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Palliative Care in California: An Overview of Hospital-Based Programs

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Palliative Care in California: An Overview of Hospital-Based Programs

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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

About the Project

In California, as across the United States, there are endemic shortfalls in the extent and quality of hospital care for people with serious, life-threatening, and terminal illnesses. Hospitals generally offer patients the most advanced treatments intended to cure illness, but state-of-the-art care to manage complex symptoms and to ease suffering is often unavailable or underused. As a result, many patients, especially those who are dying, receive unwanted, unhelpful, invasive care while their pain and other serious discomforts are poorly addressed. Instead, these patients need coordinated support in managing their symptoms, and an environment that allows them to finish important tasks, to take stock of their lives, and to say goodbye to loved ones. This support may include helping patients go home from the hospital for their final days; despite many patients' preference to be at home, at present nearly half of Californians die in the hospital.

Hospitals can best provide patients and their families with a supportive environment through the interdisciplinary approach of palliative care, which focuses on relieving both physical and emotional suffering. It provides comfort to patients and their loved ones, with attention not only to medical issues but also to social and psychological issues, without respect to disease, prognosis, or other goals of care. Despite recognition across most of the medical community that palliative care is of great help to patients, less than a quarter of California's 400 public and private hospitals offer formal palliative care services.

The California HealthCare Foundation has commissioned this report to alert, educate, and advise health care administrators, and in particular hospital leaders and their boards of trustees, about the fundamentals of palliative care and the operational requirements for launching a hospital-based palliative care service. The authors, who are members of the Palliative Care Program at the University of California, San Francisco (UCSF), 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 hospital-based palliative care services. Helping hospital administrators understand the features of successful palliative care services, as well as the barriers and

facilitators to launching and maintaining such services, is intended as an important step toward increasing the number of hospital-based services, and improving the overall quality of care for seriously ill Californians.

The Need for Hospital-Based Palliative Care

There are several reasons why it is important for hospitals to provide palliative care. The first is epidemiologic: Put simply, hospitals are where seriously ill patients receive care, and where many people die. The second reason is clinical: The care of people with serious illness is too often of poor quality. Palliative care services ensure that patients receive high-quality care and expert attention to their needs. The third reason is financial: Care at the end of life tends to be very costly. By attending to the values and wishes of patients and their families, palliative care clinicians may offer alternatives to unwanted, unrealistic, and expensive attempts to cure illness, or to artificially prolong the life of a dying patient who believes his or her quality of life has become unacceptable.

The State of Palliative Care in California Hospitals

Despite growth in the number of palliative care services, California hospitals have been slow to recognize the need for comprehensive palliative care. In 2004, only 23 percent of hospitals in the state offered comprehensive palliative care services to patients and their families. This was slightly less than the low national average of 25 percent. Even so, California has emerged as a national leader in promoting the development of palliative care services in hospitals. The California Hospital Initiative in Palliative Services (CHIPS), the Palliative Care Leadership Center at UCSF, and initiatives by hospital systems in California, including Catholic Healthcare West, Kaiser Permanente, Sutter Health, and California's Veterans Affairs hospitals, have established inpatient palliative care services, with each service creating a structure, organization, and approach designed to meet the particular needs of its

patients, clinicians, and institution. Many California institutions large and small, across all care settings, have proved that the barriers to developing and sustaining palliative care services can be overcome.

Reports in This Series

This report provides an overview of the authors' research on the state of palliative care in California hospitals, summarizes the three in-depth reports that complete the series, and offers a vision for the future of palliative care in California hospitals. The three companion reports present a detailed look at the concepts and context of palliative care, including the challenges and barriers to instituting and sustaining hospital-based palliative care services, the business case for palliative care, and an overview of statewide services, innovations, and best practices. While hospice and other services provide high quality care to seriously ill people living at home or in other care facilities, the specific mandate for these reports was to address hospital-based palliative care for adults. While much of the reports' information applies equally to pediatric palliative care services, some critical issues, such as finance, differ markedly. The reports may be read separately, or in concert, to introduce the concepts of hospital-based palliative care to administrators, trustees, or clinical staff, and to educate these constituencies about the critical elements in establishing and sustaining a palliative care service.

These reports present a snapshot rather than a longitudinal study of a rapidly emerging field, but they are unequivocal about the benefits of palliative care services. Emerging data plus copious anecdotal evidence clearly demonstrate that hospital-based palliative care services lead to improved quality of care and increased patient satisfaction. Accordingly, the reports are intended to stimulate discussion and action to achieve the goal that by 2010, 50 percent more hospitals in California will offer comprehensive palliative care services, and that one day all California hospitalized patients will have access to high-quality palliative care.

II. The Context of Palliative Care in California

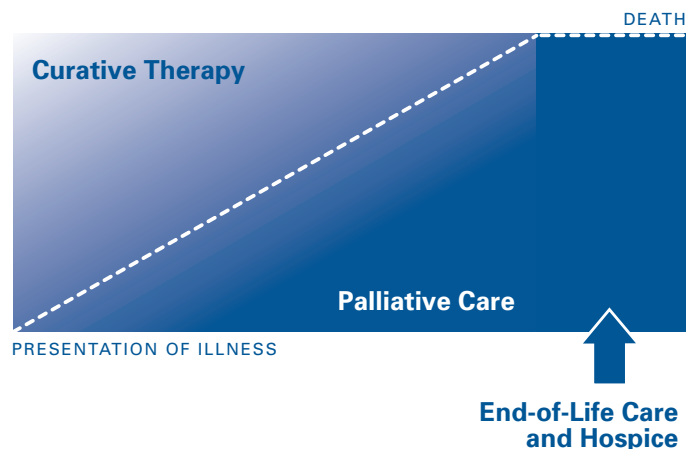
Definition of Palliative Care

Palliative care is medical care, provided across inpatient and outpatient settings, that focuses on relieving suffering of, providing comfort to, and supporting the best possible quality of life for patients and their loved ones, without respect to disease, prognosis, or other goals of care. Though hospice care is the most widely recognized service for the seriously ill, palliative care and hospice care are distinct in important ways. Hospice provides palliation (the relief of suffering) to patients who are expected to die within six months, and who have decided to forgo further attempts at treatment with curative intent. Hospice care is most often provided in the home, but can also be offered in extended care facilities, acute care hospitals, or inpatient hospices.

Unlike hospice, palliative care does not preclude attempts to pursue cure or prolong life. In fact, palliative care is often offered concurrently with curative care. Over the course of a serious illness, the relative balance of palliative and curative care may shift; toward the end of life, palliative care may comprise the entire plan of care (See Figure 1). There are no formal eligibility thresholds

Figure 1. Palliative and Curative Care

Not “either/or,” but “and” Palliative care is offered concurrently with all other appropriate medical treatments at any stage of illness regardless of prognosis. Unlike hospice, palliative care is not limited to patients who have declined further attempts at cure, have a specific prognosis, or are actively dying.



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

for palliative care; the only determinant is the need for relief of symptoms. For chronic diseases characterized by periods of stability punctuated by severe exacerbations and uncertain prognosis (e.g., congestive heart failure, cirrhosis, and dementia), providing palliative care simultaneously with curative care offers the best of what modern medicine has to offer for both medical and symptom management, and attention to psychosocial concerns. A complete review of the concepts and context of hospital-based palliative care in California may be found in *Palliative Care in California: Fundamentals of Hospital-Based Programs*, at www.chcf.org.

Comprehensive Palliative Care

Palliative care integrates the skills and knowledge of a specially trained team of clinicians from multiple disciplines to offer comprehensive care. The interdisciplinary team addresses the patient's physical, emotional, interpersonal, and spiritual needs. Palliative care, with its focus on communication, engages patients to articulate their goals and values of care.

Example. A patient with congestive heart failure might be admitted to a hospital several times, on each occasion receiving from a cardiologist the best available medications to treat the condition,

but upon discharge facing a repeating cycle of crises and readmission. With the intervention of comprehensive palliative care services, however, the patient's trajectory of care might look quite different. The palliative care team would consider not only the patient's prognosis but also the patient's goals of care. These might include the patient's preference to avoid the hospital and instead remain at home through subsequent crises. The palliative care team could discuss and create an advance directive document, arrange home care that offers transition to hospice, and put in place an effective plan for managing pain and shortness of breath. If the patient also expresses concerns about family relations, the palliative care team's social worker and/or chaplain could make efforts to facilitate resolution of those issues.

While all California physicians and nurses are required to have basic palliative care training, palliative care now has officially been accorded subspecialty status in medicine. There are 223 California physicians and 587 nurses with special expertise in palliative care. While only 23 percent of California hospitals currently provide specialty palliative care services, lagging just behind the national average of 25 percent, California's leading hospital-based palliative care services are at the forefront of training and leadership in the field.

A Day in the Life of a Palliative Care Consultation Service

It is 8 a.m. Monday morning. There are six patients on the palliative care service and one new consultation request. The team sees patients 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 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 team member has previously seen the original six patients. The nurse practitioner leads the discussion, with bedside nurses invited to participate regarding each patient they are 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 for each of the other team members.

Models of Hospital-Based Palliative Care Services

Hospital-based palliative care services can be organized in many ways, and in California there are examples of successful palliative care services of all types. Each service model has advantages and disadvantages, and it is these characteristics, along with a hospital's personnel, space, and funding resources, that help determine the best model for a particular institution.

These are the four most common models for organizing hospital-based palliative care services:

Palliative Care Consultation Service: an interdisciplinary team that sees patients and makes recommendations about their care.

Primary Palliative Care Service: an interdisciplinary team that takes over and directs patients' care.

Dedicated Palliative Care Unit: a particular space or unit that serves as a location for caring for all or most patients who need palliative care.

Swing Beds: acute care beds in rooms that are designed to be more home-like to promote palliative care, but which may serve both palliative care and non-palliative care patients, depending on need.

The palliative care consultation service is typically the simplest, fastest, and least resource-intensive to establish. It may be easily expanded to meet increasing demand, is able to provide care for patients throughout the hospital, and tends not to threaten existing relationships between patients and their physicians and nurses.

Prevalence in California of the Consultation Services Model

In an unpublished 2004 survey of 96 California hospitals, of the 22 that offered palliative care services, all had palliative care consultation services and two also had dedicated units.

Key Elements in Design of Hospital-Based Palliative 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 will guide decisions 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 diseases 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 (e.g., oncologists, hospitalists, surgeons, cardiologists, intensivists, emergency physicians)?
- Which model offers the best way to address their palliative care needs?
- What resources (personnel and space) are available or could realistically be secured for palliative care?

Additional issues must be addressed regarding the functioning of the palliative care team, including who will lead the team, how the team will function as a unit, and how the palliative care team will communicate with other personnel caring for the patient. There are also basic questions to be answered about what kinds of patients the team will see, who can request a consultation and how they go about making the request, and when the services are available.

Hospital Systemwide Contributions of a Palliative Care Service

Although the primary purpose of a palliative care service is to provide care to patients and their families, there is substantial evidence that the service also improves care generally. Palliative care teams can provide significant benefits systemwide by becoming involved in:

- **Guideline development** for specific conditions or situations, such as pain management or advance care planning.
- **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. In the first year of a program, significantly more time may be spent on educational efforts compared with clinical care. As the service establishes itself, the relative amount of time spent on 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 and cope with difficult cases and to learn about self-care for staff.

A complete review of the models of hospital-based palliative care, as well as discussion of contributions these services make to general patient care and to quality initiatives, is found in *Palliative Care in California: Fundamentals of Hospital-Based Programs*, at www.chcf.org.

III. The Business Case for Palliative Care

THE PRIMARY PURPOSE OF A PALLIATIVE CARE SERVICE is to improve quality of life. Introducing comprehensive palliative care also lowers hospital costs by reducing the resources spent on invasive curative or life-prolonging treatment of some patients with end-stage and chronic illness.

The case for lowered costs is demonstrable. Reimbursement for curative care delivered to patients for whom it is ineffective or no longer desired typically does not keep pace with hospital costs. Cost avoidance—the reduction in resource use from a palliative care team influencing the course of clinical care—is a scalable, reasonable means of documenting palliative care’s fiscal benefits. Such cost avoidance is the rationale most commonly used to justify the allocation of resources to support these services. For a full discussion of the business case for palliative care, see *Palliative Care in California: The Business Case for Hospital-Based Programs*, at www.chcf.org.

How Palliative Care Influences Resource Use

The palliative care target population—patients with serious, chronic, life-limiting illness—has distinct resource utilization patterns characterized by frequent admissions, long lengths of stay (LOS), and high costs per case. By helping these patients clarify goals of care, palliative care teams influence hospital costs. Changes in a patient’s course of care can be achieved when the team’s expertise in assessing and managing pain and other symptoms, and its communication skills, are used to identify and respond to patient and family needs. Proactive palliative care intervention can avoid redundant, unproductive, or unwanted care and the associated costs of supplies, pharmaceuticals, diagnostic tests, and other ancillary services. Palliative care’s coordinated review of services assures high-quality care (e.g., adequate pain control) while reducing hospital costs (e.g., discontinuing unnecessarily repetitive labs or x-rays, or facilitating transfer from a critical care bed to an in-hospital setting that is more in keeping with a patient’s wishes and needs), and commonly results in shorter LOS by arranging for transfer to home or another setting, often with hospice services.

Cost Avoidance and Other Fiscal Benefits

In most cases the high resource use commonly seen in the palliative care target population is coupled with a revenue structure that does not vary according to the volume and nature of services provided in the course of a particular hospital admission. Generally, and in particular for the palliative care target population, compensation for acute care services is such that hospitals are rewarded for controlling costs. The business case for palliative care is based on the premise that the benefits derived from reducing daily costs in the setting of fixed or inadequate reimbursement will typically more than offset the cost of running and staffing the service. As with all program plans, financial projections should be reviewed with the organization's finance and compliance officers.

Less direct fiscal benefits may also be realized. Sites with very high occupancy rates may find that a palliative care service improves patient flow, thereby reducing the toll that emergency department backup and insufficient ICU beds can take on quality of care and staff and patient satisfaction. Sites that are in competition for admissions have found that palliative care services can improve their ability to compete.

Estimating Financial Impact

A number of published studies have evaluated the financial impact of hospital-based palliative care services. All consistently report that such services lower hospital costs by reducing total LOS, ICU LOS, daily costs, and/or use of emergency services; by increasing hospital capacity; or by a combination of these factors. Typically, institutions realize a \$300 to \$1,000 per patient/per day reduction in costs; the amount varies according to baseline resource utilization. Dramatic cost savings can be realized in cases where changes in treatment goals lead to transfer out of critical care beds, shortened hospital stays, and fewer unproductive interventions. Because the source and magnitude of savings vary from service to service and patient to patient, financial

impact analyses need to be drawn from the entire population of patients served.

Several variables influence the degree to which costs can be reduced for individual patients and for the population of palliative care patients as a whole at any given institution. Current resource utilization and costs for target population patients determine the magnitude of the fiscal impact opportunity. The longer the current “usual care” average LOS (ALOS), the greater the potential savings in bed days and room and care costs; a pattern of lengthy ICU stays indicates an opportunity to facilitate transfer to a lower-intensity environment; high daily costs regardless of care setting suggest savings may be realized through reduced use of laboratory tests, pharmaceuticals, radiology studies, and other ancillary services. Because they tend to have longer ALOS and higher costs, mortality cases typically offer the greatest potential for financial impact, and savings generated from these cases can help underwrite services provided to target population patients whose baseline resource utilization is less elevated.

Costs of Staffing and Running a Service

Salary and benefit costs for the clinical team and administrative support staff are the largest expense for a hospital-based palliative care service. Other expenses include advanced clinical training for the palliative care team; developing and disseminating marketing and educational materials for referring providers and patients; and patient/family amenities. Nearly all costs are scalable, meaning that sites expecting to see relatively few patients and to generate relatively modest savings will have lower service expenses. Some palliative care service costs can be offset by professional fee revenue, donations, or contract and grant monies, but in nearly all cases the bulk of operational resources are provided by the hospital. As a result, in most cases the cost of staffing and running the palliative care service is less than the total costs avoided as a result of the service's efforts. Many hospitals in California and throughout the United States have used this model to launch and maintain inpatient palliative care services.

IV. Challenges to Developing a Palliative Care Service

DESPITE AN OBVIOUS NEED FOR AND CLEAR FINANCIAL benefits of hospital-based palliative care, numerous barriers create challenges in developing palliative care services. These barriers are located within both the culture of medical training and the institutional paradigm of hospital structures. Established programs may also encounter barriers in sustaining services. These barriers have to do with the ability to maintain proper staffing and to provide evidence of a service's financial viability. These barriers, and strategies for overcoming them, are discussed in detail in *Palliative Care in California: Fundamentals of Hospital-Based Programs*, at www.chcf.org.

Limited Training and Expertise Among Physicians, Nurses, and Other Staff

Providing good palliative care requires physicians to expand their concept of professional identity—from that of disease-fighters who view every death as a failure, to caregivers who recognize that relief of suffering is central to medical practice and that death is a natural part of life. California's five state and three private medical schools are making efforts to expand their palliative care training for both pre-clinical and clinical students. These efforts include a unique University of California medical school-wide curricular initiative funded by the National Cancer Institute. A nursing training program called the End-of-Life Nursing Education Consortium (ELNEC), developed at the City of Hope Medical Center in Duarte, California, has become the leading national program providing palliative care training for nurses.

Limited Staffing Capabilities

The as-yet limited palliative care training of physicians and nurses means that staff shortages are a serious barrier to the development of hospital-based palliative care services. However, an increasing number of hospitalist physicians offers a promising source of clinicians who could provide palliative care if they receive appropriate clinical training. A statewide nursing shortage also poses a real threat to the development of new palliative care services, and to the overall quality of palliative care in California.

Intra-Institution Competition

Within hospitals, emerging palliative care services sometimes face internal competition for resources and support. However, palliative care adds value to and complements other hospital services. For example, a palliative care service can allow a pain management service to focus exclusively on its tasks and can assist busy intensivists and hospitalists by conducting conversations about goals of care with patients and families. A good palliative care service also helps primary physicians improve their relationships with patients and families. Once hospital staff understand the advantages to them of a palliative care service, they can be turned from competitors to allies.

Initial Costs Outweighing Savings

The start-up costs for building a hospital-based palliative care service, which are incurred before cost avoidance savings can be accrued, present a temporary but real barrier for many institutions. Although grants or philanthropy can provide initial funding to help establish a service and allow the palliative care team to collect the outcome and financial data to convince the hospital to fully support it, typically the hospital provides all or nearly all of the funds to establish the service.

Staff Burden and Burnout

Even successful services may quickly face the challenge of staff burden and burnout. Initial staffing frequently requires adjustment and these changes must be made before staff become overwhelmed by unsustainable workloads. From the outset, it is crucial to collect data capturing clinical and financial outcomes, which can be used to support requests for additional resources to help increasingly busy services sustain themselves and protect against staff burnout.

V. Supports for Hospital-Based Palliative Care Services

WHILE THERE ARE SUBSTANTIAL BARRIERS TO THE creation, growth, and maintenance of hospital-based palliative care services, there are also countervailing factors that can provide support for such services. Some of these supports are emerging from the state and national palliative care community; for example, California is one of just a handful of states that require physician continuing education in pain management and palliative care as a condition for ongoing licensure. The bulk of supportive elements, however, must still come from individual palliative care teams and their hospital administrators. Strategies to support hospital-based palliative care services are discussed in detail in *Palliative Care in California: Fundamentals of Hospital-Based Programs*, at www.chcf.org.

Institutional Buy-in

Those seeking to create a palliative care service can help overcome institutional resistance and inertia by showing hospital executives and administrators that palliative care both enhances the institution's reputation and provides financial advantages to the hospital. Palliative care is increasingly recognized by health care executives, lay media, and consumers as an important element of quality care. Palliative care services help hospitals comply with the Joint Commission regulations. Their cost efficiencies allow hospitals to reap the benefits of appropriate utilization of high-technology curative interventions. Developers of palliative care services can help their cause by providing good information to hospital decisionmakers, demonstrating that with nearly one-fourth of hospitals now providing this service and new services in development, hospitals without palliative care services risk being left behind.

Dedicated Funding

Sustaining a palliative care program requires dedicated funding. Securing this funding is especially important in cases where initial efforts are staffed by providers who undertake the palliative care work in addition to, not in place of, existing responsibilities. While many sites successfully start new services with volunteer staffing, such arrangements are not sustainable.

Review of hospital resource utilization data may be sufficient initially to convince institutional leaders that there is a need for a palliative care service and that opportunities exist for reducing costs. However, securing dedicated, ongoing funding may require significantly more substantial and service-specific evidence, including pilot data that establish the service's ability to attract referrals, and outcomes data that document financial impact, improvements in clinical care, or patient and family satisfaction. It is critical that palliative care service leaders and hospital administrators agree as to mission-critical data, that this information is collected, and that resources are allocated to analyze the data.

Data Management and Reporting

One of the best ways for new hospital-based services to ensure and enhance sustainability is to attend to data management and reporting activities. Senior administrative and clinical leaders should be kept abreast of financial and clinical outcomes. Data describing the number of patients seen and the sources of referrals demonstrate the hospitalwide need for the service. Quality measures include patient, family, and referring clinician satisfaction, and clinical outcome indicators.

Planning for Growth

While some hospital-based services struggle to attract referrals, more often sites are overwhelmed by rapid growth. Failure to adequately fund and staff a busy service can lead to program failure. Insufficient resources limit the palliative care team's ability to influence clinical care, which results in reduced financial impact. Equally damaging are situations in which there is delay in attending to patients, or the palliative care team lacks adequate time to assess and meet patients' needs. In such situations, referrals will decline or disappear. In most cases, increased volume yields increased fiscal benefits, so data-based requests for additional funding are typically well received.

Expansion of the Core Team

Building a solid team is another key task to ensure sustainability. Palliative care programs are commonly started by a handful of passionately committed volunteers. New programs can fold if one or two key individuals depart unexpectedly. Recruiting, training, and engaging a core group to participate in staffing and running the service eliminates this vulnerability.

Given the intensity of the work, burnout prevention is also key to sustainability. Providers should be trained to monitor and tend to their own emotional well-being. Financial and administrative support and infrastructure are needed to keep workloads manageable.

Referral Base

Maintaining and growing a referral base is vital to the continuing health of a hospital-based palliative care service. Ensuring that the service is responsive to the needs of referring providers and patients maximizes the likelihood of continued and increasing referrals. Patient, family, and physician satisfaction surveys can help services understand and respond to the needs of patients and providers. Marketing and outreach efforts should be ongoing tasks, and appropriately budgeted.

VI. Innovations in Hospital-Based Palliative Care

CALIFORNIA BOASTS MANY INITIATIVES PROMOTING the development of hospital-based palliative care services. Some of these initiatives were generated by national and statewide collaborations among nonprofit health care organizations, philanthropic institutions, and participating hospitals. Others have been the products of individual hospital systems seeking to develop palliative care services appropriate to their own needs. Certain health care systems nationwide have likewise established innovative hospital-based palliative care services, across institutionally, geographically, and demographically diverse sites. These California and national initiatives and their salient innovative features are discussed in detail in *Palliative Care in California: Innovations in Hospital-Based Programs*, at www.chcf.org.

California Hospital Initiative in Palliative Services

The California Hospital Initiative in Palliative Services (CHIPS), begun in 2001 with funding through the Center to Advance Palliative Care (CAPC) from the Robert Wood Johnson Foundation, in collaboration with the California Healthcare Association and the California Coalition for Compassionate Care, was one of the first programs in the nation to focus on helping hospitals establish palliative care services. Over two years, CHIPS recruited 38 California hospitals to participate in an innovative, 12-month training program. With assistance from the CHIPS program, 60 percent of the participating hospitals established palliative care services.

Palliative Care Leadership Center

The Palliative Care Leadership Center (PCLC) initiative, funded through CAPC by the Robert Wood Johnson Foundation, includes six training centers across the country, one of which is based at the University of California, San Francisco. Currently the UCSF PCLC is funded by the California HealthCare Foundation, the JEHT Foundation, and the Archstone Foundation. As with CHIPS, the program's goal is to increase the number of hospitals with palliative care services. Overall, 493 hospitals nationally, including 64 from California, have participated in PCLC training, which consists of a two-day curriculum with a year of follow-up mentoring. Enrollment in PCLC began in 2004 and is ongoing through 2009.

California Hospital System Initiatives

CHIPS and PCLC enrolled hospitals from both large systems and stand-alone institutions. Each type succeeded in establishing palliative care services. Hospitals in several systems within California have completed CHIPS or PCLC training, and/or have independently launched palliative care initiatives. Some examples include:

- **Catholic Healthcare West (CHW).** Following participation in CHIPS by seven of the 40 hospitals in its system, CHW began a systemwide palliative care initiative, which to date includes all but three of its hospitals.
- **Kaiser Permanente.** Of Kaiser's 29 California hospitals, eight participated in CHIPS or PCLC. Twenty now have or are planning a palliative care service and Kaiser is launching a national initiative to provide inpatient palliative care services to all of its patients.
- **University of California (UC) Hospitals.** All five UC hospitals offer palliative care services, and all teach palliative care to their medical, nursing and pharmacy students. Several UC hospitals have developed data demonstrating improved patient symptoms and family satisfaction.
- **Veterans Affairs Medical Centers (VAMC).** Eight VAMCs in California offer inpatient palliative care services, as mandated by the Veterans Health Administration. The Palo Alto facility also has an outpatient palliative care clinic, which is the hub site for the VA's national interdisciplinary palliative care fellowship program.
- **Sutter Health.** Six of Sutter's 26 hospitals in California have palliative care services using a variety of models. Sutter is opening about one new service a year.

California's statewide programs like CHIPS and PCLC, as well as a climate generally supportive of expanding palliative care, have led to the establishment of a number of new services in smaller hospital systems and stand-alone institutions.

Despite this progress, less than a quarter of hospitals statewide have palliative care services. Of particular concern is that only three of 22 county hospitals have palliative care services, meaning that most of the state's poorest and most vulnerable hospital patients have little access to palliative care.

Noteworthy National Innovations in Palliative Care Services

California is a leader in the development of hospital-based services, but across the nation several health care organizations have designed innovative strategies for the organization and implementation of palliative care services. These innovations, while not subjected uniformly to controlled trials, have worked, and continue to work, across a variety of settings. The innovations, discussed in detail in *Palliative Care in California: Innovations in Hospital-Based Programs*, include examples of:

- Leadership models (services directed by physicians, nurse practitioners, nurses, social workers, and clergy);
- Structural models (consultation services, dedicated units, swing beds, carts);
- Motivating factors (hospital systemwide initiative, administrative initiative, clinician-driven);
- Settings (academic centers, large and small community hospitals, rural and urban sites, county hospitals, large health care systems, VA hospitals);
- Administrative approaches (model guidelines, protocols, brochures, policies);
- Culturally sensitive care; and
- Bereavement services.

These successful palliative care services from across the country present organizational and operational models and other innovations that, as modified to fit local context, can provide initial templates for planners and designers of emerging services in California.

VII. A Vision of Hospital-Based Palliative Care in 2010

THESE REPORTS ON HOSPITAL BASED-PALLIATIVE CARE services offer the picture of a relatively recent development in which many California hospitals have taken the lead. Formal palliative care services are still not the rule, however, in California hospitals. The authors of these reports intend them to contribute to the continuing expansion of high-quality, hospital-based palliative care services throughout the state. The authors envision an enlarged universe of palliative care services by the year 2010, with high-quality palliative care eventually available for all hospitalized patients in California. To attain this vision, four goals must be reached.

First, by 2010, hospital-based palliative care services in California hospitals should expand by 50 percent. That would reach the tipping point for making palliative care standard practice, with sufficient knowledge and pressure to lead all hospitals to develop palliative care programs. Currently only 23 percent of California's 400 acute care hospitals have palliative care services. The goal for 2010 is to establish 46 new services, with sustained growth in all existing services.

Second, the cohort of practicing physicians, nurses, social workers, and pharmacists trained in palliative care must increase significantly. Only 223 physicians in California are board certified in palliative care by the American Board of Hospice and Palliative Medicine. That number is barely one certified physician for every two acute care hospitals in the state. Within a few years, physician certification in hospice and palliative medicine is going to become more difficult: Beginning in 2012, physicians will need to complete fellowship training to become certified in hospice and palliative medicine. Until 2012, however, physicians can still "grandparent in" for certification without fellowship training (see the "Physician Certification Fact Sheet" at www.capc.org). Among nurses, only 587 are certified in palliative care by the National Board for Certification of Hospice and Palliative Nurses, which is less than 1.5 nurses per hospital. A goal for 2010 is for 400 certified physicians (178 more physicians [44 per year]), which would mean one trained physician per hospital, and for 1,000 certified nurses (413 more nurses [103 per year]), resulting in 2.5 trained nurses per hospital.

Third, all nursing, pharmacy, social work, and medical students should receive training that enables them to competently provide basic palliative care to their patients. A goal for 2010 is for students in these clinical disciplines to receive palliative care training across all years of their education. A start toward this goal was made by the enactment of California Assembly Bill 791, signed into law in 2000, which requires that all students at University of California medical schools receive education in palliative care.

Fourth, hospital-based palliative care services must systematically measure and report on the quality of the care they provide. This data collection will allow the services to monitor, and thereby improve, the quality of care their patients receive. The services can use data pertaining to quality of care, patient satisfaction, and cost avoidance to support continued and expanded funding.

Achieving these goals will require concerted, focused effort by many constituencies in the state, including health care leaders; hospital CEOs and members of boards of directors; health care providers; payers; professional organizations; foundations supporting health care innovation; medical, nursing, pharmacy, and social work faculty; and state and local governments. Working together, these goals can be achieved so that every Californian will have access to high-quality palliative care. The reports in this series are intended to serve as a touchstone in that effort.

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 (EPEC)
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_cccertificate.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/product-pub/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

American Medical Association (AMA). Report from the Council on Scientific Affairs: “Good Care of the Dying Patient.” *Journal of the American Medical Association (JAMA)* 1996; 275:474–478.

AMA. “Optimal Use of Orders-Not-to-Intervene and Advance Directives,” www.ama-assn.org/ama/pub/category/8462.html

AMA Council on Ethical and Judicial Affairs. “Guidelines for Appropriate Use of Do-Not-Resuscitate Orders.” *JAMA* 1991; 265:1868–71.

American Nurses Association. “Pain Management and Control of Distressing Symptoms in Dying Patients” (1991; revised 2003), www.nursingworld.org/readroom/position/ethics/etpain.htm

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.

Cassel, C.K., and Foley, K.M. “Principles for Care of Patients at the End of Life: An Emerging Consensus Among the Specialties of Medicine” (1999), Milbank Memorial Fund, www.milbank.org/endoflife/index.html

Cherny, N.I., Coyle, N., and Foley, K.M. “Guidelines in the care of the dying patient.” *Hematol Oncol Clin North Am* 1996;10: 261–86.

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/

NHPCO and the National Hospice Work Group. “End Report on the Alpha and Beta Pilots of End Result Outcome Measures” (1998-2000), www.nhpc.org/files/public/OCFFINALRPT.pdf

NHPCO. “A Pathway for Patients & Families Facing Terminal Illness” (1997). www.nhpc.org/public/articles/FOR.pdf

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](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](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](http://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/



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