently revised its 1994 pain management guidelines, underscoring the imperative for physicians to expertly manage their patients' pain.[23]

Hospitals, too, are now required by the Joint Commission to provide certain palliative care services. Under Joint Commission rules, hospitals must provide information about advance directives (since 1991) and assess and treat patients' pain (since 2001).[24]

Figure 4. Prevalence of Symptoms at the End of Life[14]



Source: Used by permission from the *Annals of Internal Medicine.*

The Financial Imperative

Hospitals have a significant financial incentive to provide palliative care services, given the well-documented cost avoidance achieved by palliative care. Palliative care patients are generally already in the hospital, so the issue is not whether to admit these patients to the hospital, but how to care for them in a clinically appropriate way and in accordance with their wishes. (The subject of the financial incentives for hospitals to institute comprehensive palliative care services is covered extensively in *Palliative Care in California: The Business Case for Hospital-Based Programs,* at www.chcf.org.) Multiple studies of hospital-based palliative care have demonstrated significant cost savings via a number of mechanisms: decreased hospital and intensive care unit length of stay, more appropriate use of technology and services such as laboratory and radiological tests, and use of less expensive medications.[25–30] In this way, palliative care services improve the efficiency of hospitals. Importantly, high-quality palliative care for patients at the end of life is not associated with any increase in risk-adjusted mortality.[31]

Current Palliative Care Needs and Services in California Hospitals

Of the 2,393,000 deaths in the United States in 2004, 238,958 (10 percent) occurred in California.[32] About one-half of these California deaths take place in the state's 400 hospitals.[33] By the year 2030 in the United States, those over age 85 will number 10 million, an increase of 200 percent from 2002.[34] Among the ten most frequent causes of death in California are both terminal and chronic illness, the numbers of which will increase, reflecting the aging of the population.

Despite the large proportion of U.S. deaths that occur in California, and in California hospitals, only a minority of California hospitals provides palliative care services consisting of palliative care-trained experts, usually serving as consultants to the primary physician. The most recent reliable published survey indicates that among California hospitals, only 18 percent have a palliative care service, and 6 percent have an inpatient palliative care unit. [35] Though these figures are based on a 25 percent random sample of California hospitals, they appear to be reliable as the methodology is sound and the results are consistent with national data.[36–38] More recent unpublished data suggest that the percentage of California hospitals with palliative care services had increased to 23 percent by 2004. However, this still trails the national average of 30 percent, and California hospitals are significantly less likely than those in certain other regions (e.g., New England) to report having a palliative care service.[39]

Unfortunately, precise characterization of the composition and activities of current California hospital-based palliative care services is not available. Even the most recent data from the American Hospital Association, which includes California hospitals, is far from complete in providing reliable, detailed information about the nature of palliative care services, the numbers of patients seen, and the funding of these programs.[40]

An Encouraging Trend in California

Despite the limited penetration of palliative care services in California hospitals as described above, a number of large hospital systems in California are promoting, encouraging, mandating, and/or supporting the development of palliative care services at their member hospitals. This encouraging trend is examined in *Palliative Care in California: Innovations in Hospital-Based Programs* at www.chcf.org.

IV. Models of Hospital-Based Palliative Care Services

Every palliative care program should be designed and implemented to meet the specific needs of its institution. Hospital-based palliative care services can be organized in many ways. No single model is best, and in California there are examples of successful palliative care services of all types. Each model has its advantages and disadvantages, and it is these characteristics, matched with a hospital's personnel, space, and funding resources, that determines the best model for each institution. One characteristic that all services share, which is also promulgated in the National Consensus Project Guideline,[41] is an interdisciplinary approach to care.

In determining how to design and implement a hospital-based palliative care service, a number of variables must be considered. Each hospital's specific combination of answers to the following questions can guide their decision regarding structure, staffing, and financing:

- Which set of the hospital's patients needs palliative care (e.g., those with certain diseases, those with prolonged stays who are not getting better, those with repeated admissions for exacerbations of chronic illness)?
- Where are these patients currently cared for in the hospital (e.g., ICU, medical ward, oncology unit)?
- What conditions do most of the hospital's palliative care candidate patients suffer from (e.g., cancer, stroke, heart failure, cirrhosis, dementia, trauma)?
- At what level of acuity are the needs of the majority of these patients (e.g., intensive care, step-down, medical/surgical, skilled nursing)?
- Which physicians and nurses provide care for most of them now (oncologists, hospitalists, surgeons, cardiologists, intensivists, emergency physicians)?
- What resources (personnel and space) are available or could realistically be secured for palliative care?
- Given the answers to these questions, which organizational model would offer the best way to address the hospital's palliative care needs and capacities?

Structure of Hospital-Based Palliative Care

Palliative care has become a recognized sub-specialty of medicine. As with other medical sub-specialties, such as cardiology, palliative care can be offered at three different levels of expertise.[42]

Primary palliative care is the basic level of skill in pain and symptom management expected of all physicians. California licensing requirements promote basic palliative care knowledge among all physicians via continuing education requirements.

Secondary palliative care is specialist-level care. As with cardiology, complex serious problems are best managed by a specialist in the field. The American Board of Medical Specialties (ABMS) has approved a new sub-specialty certificate for physicians in palliative medicine and an equivalent certification is available to nurses. The American Board of Hospice and Palliative Medicine (ABHPM) has certified a national total of 2,146 physicians as experts in palliative care; 223 of them in California.

Tertiary palliative care is offered at medical centers where palliative care research is pursued and regional referrals are made. California is at the forefront of training and leadership in palliative care. The state is home to three of the nation's 17 palliative care fellowship programs accredited by the Palliative Medicine Review Committee: VA Greater Los Angeles Health Care System; San Diego Hospice and Palliative Care; and VA Palo Alto Health Care Service/Stanford University. In addition to these three, the state has five other tertiary palliative care centers: City of Hope Medical Center, Duarte; University of California, Davis; University of California, Irvine; University of California, San Diego; and University of California, San Francisco.

Organizational Models

The most common hospital-based palliative care models are described below. Included is a discussion of their respective advantages and disadvantages, as well as identification of the types of hospitals to which each might be best suited.

Palliative Care Consultation Service

This is the most common type of palliative care service in California hospitals. As defined in the literature,[43] a palliative care consultation service is "an interdisciplinary team that sees patients and makes recommendations about their care." Consultation teams are invited to participate in the care of patients by attending physicians, or in some institutions by nurses, social workers, patients, or patients' families. Team members may go together or individually to see patients. Typically, the team meets daily to discuss patient care. A member of the team leaves care recommendations in the patients' charts and communicates these directly to patients' nurses and physicians.

An important limitation of this model is that the palliative care consultation team does not assume care of patients; instead, the attending physicians of record remain in charge. Depending on the particular institution's culture and norms, the team may write orders pertaining to palliative care needs, or may be restricted to leaving recommendations for the primary service to implement. In the latter case, for the team to impact the care of patients, its recommendations must be implemented by others. Therefore, the palliative care team must communicate clearly and efficiently with the patients' physicians, nurses, social workers, and pharmacists.

Although the consultation model does not offer complete control over patient care by the palliative care team, it provides support for the existing relationships between patients and primary team physicians that can be particularly important for patients with serious and life-threatening illness. Other advantages of this model, which have contributed significantly to its popularity, are that it requires a smaller investment of resources at the outset and is more easily expanded as demand increases.

Primary Palliative Care Service

Similar to a consultation service, a primary palliative care service consists of an interdisciplinary team. However, rather than simply making recommendations, a primary service takes over and directs the care of patients. Ideally, the previous attending primary teams remain involved in the patients' care, though the attending physicians no longer have primary responsibility. In a primary service model, the palliative care team implements the plan of care thereby ensuring that all recommendations are followed. This control requires that the team be available at all times to field questions and assess the patients.

One of the barriers to the successful implementation and operation of this model is its requirement that primary care physicians relinquish control of the patients' care. Some physicians may be reluctant to give up this role, especially when the physician or other members of an existing care team know the patient and family well.

Dedicated Inpatient Unit

Palliative care services can also be organized around a particular place or unit where all or most palliative care patients receive their care. The unit can accept patients from throughout the hospital, and may even have the ability to care for patients who require mechanical ventilation. An advantage to this model is that by concentrating care in a particular unit, the unit staff can refine its expertise in palliative care and ensure high quality care.

A disadvantage of this model is that a patient must physically move to a certain unit in order to receive palliative care. This can be an issue for some patients who have been hospitalized repeatedly and who have come to know the nurses and other staff on a particular unit and thus may be reluctant to transfer elsewhere in the hospital.

An additional disadvantage or barrier is that such a unit requires dedicated space that is unavailable for other uses and requires a considerable financial investment to support its infrastructure, including a head nurse, ward clerk, and others. Because this infrastructure must remain in place regardless of whether the unit is full, such units are best suited to hospitals that have consistent excess bed capacity or a large enough population of palliative care patients to keep the unit filled. A dedicated unit can stand alone as the sole component of a palliative care service (as with the inpatient palliative care unit at Laguna Honda Hospital in San Francisco) or it can be combined with a consultation service.

Swing Beds

Many hospitals in California run a very high census and therefore do not have space for a dedicated unit. Swing beds, which are single rooms that are re-designed to be more home-like and can serve either palliative care or non-palliative care patients, may be the best model for these hospitals. One advantage of the swing-bed model is its efficient and flexible use of beds. When not occupied by a palliative care patient, the bed can be used for a non-palliative care patient. Another advantage is the potential to distribute palliative care beds throughout the hospital so that patients need not move from one unit to another in order to receive comprehensive palliative care. However, while some hospitals place swing beds on several different units, many choose to concentrate swing beds on one unit to allow for expertise to develop among nurses and other unit-based staff.

Swing beds rarely stand alone, and are typically combined with a palliative care consultation service as is done at the University of California, San Francisco. This combination of services means that any patient in any part of the hospital can receive palliative care expertise from the team and, when appropriate and a place is available, patients can be moved to one of the swing beds. Swing beds are usually designated as acute care beds although some hospitals also use them as respite beds for hospice patients. The ability to provide respite or acute inpatient care for hospice patients provides another way to make use of the palliative care resource when the hospital census runs consistently below capacity.

Integrated Model

Some institutions find that the needs of their patients and staff are best served by trying to train all health care providers in palliative care rather than by developing a specialized team or unit. In this model, palliative care is "integrated" into the clinical care of the institution. The integrated model places a large emphasis on staff education and requires a designated person with palliative care expertise and training skills to lead the program. An integrated model can work in any size institution but is much easier to implement in a smaller hospital where there are fewer employees to train in palliative care. The palliative care program at the University of California, Irvine operates under this model.

One disadvantage of the integrated model is that it is harder to impact the care of any one patient, or to deal effectively with challenging situations such as severe pain refractory to standard treatment, because there is no team of experts regularly available to provide real-time clinical consultation.

Hospice–Hospital Collaboration

Many hospitals that recognize a need for palliative care lack staff with expertise. Fortunately, nearly every community in California has access to expertise in palliative care through hospice. Of 58 counties, 56 (97 percent) have hospices, and 49 counties (84 percent) have more than one hospice. Hospices and hospitals can work together to establish inpatient palliative care programs that benefit both. In these partnerships the hospice typically provides palliative care expertise in the form of a nurse, nurse practitioner, advanced-practice nurse, or social worker who is paid in whole or in part by the hospice and who provides palliative care consultation in the hospital.

The hospice benefits from this collaboration by identifying more patients who might be appropriate for hospice and receiving referrals earlier in the course of illness. The hospital benefits by getting palliative care expertise with little expense. The hospital will likely need to commit resources in the form of time for other members of the interdisciplinary team but the total financial contribution is typically far less than if the hospital were establishing the palliative care service alone. Such collaboration has been successfully implemented in many hospitals in the United States. Details about forming such collaborations can be found at www.capc.org/palliative-care-across-the-continuum/hospital-hospice.

Multiple Services

A palliative care service can meld features of several models. Beginning a service with more than one model type makes the initial steps more complex and costly. However, mature palliative care programs have had success adding other models based on the unmet needs they encounter. Adding aspects of different models to a service already in place typically is easier than implementing a new multiple-model service. Building onto an existing service allows for economies of scale, and for one aspect of the service, for example the inpatient consultation service, to feed another, for example a dedicated unit.

Table 3. Advantages and Disadvantages of the Most Common Palliative Care Service Models*

ADVANTAGES	DISADVANTAGES
Consultation Service	
• Small, dedicated staff at outset • Interdisciplinary collaboration throughout site • Low financial risk • Educational efforts more widespread as consultations occur on all services in all units of the hospital • Allows for more rapid initiation of palliative care services	• Rarely 24/7; high risk of burnout • As palliative care team is not in complete control, the impact on care may be limited as the primary team may not implement palliative care team recommendations • Cost-avoidance lower if clinical control is low • Educational opportunities may be more difficult as they happen one at a time, case by case • May be more difficult to obtain and track data
Inpatient Unit	
• Dedicated trained nursing staff improves care • Complete control over patient care (unless using an "open" unit where any service can admit and place orders) • Eases burden of educating visitors and staff , "one stop shopping" • Identifiable target for philanthropy • Encourages clinical research • Environment specific to palliative care: implies special skills, needs • May allow for easier transition when goals of care change to palliation • Opportunity to streamline care may prove more cost effective • May provide opportunities to improve staff recruitment and retention • May be able to partner with hospices more easily due to volume and centralized location • Creates opportunities for volunteers, therefore increasing involvement and philanthropic potential	• Other site staff may lose comfort with caring for dying patients because of even more limited exposure to patients with palliative care needs • Primary/sub-specialty M.D.s may not want to relinquish control (unless unit is "open" or is co-managed with primary M.D.) • Interdisciplinary collaboration with other services may be limited • Finding space may be difficult; • Burden of meeting usual benchmarks of dedicated units: e.g., maintaining census, profit margins • May be perceived as a "death unit," or a sign that the clinician has given up • May be perceived as withholding disease specific treatment • If census is low and staff floated out, may increase dissatisfaction, stress; non-palliative care patients may be admitted there • Hospice per diem may not cover costs (if that is sole source of reimbursement for those patients)
Swing-Bed Unit	
• Better utilization of available beds • All staff may learn some palliative techniques • Without special designation, fewer reimbursement problems • Less stigmatization	• Fractured, non-specialized care, because unit staff are not all dedicated to palliative care • Care may be less standardized and controlled, resulting in less cost savings • Possibly fewer opportunities for philanthropy; less centralized for volunteer opportunities

*Adapted from Medical College of Wisconsin Pediatrics Module and the Palliative Care Leadership Center curriculum

Prevalence of Palliative Care Models Used in California

Although all of the models discussed above have been successfully implemented at hospitals across California, the most common model is the consultation service. There are many reasons for the popularity of this model, as set forth in Table 3, particularly as a hospital's initial palliative care service. The major reasons that most hospitals begin with a consultation service is that it requires the smallest financial investment, is most easily scalable, and is the fastest to make operational, requiring personnel but no remodeling. In addition, a consultation service respects existing physician-patient relationships and may be more easily accepted by attending physicians. Consultation services can also serve patients throughout the hospital, thereby educating staff throughout the institution, which means that the model can also serve as a step toward expanded services.

In a survey of 107 California hospitals conducted in 2000, among the 19 hospitals that offered palliative care services, 18 (17 percent of hospitals surveyed) offered consultation services.[44] Only six hospitals (5.5 percent) had a palliative care unit, and five of these units were affiliated with a consultation service. Of these six palliative care units, four were in acute care hospitals, one was a freestanding unit and one was in a skilled nursing facility. Unpublished results from 2004 were similar, with 22 of 96 hospitals (23 percent) offering palliative care services and two hospitals (2 percent) offering palliative care units.

V. How a Palliative Care Service Functions

Regardless of the model chosen, each palliative care service needs clinical and organizational leadership. It also needs to develop its own set of protocols for the daily functioning of the service. Furthermore, a palliative care service can enhance its own standing within the hospital, as well as provide broader contributions to the institution, by engaging in hospital-wide activities in addition to providing palliative care.

Leadership Structure for a Palliative Care Service

As with the question of which model to choose, the decision about who will lead a clinical palliative care service depends on the needs and culture of the individual hospital. Potential clinical and organizational leaders include physicians (hospitalists, internists, family physicians, intensivists, oncologists, and others), nurses, nurse practitioners, advance practice nurses, physician assistants, social workers, and chaplains.

The clinical leader of a service is typically the person who makes first contact with the referring clinician and coordinates the efforts of the other team members. In some hospitals, physician leadership will be key for convincing other physicians to support and use the palliative care service. In hospitals with a history of nurse-, chaplain-, or social worker-led services, such leadership of a palliative care service is more likely to gain broad acceptance.

The organizational leader of the palliative care service oversees the team, schedules team meetings, and leads administrative efforts such as guideline and protocol development, data management and analysis, and reporting to hospital leadership. Any member of the palliative care team may serve as the organizational leader. Occasionally the clinical and organizational leader is the same person, but those roles often are filled by different people since the demands and skill sets are quite distinct.

Typically, both the clinical and organizational leaders will require dedicated funding. This funding can be direct, for the service provided, or it can be in-kind support, such as freeing the leader from other hospital responsibilities in order to attend to the palliative care service.

How a Palliative Care Team Functions

In addition to the overall structure of a palliative care service, it is also important to consider the nuts and bolts of how a team functions in its delivery of care. In fashioning a delivery system from the variety of ways in which a palliative care team can operate, a team needs to consider certain basic issues.

Nature of Patients

The first issue a team needs to identify and settle is the kind of patients it wants to see. For example, a common threshold question is whether the team will care for patients with chronic pain but who do not have a life-threatening illness. In hospitals without a separate pain consultation service, a palliative care team can receive many requests to see such patients. To the extent that caring for these patients addresses an unmet need, it would likely be appreciated by physicians, nurses, hospital administration, and patients. However, the unmet need may be so great that it could overwhelm a fledgling palliative care service and limit the team's ability to care for patients with broader palliative care needs.

Source of Consultation Requests

Another start-up decision is to determine who can request a palliative care consultation. In some hospitals, anyone can request a consultation — physician, nurse, social worker, respiratory therapist, chaplain, pharmacist, patient, or family member — while in other hospitals requests can be made only by a physician's order. Or, consultation requests might be generated by some combination of these sources. There are various elements to this decision. One issue is that physicians can only bill for a consultation that is requested by the patient's attending physician. Also, many physicians bristle at the notion of another physician becoming involved in a patient's care without an explicit invitation from the attending physician. Palliative care services led by nurses, chaplains, or social workers may be able to provide consultation without a specific physician order if there is precedent for such consultation within the institution. For example, many hospitals have nurses with specialized expertise, such as wound care, who see patients and make recommendations about care based on a nurse's request, without a physician's explicit authorization. However a service answers this set of questions about consultation requests, at least initially it is generally best to be consistent with the institution's general practice.

Consultation Request Procedure

The service must also decide how a request for a consultation reaches the palliative care team. Options include pager, voicemail, e-mail, or written request in the chart that is phoned or faxed to the palliative care team. Regardless of which methods are chosen, the team must ensure that the hospital operators know where to direct a request for a palliative care consultation. The service must determine the hours that the team will be available to provide consultation, which also helps to establish how quickly team members will see a patient after the referral is requested. In doing so, a service needs to balance availability with the resources it has to ensure that it can deliver on its promise. Some teams are available by pager or phone 24/7 but see patients only during the day. Others are available Monday through Friday 8 a.m. to 5 p.m., and still others are available only three days a week. A team that is less available may miss out on consultations as patients are discharged or die before the team can see them. Still, it is best not to promise availability that the team cannot deliver; failing to meet expectations may limit the number of future consultations as providers lose faith in the palliative care service. If a team begins with limited availability, it should attempt to keep track of missed opportunities for consultation that could make the case for expanding the service in the future.

Team Functioning

A palliative care service must determine how it will function as a team. Ideally, all members of the clinical team meet daily to discuss care issues in real time and to share information about patients and their families. A palliative care team should see a patient daily until all palliative care issues are resolved, the patient is discharged or dies, or the patient no longer wishes to see the team. Some teams fulfill this duty by going together to see a patient and family; others have each team member see the patient separately, then meet to discuss care. If the team is large, visiting en masse may overwhelm a patient and family. On the other hand, having a series of providers visit the patient and ask similar questions can be exhausting to the patient and interfere with the patient attending to other important issues. It may also be an inefficient use of team time and energy.

Regardless of the approach chosen, each day that the team sees the patient it must communicate its findings and recommendations to the patient's primary care team, including the physician, bedside nurse, and social worker. Ideally, the team communicates its recommendations directly to the primary care provider, in person or by telephone, in addition to leaving a note in the chart. Direct contact helps ensure that important recommendations are not lost or delayed. Such contact also allows the palliative care team to offer to write orders in the chart at the request of the primary attending physician. Clinical data collection should be built in to the daily work flow of the team and should be useful clinically as well as providing evidence to support the service. The more clinically relevant the data, the more likely it is to be collected.

Hospital-Wide Contributions of a Palliative Care Service

Although a palliative care service is judged first and foremost by the quality of clinical care it provides, the service can participate in many other activities within the hospital to improve care generally. Many of these activities focus on the palliative care service and are directly related to the service's sustainability. Others can have broader impact and demonstrate to the institution the hospital-wide contributions that a palliative care team can make. In addition to clinical care, the palliative care service can become involved in hospital-wide activities such as:

- **Guideline development** for specific conditions or situations such as pain management or advance care planning discussion and documentation.
- **Protocols** to guide care in certain clinical situations, such as withdrawal of mechanical ventilation.
- **Policies** regarding artificial nutrition in patients with severe dementia or palliative sedation.
- **Education of staff** at all levels throughout the hospital on topics in palliative care, including

A Day in the Life of a Palliative Care Consultation Service

It is 8 a.m. on Monday. There are six patients on the palliative care service and one new consultation request. The team sees patients only Monday through Friday, 8 a.m. to 5 p.m. The nurse practitioner, who is the clinical leader of the service, received the consultation request by pager from the attending surgeon on Sunday evening. The nurse practitioner reviews the patient's chart and sees the patient. At 11 a.m. the entire team—nurse practitioner, physician, social worker, chaplain, and pharmacist—meets to discuss patients. Each other team member has seen the original six patients. The nurse practitioner leads the discussion, with a bedside nurse invited to participate as to each patient he/she is caring for.

The team members share information and insights, together formulating a plan and recommendations. This morning the team decides to recommend increasing the morphine dose for the woman with metastatic breast cancer, and agrees to arrange a family meeting for the man with congestive heart failure admitted for the third time in two months. The nurse practitioner will contact the primary attending physicians and the bedside nurses regarding these recommendations, and will leave a note in each patient's chart. The other team members will see the new patient after rounds and contact the nurse practitioner with recommendations. Seeing the patients, discussing their care, and contacting clinicians for the seven patients on the palliative care service takes eight hours for the nurse practitioner and three hours each for the other team members.

pain and symptom management, advance care planning, goals of care discussions, ethical issues, and others. In the first year of a service, significantly more time may be spent in educational efforts compared with clinical care. As the service establishes itself, the relative amount of time spent in each activity will likely switch.

- **Data collection and management** of clinical and financial information, including patient demographics, clinical outcomes, patient and family satisfaction, and referring clinician satisfaction.
- **Staff support** to debrief about and cope with difficult cases and to learn about self-care.

VI. Challenges to Developing a Palliative Care Service

Despite the significant imperatives to establish hospital-based palliative care services, numerous barriers exist that can hinder their development. These barriers are located, in part, within the training framework of physicians and other professional staff. Barriers are also created by competition for resources within hospitals and hospital systems, and by various forms of institutional inertia.

Professional Development and Training of Physicians

A physician's professional identity has long been bound up with curing disease as the sole goal of treatment.[45] In this context, death is considered by many to be a failure of science and the individual physician. Providing good palliative care requires physicians to expand this concept of professional identity. Furthermore, hospital-based palliative care services require physicians specially trained in palliative care. This training includes specific skills in pain and other symptom management, as well as the ability to facilitate communication, decision making, and interdisciplinary teamwork.

All That Can Be Done

Physicians and patients alike may perceive palliative care as akin to "giving up." When cure is no longer possible, physicians have devised phrases such as, "I'm sorry, there's nothing more we can do." This expression is both painful and inaccurate. While there may be little hope of curing a disease, there is always hope for improving a patient's level of comfort in the last days, weeks, and months. There even remains the possibility of growth and new meaningful experiences for patients, families, and physicians as a patient's life draws to a close.

Traditionally, palliative care skills have neither been taught nor supported in the curricula and cultures of modern medical schools.[46–49] Most medical textbooks have had limited high-quality end-of-life care content.[50] Positive role-modeling in this domain is scarce, and students may even face an erosion of their compassion and ethical standards during school.[51, 52] Residency training in palliative care is also limited.[53] Until recently, board certification and licensing examinations did not require any competence in the basics of palliative care, and continuing medical education generally did not address the subject. While the climate in medical schools is becoming more accepting of palliative care and training is increasing, there are still significant shortfalls in the number of physicians specifically trained in and dedicated to the specialty of palliative medicine.

Professional Development and Training of Other Clinicians

Along with physicians, clinicians from many other disciplines suffer from knowledge gaps and may harbor negative attitudes about palliative and end-of-life care. Historically, nurses have been deeply engaged in relieving symptoms and suffering. However, nurses frequently do not receive the specific training needed to provide the best possible palliative care.[54] For example, less than 2 percent of content in leading nursing textbooks is devoted to the end of life[55]. Similarly, pharmacists have traditionally had little training in palliative pharmacology. A study of leading pharmacy textbooks revealed limited end-of-life content,[56] and schools of pharmacy, with some notable exceptions, generally have not offered coursework in palliative care.

Until recently, training has been poor or non-existent for social workers as well. Textbook analysis has shown end-of-life care content in social work to be as limited as that in nursing, pharmacy, and medicine. As with pharmacy, very few programs offer clinical training in this area.[57]

Dying patients have long been referred to hospital chaplains when “there is nothing left to do.” But chaplains have rarely been integrated into comprehensive palliative care approaches. Nor have Clinical Pastoral Education (CPE) programs, charged with training hospital chaplains, included significant content on palliative care. Community-based spiritual and religious leaders also typically lack formal training in addressing patient and family palliative care needs at the end of life.

Staffing Capabilities

Although training opportunities for all disciplines are increasing, serious staffing limitations exist for hospital-based palliative care services in California. The availability of board-certified palliative care physicians and nurses is limited. For example, with only 223 California physicians board-certified in palliative care, approximately 200 new certifications would be required to make specialist physician consultation in palliative care available at every hospital in California. Similar staffing problems exist with regard to nurses. California has 587 licensed/vocational nurses certified by the National Board for Certification of Hospice and Palliative Nurses.[58] Moreover, the lack of specialty training in palliative care nursing is exacerbated by a general shortage of nurses statewide.[59] Recent trends, which show increasing enrollment in these certification programs, are encouraging.

In smaller hospitals, qualified specialist clinical staff may not be available. Even when it is, the census of patients requiring such care may not support full-time palliative care staffing. The need for part-time clinical jobs in palliative care may further limit staffing options as these clinicians may have difficulty supplementing their palliative care work with other part-time clinical work either in the hospital or in the outpatient setting.

A positive development in palliative care staffing in California is the growth of the hospitalist movement. Currently, hospitalists are on staff in approximately 60 percent of California hospitals.[60] Because hospitalists are always on-site and care for many hospitalized patients, they deliver a significant amount of palliative care. The Society of Hospital Medicine includes palliative care as a core competency for hospital medicine,[61] and since many hospitalists are recently graduated, they have a greater likelihood of having received palliative care training in medical school and residency. Also, hospitalist physicians may be particularly suited to part-time palliative care work as many can combine inpatient palliative care with down-scheduled or limited inpatient general medicine responsibilities.

Institutional Buy-In

The Question of "How?"

Most hospitals are already caring for the patients that palliative care serves. So it is not a question of whether a hospital will be caring for these patients, but how?

Institutional commitment is crucial to a successful hospital-based palliative care service. Notably, the task of generating hospital leadership's commitment to palliative care is facilitated by the fact that the mission of a palliative care service is usually aligned with the overall mission of the hospital. Typically, two important aspects of a hospital's mission are to combine high quality care with fiscal responsibility. Palliative care services can contribute to both these aims. Aside from the direct cost savings resulting from adjusting use of laboratory, radiology, and pharmacology interventions to align with patient and family preferences (discussed below), palliative care services also support other hospital needs. Palliative care has been shown to increase the efficiency of care for seriously ill hospitalized patients[62] and to improve patient and family satisfaction. In helping to triage patients to appropriate levels of care, palliative care services can improve patient flow through the emergency department, step-down units, and the intensive care unit. This improved flow helps to relieve bed shortages and reduces the need for hospital emergency department diversion.

Institutional support can also be courted by positioning the palliative care service as a strong marketing feature. Palliative care services can help distinguish a hospital from its local and national competition. Increasingly, patients, lay media, and national quality and compliance organizations are asking not "Is it worthwhile to develop palliative care services?" but rather "Why are you not providing palliative care services?" With nearly one-fourth of California hospitals now providing this service and the number on the rise, hospitals without palliative care services are at risk of being "left behind." Increasingly, hospitals are marketing quality measures to consumers. Palliative care is being recognized more and more as an important element of quality care.[63]

Recognition and Regulation

U.S. News and World Report considers hospice and palliative care in its widely-cited ranking of high-quality U.S. hospitals.[64] In addition, palliative care can help hospitals to comply with federal regulatory obligations, as well as to satisfy many Joint Commission requirements.[65]

Intra-Institution Competition

Within hospitals, some emerging palliative care services face internal competition for resources and support. Typically, there are two sources of concern. First, pain-management consultation services and ethics consultation services may feel threatened by emerging palliative care services. However, palliative care is complementary to each of these services. Palliative care is focused on all symptoms, not just pain, and provides additional psychological and spiritual services for patients cared for by pain services. Although ethical dilemmas certainly can arise around care at the end of life, they are not a routine occurrence. Often, ethics consultations are sought when a timely, caring family discussion would be the more appropriate intervention. Palliative care consultation can recommend ethics consultations as needed and vice versa, and help avoid confrontations among family members or between the family and the hospital.

Some primary treating physicians and oncologists worry that they will "lose" their patients (and the ability to bill for services) to palliative care consultants. In fact, palliative care services are designed to support the work of primary physicians and oncologists, not to replace it. Neither primary care physicians nor oncologists are necessarily experts in palliative care. Particularly for oncologists, care traditionally focuses on prolonging life, and not always with concurrent attention paid to quality of life.[66] Most referring physicians have found that patients and families convey appreciation when the physician arranges palliative care consultation and includes it in the overall care plan. As for the billing consideration, most palliative care is delivered through consultation services. The consultation services' practices of billing for symptom management do not preclude primary treating physicians from billing under the usual diagnosis codes.

Added Value

Simply because they take care of patients with serious illness and those who die, many physicians, consultation services, and hospitals may feel, in regard to palliative care, that "we already do this." Yet, the quality of care these patients receive and the efficiency of their hospital care clearly improve with specialist palliative care.

Financial Considerations

The start-up costs for building a palliative care service, which are incurred before cost avoidance savings can be accrued, present a temporary but real barrier for many institutions. This challenge may be especially difficult at smaller hospitals, where the absolute number of patients who need palliative care is smaller. Unlike hospital programs that generate profit, palliative care services are financially viable through cost-avoidance. The delay between instituting a palliative care service and the reaping of its cost-avoidance benefits, added to the need to fully understand and trust this financing mechanism, may lead some hospital administrators intent on cutting costs to resist outlays of new money to create a palliative care service, even though the proposed service may have a solid plan for a significant return on the hospital's investment. Unfortunately, although physicians and nurse practitioners can bill insurance for the palliative care services they provide, the professional fees generated typically do not compensate for the time needed to provide high quality palliative care, so hospital support is necessary to sustain the service.

Billing for Palliative Care

Palliative care consultation can be very time-intensive. Palliative care nursing frequently reaches levels that parallel nursing in the intensive care unit. Both physicians and nurses may spend a great deal of time counseling patients and families. Physicians and advance practice nurses can bill insurance, including Medicare, for palliative care consultation to help compensate their time. Detailed resources are available to help physicians with this practice.[67]

The specific financial model to adopt for a successful palliative care service depends on the nature of the hospital's financing and revenue sources. It will also depend on the nature and extent of the service; for example, a dedicated palliative care unit requires both space and continuous staffing while a consultation service has little expense beyond clinical staff support. Integrated health care systems may benefit from reduction of hospitalizations achieved by outpatient palliative care services, while most hospitals benefit from decreased length of stay and more appropriate use of resources, including labs, radiology, medications, and ICU care achieved by hospital-based palliative care services. At hospitals that already have a short average length of stay, it will be difficult for a palliative care service to reduce it further. Efficiencies of care within the hospital may differ depending on the need for increasing availability of beds in the emergency department versus the ICU and step-down units. Hospitals with affiliated post-acute care facilities and institutional hospices also have unique opportunities for systemic efficiencies. (For more on financing, cost avoidance, and billing issues, see *Palliative Care in California: The Business Case for Hospital-Based Programs,* at www.chcf.org.)

VII. Sustaining Palliative Care Services

Successfully establishing a new hospital-based palliative care service does not guarantee its sustainability over time. New barriers arise to the maintenance and expansion of an existing palliative care service. These challenges must be anticipated and responded to in order for the palliative care service to sustain itself and grow.

Creating and Maintaining a Referral Base

No matter how well a new palliative care service is structured and staffed, it cannot maintain itself over time without a sufficient flow of patient referrals. To establish and sustain such referrals, a palliative care service has to make itself known, through marketing efforts, to the consumers it serves. There are multiple “consumers” of palliative care services, including patients and families, referring clinicians and staff, and hospital administrative and corporate leadership, to whom marketing efforts must be tailored. To do so, the Center to Advance Palliative Care (CAPC) advocates an “audience-based” communications strategy that includes six core steps, as follows:[68]

The Six Steps of Marketing Palliative Care

1. **Target:** Who are you trying to reach and what are they like?
2. **Action:** What do you want them to do?
3. **Reward:** What benefit (reward) can you offer in exchange for the action?
4. **Support:** What will make the audience members believe that they will get their reward?
5. **Opening:** When might your audience be open to hearing your message?
6. **Image:** What is your current image and what is your desired image?

Within this strategy, different constituencies require different approaches. For example, while hospital administrators may respond enthusiastically to financial arguments, individual clinicians may not be as concerned with hospital-based cost savings as they are with the potential clinical support and time-savings provided by a comprehensive palliative care service. Patients and family members, on the other hand, may even be suspicious of financial considerations and instead focus entirely on the potential for comprehensive and coordinated care dedicated to the relief of suffering.

Marketing of palliative care services must also address the image biases and negative associations that some consumers may have. The most common incorrect assumption about palliative care is that it is the same as hospice care, or that it is limited to end-of-life care. Families may be reluctant to embrace palliative services if they conceive of them as part of a decision to "not do everything" or to "give up." Hospitals must highlight what palliative care offers rather than just what is avoided. They must also try to move palliative care "upstream," so that it begins to serve patients long before they are identified as dying.

In addition to ongoing marketing and outreach, building and maintaining a referral base requires that program leaders ensure that their services are responsive to the needs of referring providers and patients. In that regard, interval assessment of referring clinician satisfaction and routine assessment of patient and family satisfaction can provide the service with valuable information about improvement opportunities.

Securing Dedicated Funding

For many palliative care services, securing permanent funding is a critical step toward assuring sustainability, particularly in settings where staff members undertook the palliative care work in addition to, rather than instead of, existing responsibilities. While many sites successfully start services with volunteer staffing, such arrangements are ultimately unsustainable.

Review of resource utilization data is often sufficient to convince institutional leaders that there is a need for a palliative care service and that opportunities exist for such a service to help reduce costs. However, to obtain permanent dedicated funding, a service needs to collect, organize, and present data that establish the service's ongoing ability to attract referrals, in addition to data documenting financial impact, improvements in clinical care, and/or patient and family satisfaction. It is critical that palliative care service leaders and the hospital administration agree as to what the mission-critical data are, that this information is collected, and that resources to analyze the data are allocated.

Among the most useful data to demonstrate the hospital-wide need for the service are those describing the number of patients seen and the sources of referrals. Data describing symptom control demonstrate contributions to the quality of care. Patient and staff satisfaction surveys are also often used to highlight benefits delivered by the service. Reporting of financial impact, including descriptions of reduced costs and decreased resource utilization, helps to justify ongoing funding and can provide evidence of the need for increased funding in the setting of service growth.

Accounting for Growth

Staffing and funding of a palliative care service need to be adjusted periodically to meet actual and expected growth. While some services initially struggle to attract referrals, many sites are overwhelmed by rapid growth. Insufficient resources limit the palliative care team's ability to influence clinical care, which results in reduced clinical and financial impact. Equally damaging, if referring physicians must wait several days for their patients to be seen, or if the palliative care team lacks adequate time to assess and meet patients' needs, referrals will decline or disappear, putting in jeopardy the very existence of the service.

In most cases, increased volume will yield increased fiscal benefits, so data-based requests for additional funding are typically well received. Regular reporting of clinical and financial outcomes to hospital clinical and administrative leaders is especially important in cases where increases in financial and/or staff support are needed to sustain a service or foster growth.

While such reports vary according to the culture and needs of the individual site, they typically include the following:

A brief description of the program. This includes the individuals who staff the service and the disciplines they represent, a general description of the care delivery model, and the kinds of services provided to various types of patients.

Demographics of the patient population. These data include the number of patients seen, when in the hospital stay the palliative care team becomes involved in their care, length of stay in the hospital before and after the palliative care team became involved, common diagnoses and/or the clinical services on which patients were being managed (medicine, oncology, surgery, etc.), the location of patients at the time of palliative care referral (ICU, emergency department (ED) , acute care, etc.), and discharge dispositions (home, hospice, death, etc.)

Clinical outcomes. While levels of pain, anxiety, and dyspnea are the most commonly measured outcomes, some services also measure depression, nausea, constipation, delirium, and fatigue.

Process measures. These measures capture activities associated with quality of care, such as family meetings or the presence of an advance directive in patients' charts.

Changes in resource utilization after palliative care team involvement. Data here include discontinuation of ventilator support, removal of a feeding tube, or transfer out of a critical care bed to a lower level of care.

Patient and family satisfaction. Patient and family satisfaction data are sometimes supplemented with data describing staff or referring physician satisfaction.

Financial outcomes. Data include reductions in average daily variable direct costs following involvement of the palliative care service.

Current and projected levels of support. This includes a specific description of the amount of support currently being received, the amount of support needed to sustain or expand the program, and an estimate of the increased benefits the hospital will realize if the request is granted.

Evidence-Base and Quality of Care

Data describing quality of care and satisfaction deserve special mention. Quality measures include patient, family, and referring clinician satisfaction and clinical outcome indicators. Existing hospital-wide satisfaction surveys generally need to be revised to identify the impact of a new palliative care consultation service. For example, many hospitals do not survey the family members of patients who have died.

Assessing Pain

Clinical outcome measures are key to documenting the impact of palliative care as well as providing direction for quality improvement efforts. The Joint Commission now requires hospitals to document pain as "a fifth vital sign," providing regular assessment by nurses of patient pain. These data are invaluable to palliative care services focused on improving the quality of pain management.

Hospitals focused on providing quality palliative care have benefited from the published results of two recent national efforts. In 2004, the National Consensus Project released its guidelines on quality measures for palliative care.[69] These guidelines are being used as a foundation for a national set of practice recommendations by the National Quality Forum.[70] Also, in 2004 the University HealthSystem Consortium (UHC) published data on benchmarking actual clinical palliative care outcomes.[71] This ground-breaking work created a practical data set against which medical centers nationally can compare palliative care outcomes across 11 evidence-based measures of excellent palliative care. (See box on next page.)

Key Palliative Care Performance Measures in the University HealthSystem Consortium Benchmarking Project[72]

1. Documentation of patient status within 48 hours of admission
2. Plan for discharge disposition documented within four days of admission
3. Patient/family meeting within one week of admission
4. Discharge planner/social services-arranged services required for discharge
5. Pain assessment within 48 hours of admission
6. Use of a numeric scale to assess pain
7. Pain relief or reduction within 48 hours of admission
8. Bowel regimen ordered in conjunction with opioid
9. Dyspnea assessment within 48 hours of admission
10. Dyspnea relief or reduction within 48 hours of admission
11. Psychosocial assessment within four days of admission

The UHC project included data and leadership from four California medical centers—Harbor-UCLA, University of California, Irvine, University of California, San Diego, and University of California, San Francisco—among its 35 participants. The UHC reviewed top-performing palliative care services (including University of California, Irvine in the top five) and identified the following elements as critical to success:

- Patient/family-centered philosophy
- Effective communication/education strategies
- Active support of senior leadership
- Multidisciplinary team approach
- Committed physician champion
- A culture of quality improvement

A number of California hospitals are making important contributions to the database on quality palliative care: City of Hope's Betty Ferrell, Ph.D., F.A.A.N., is director of the End-of-Life Nursing Education Consortium (ELNEC) and co-editor of the *Textbook of Palliative Nursing;* UC San Diego's Frank D. Ferris, M.D., is the principal author of the Canadian Hospice Palliative Care Association's resource *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice,* and UCSF is participating in a Center to Advance Palliative Care research project to document clinical outcomes among palliative care consultation services nationally. In December 2004, the National Institutes of Health held a "State of the Science" conference on palliative care, characterizing the quality of evidence-based palliative care practices and directions for research.[73] Among the palliative care leaders invited to speak at this conference, four were from California.

Regulatory Support for Palliative Care Services

Regulation and legislation can help sustain active palliative care programs. Palliative care services help hospitals comply with Joint Commission regulations that require adequate pain management, a certain level of patient-staff communication, advance directives, and informed consent.[74] The Medical Board of California is also deeply committed to encouraging and requiring physicians to provide excellent pain management. The board reissued its 1994 guidelines with new entries regarding active physician management of patient pain. New continuing education requirements further support this effort.[75] California is one of just a handful of states to require physician continuing education in pain and palliative care as a requirement for ongoing licensure.[76] Further, in January 2005, California enacted a new system of secure prescription forms and discontinued triplicate prescription forms, partly to normalize the use of opioids for pain management.

Suing Over Inadequate Palliative Care

Historically, physicians worried most about possible legal consequences from over-treating pain. A recent case in California, in which a physician was successfully sued for malpractice and elder abuse for inadequate pain management for a man with terminal cancer, suggests that physicians can also be held liable for under-treating pain. This case highlights the need to provide scrupulous palliative care.[77] Fortunately, there is a wide swath of appropriate care that allows physicians to adequately and appropriately treat pain without risking under- or over-treatment.

Self-Care for Palliative Care Providers

Palliative care programs are commonly started by a handful of passionately committed clinicians, and new services can fold if one or two key individuals depart. Recruiting, training, and engaging a core group to staff and run the service helps eliminate this vulnerability. Though early on it is often impossible for new services to avoid overdependence on a few individuals, adequate funding can allow programs to develop the "deep bench" that is needed to ensure sustainability.

In addition, the intensity of palliative care work is such that self-care is necessary to prevent burnout. Each patient death is a loss, and the effects are cumulative. Clinicians who do not care for themselves and fail to address the strong emotions evoked by caring for seriously and terminally ill patients run the risk of losing commitment to, and satisfaction with, their jobs.[78] Burnout can also compromise patient care.[79] All members of the health care team should be trained to monitor their own emotional well-being and need to practice self-care as prophylaxis against burnout. A key first step is to ensure the financial and administrative support necessary to keep workloads manageable. Individuals and teams also need to develop activities they can incorporate on a daily, weekly, monthly, and yearly basis—including ongoing discussions about emotional well-being, regular collective and individual activities outside the hospital, and professional psychological oversight—to prevent burnout and promote job satisfaction.

Table 4. Self-Care for Individuals and Teams in Palliative Care

INDIVIDUAL RESPONSES	COLLECTIVE RESPONSES FOR THE TEAM
• Talk with a trusted colleague or friend	• Hold a memorial service one or more times yearly
• Develop a ritual for when patients die	• Have fun together
• Exercise regularly	• Organize a facilitated debriefing
• Meditate	• Discuss difficult cases regularly
• Take breaks from clinical work	• Begin team meetings with a reading or poem
• Engage in enjoyable activities outside the hospital	• Share cards and letters from patients and families
• Read or write poetry	• Create flexible schedules to accommodate home life
• Obtain professional supervision and psychotherapy	• Schedule regular processing and support groups
	• Hold a yearly retreat for the team

VIII. Conclusion

Substantial evidence supports an extensive list of benefits derived from hospital-based palliative care services. These include improved quality of care, increased patient and family satisfaction, and more appropriate resource utilization resulting in cost savings. Despite this evidence, less than a quarter of California hospitals maintain palliative care services. Barriers to program implementation and sustainability include a lack of trained professionals to staff a service, little or no institutional and administrative support, and a lack of funding, all exacerbated by a lack of information about the extent of the benefits that a comprehensive palliative care service can bring to both patients and institutions. Nonetheless, these and other barriers can be overcome. Careful advance planning, matching the service model and structure to the needs and capabilities of the institution and its staff, collecting data to prove program benefits, and preventing staff burnout can facilitate the implementation, growth, and sustainability of palliative care services.

Appendix A: Resources

The authors have found the following resources to be useful across the spectrum of information available for palliative care operational models, clinical services, and educational opportunities. This list is representative but by no means exhaustive, and the authors do not attest to the accuracy of all the information contained in each resource.

Advance Directives

California Coalition for Compassionate Care
www.finalchoices.calhealth.org/advance_health_care_directives.htm

California's Physician Continuing Education in Pain and End-of-Life Care Requirement (AB487)

California Business and Professions Code
www.leginfo.ca.gov/cgi-bin/displaycode?section=bpc&group=02001-03000&file=2190-2196.5

California Coalition for Compassionate Care
www.finalchoices.calhealth.org/C4_textfiles/ab_487_bill_20011005_chaptered.pdf

Designing Hospital-Based Palliative Care Services

Center to Advance Palliative Care (CAPC) www.capc.org/

End-of-Life Data Sets

Epidemiology of Dying and End-of-Life Experience
www.edeledata.org/search/home.html

Epidemiologic Data About Deaths / Death in California

Brown Atlas of Dying. "Facts on Dying: California State Profile," www.chcr.brown.edu/dying/caprofile.htm

Educational Resources

American Academy of Hospice and Palliative Medicine (AAHPM) www.aahpm.org
Resources: www.aahpm.org/resources/
UNIPAC Book Series: Hospice/Palliative Care Training for Physicians, A Self Study Program: www.association-office.com/aahpm/etools/products/index.cfm
Primer in Palliative Care: www.association-office.com/AAHPM/etools/products/products.cfm

Americans for Better Care of the Dying (ABCD)
"Clinicians—to Improve Daily Practice":
www.abcd-caring.org/tools/actionguides.htm#clinicians

Disseminating End-of-Life Education to Cancer Centers (DELEtCC) http://deletcc.coh.org/

Education in Palliative and End-of-Life Care (EPEC)
www.epec.net

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

End of Life/Palliative Education Resource Center (EPERC)
www.eperc.mcw.edu/
"Fast Facts": www.eperc.mcw.edu/ff_index.htm

National Internal Medicine Residency Curriculum Project
www.mcw.edu/pallmed/html/about1.html

Ian Anderson Continuing Education Program in End-of-Life Care www.cme.utoronto.ca/endoflife/

Expertise in Palliative Care

Chaplain Expertise

Association for Clinical Pastoral Education Inc. (ACPE)
www.acpe.edu/

Curricula / Competencies

AAHPM Core Curriculum www.aahpm.org/resources/

American Board of Hospice and Palliative Medicine (ABHPM) www.abhpm.org/

Department of Veterans Affairs Interprofessional Fellowship Program in Palliative Care
www.va.gov/oaa/fellowships/Palliative.asp

EPEC Faculty Development Conference www.epec.net

Harvard Medical School Center for Palliative Care Program in Palliative Care Education and Practice Faculty Development
www.hms.harvard.edu/cdi/pallcare/

Hospice and Palliative Nurses Association (HPNA)
www.hpna.org/

Open Society Institute and Soros Foundations Network Project on Death in America (PDIA) Faculty Scholars Program www.soros.org/death/fs_announcement.htm

PDIA Social Work Leadership Development Awards
www2.soros.org/death/socialrfa.htm

Stanford Faculty Development Center for Medical Teachers www.stanford.edu/group/SFDP/

Nurse Expertise

ELNEC www.aacn.nche.edu/ELNEC/

HPNA www.hpna.org/

National Board for Certification of Hospice and Palliative Nurses www.nbchpn.org/

Physician Expertise

ABHPM www.abhpm.org

EPEC Faculty Development Conference www.epec.net

Harvard Medical School Center for Palliative Care Program in Palliative Care Education and Practice Faculty Development Course www.hms.harvard.edu/cdi/pallcare/

PDIA Faculty Scholars Program www2.soros.org/death/faculty_scholars_program.htm

Stanford Faculty Development Center for Medical Teachers www.stanford.edu/group/SFDP/

Social Work Expertise

PDIA Social Work Leadership Development Award www.swlda.org/archive/

Smith College School for Social Work www.smith.edu/ssw/geaa/academics_cecertificate.php

Guidelines

Published standards, guidelines, professional recommendations, position or consensus papers, principles of professional practice for palliative care include:

Agency for Health Care Policy and Research. "Cancer Pain Management Guidelines" (1994).

American Academy of Neurology. "Palliative Care in Neurology" (1996), www.aan.com/about/ethics/Palliative%20Care.pdf

American Academy of Pain Medicine. "Quality Care at the End of Life" (1998), www.painmed.org/productpub/statements/pdfs/quality_care-end_of_life.pdf

American Geriatric Society. "The Care of Dying Patients" (1994; revised 2002), www.americangeriatrics.org/products/positionpapers/careofd.shtml

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American Pain Society. "Principles of Analgesic Use in the Treatment of Acute and Cancer Pain" (5th edition), www.ampainsoc.org/pub/principles.htm

American Society of Pain Management Nurses. Position statement: "Treatment of Pain at the End of Life" (1997; revised 2006), www.ampainsoc.org/advocacy/treatment.htm

American Thoracic Society. "Withholding and Withdrawing Life-Sustaining Therapy" (1991), www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=1892317 Society of Critical Care Medicine Ethics Task Force.

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Consensus Report on the Ethics of Forgoing Life-Sustaining Treatments in the Critically Ill. Critical Care Medicine 1990;18:1435–1439

HPNA. "Statement on the Scope and Standards of Hospice and Palliative Nursing Practice" (2000), www.hpna.org/Publications_Home.aspx

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

National Consensus Project for Quality Palliative Care. "Clinical Practice Guidelines for Quality Palliative Care," www.nationalconsensusproject.org/

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Oncology Nursing Society and Association of Oncology Social Work. "Joint Position on End-of-Life Care" (1998; revised 2003), www.aosw.org/docs/pos-ons.pdf

Teno, J.M. et al. "Toolkit of Instruments to Measure End-of-Life Care (TIME)," www.chcr.brown.edu/pcoc/Advanc.htm

Weissman, D. *Improving End-of-Life Care: A Resource Guide for Physician Education.* Medical College of Wisconsin, 1998 www.mcw.edu/display/router.asp?DocID=196

World Health Organization. "Palliative Care," www.who.int/cancer/palliative/en/

Marketing Materials

CAPC www.capc.org/building-a-hospital-based-palliative-care-program/implementation/marketing

Medicare Fee-for-Service Policies

Centers for Medicare and Medicaid Services www.cms.hhs.gov/home/medicare.asp

Norms / Standards of Practice, Accreditation

California Hospice & Palliative Care Association (CHAPCA) www.calhospice.org

Canadian Hospice Palliative Care Association (CHPCA) www.chpca.net/home.htm
Norms of Practice:
www.chpca.net/initiatives/norms-general.htm

Joint Commission www.jointcommission.org

National Hospice and Palliative Care Organization (NHPCO) www.nhpco.org
Hospice Standards of Practice:
This material is no longer available to view online, but you may purchase it at:
http://iweb.nhpco.org/iweb/Purchase/ProductDetail.aspx?Product_code=711077

State of Palliative Care Research

National Institutes of Health State-of-the-Science Conference. "Statement on Improving End-of-Life Care," http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm

Crosswalk of JCAHO Standards and Palliative Care, CAPC www.capc.org/jcaho-crosswalk

National Quality Forum www.qualityforum.org

University HealthSystem Consortium. Palliative Care Benchmarking Project (2004), www.uhc.edu/

U.S. News and World Report. "Best Hospitals 2006," www.usnews.com/usnews/health/best-hospitals/tophosp.htm

Tools for Analyzing Financial Outcomes and Developing a Business Case

CAPC www.capc.org/

Utilization of Acute Care Services in California

Office of Statewide Health Planning and Development www.oshpd.cahwnet.gov/

Appendix B: Endnotes

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