Improving the Quality of End-of-Life Care for Californians

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Prepared for the California HealthCare Foundation by

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POWERS & ASSOCIATES
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“Dying people have a special claim on us. There is a duty to care for the dying that is absolute in the same way that one has to take care of a woman in childbirth. One should stop the world to take care of a dying person.”

– Laurie Zoloth, Professor of Social Ethics and Chair of Jewish Studies, San Francisco State University
Executive Summary

Due to the aging of the population in the United States and a shift in the causes of death from acute, infectious diseases to chronic, long-term illnesses, the quality of end-of-life care has become increasingly important over the past few decades. Roughly 225,000 Californians die each year, and the majority of these individuals suffer from chronic illness. Patients requiring end-of-life care typically have multiple significant medical problems, and more than a quarter of dying patients are demented.

Dying patients spend the last part of life in a variety of settings, and sometimes in multiple settings during the last year. In California, approximately 50 percent of deaths occur in hospitals, 26 percent in nursing homes, and only 25 percent at home. Between 10 and 15 percent of patients receive hospice services either at home or in a hospice facility. Most of these patients have cancer. Considering that the majority of people would prefer to die at home, there are tremendous opportunities for better adhering to patients’ preferences.

In addition, the cost of end-of-life care is substantial, accounting for 10 to 12 percent of the total health care budget and 27 percent of the Medicare budget. Most experts believe that attentive care management will enable patients to remain at home or in settings of their choosing and to avoid unnecessary crisis interventions and unwanted hospitalizations. Research and demonstration projects indicate that quality palliative care could reduce the use of expensive resources and lead to overall savings.

Despite the sophistication of our health care system, there are multiple barriers to the provision of appropriate end-of-life care. Lack of public education and misconceptions about the circumstances surrounding palliative care are reasons why many patients and families are reluctant to elect palliative care. In addition, the United States does not have a highly integrated and supportive system for taking care of persons at the end of their lives. The health care system suffers from multiple shortcomings, including extreme variation in the degree and kinds of services utilized across the state of California. Another problematic area is inadequate pain management; it is possible that recent legislation will lead to improvements in this area. The lack of professional education at any level of training has resulted in a clinical workforce that lacks the appropriate knowledge and skills to care for dying patients. Outdated federal reimbursement strategies result in barriers to hospice entry, inadequate reimbursement for hospitals, SNFs, and
hospices, and to the transferring or “dumping” patients into different settings as their needs change. Finally, end-of-life care is a relatively new field of research, so there is little consensus about how to define guidelines and standards for quality palliative care.

Experts agree that the greatest priorities for improving the quality of end-of-life care include (1) the overall coordination of care, as well as specifically improving public engagement on end-of-life issues, (2) professional education, (3) pain management, and (4) reimbursement. Although end-of-life care is a relatively young field, some stakeholders in California are implementing initiatives in each of these areas. The broadest effort comes from the California Coalition for Compassionate Care, which has a dedicated Steering Committee that embraces the challenge of improving professional education and palliative care program development. Also, four California sites under the auspices of the Robert Wood Johnson Foundation’s Promoting Excellence in End-of-Life Care national program have built models for best practices, demonstrating both improved palliative care services and cost savings. Two health plans and a few physician organizations have developed comprehensive care management programs with systematic changes to facilitate best practices. These initiatives demonstrate that organized efforts can greatly improve the access to and quality of palliative care in many settings.

This paper recommends seven ways in which CHCF and others can invest in end-of-life care quality improvement in California. Building upon current efforts, the first recommendation is broad and suggests that CHCF help to institutionalize the overall coordination of care, with particular focus on hospitals and skilled nursing facilities and their affiliated professionals. Strengthening and integrating several initiatives sponsored by the California Coalition for Compassionate Care can accomplish this. The remaining recommendations focus on expanding advance care planning through public and professional education; improving pain management; obtaining consensus on quality metrics for end-of-life care; advancing research on the relative cost of hospice and palliative care; and creating reimbursement strategies to support palliative care services. Such investments can lead to significant and enduring improvement in the quality of end-of-life care in California.
I. Introduction

This paper is one of five white papers produced by Powers & Associates at the request of the California HealthCare Foundation (CHCF). Besides end-of-life care, the other four topics are breast cancer, diabetes, heart failure, and pediatric asthma. The primary purpose of each paper is to assist CHCF staff and others in determining priority areas for investment in quality improvement in the state of California. Although each paper stands alone, together the five form an integrated body of work. In order to preserve the readability of the paper and limit its length, most of the sections are illustrative, rather than exhaustive. Any omission of specific information or an initiative does not intentionally imply it has been deemed unworthy of acknowledgement.

As the team of authors writing these papers delved into opportunities for fundamentally improving quality of care, it became apparent that improvements in the overall coordination of care are common to all diseases/conditions. Each paper includes a broad recommendation for CHCF and/or other stakeholders to invest in implementing aspects of a chronic care model in partnership with the respective leading organizations devoted to each disease/condition. Other recommendations specific to priorities identified by key stakeholders within each disease/condition are included in the papers.

Due to the aging of the U.S. population and a shift in the causes of death from acute, infectious diseases to chronic, long-term illnesses, the quality of end-of-life care has become increasingly important over the past few decades. In the early 1900s, average life expectancy was 50 years and childhood mortality was high. People tended to die quickly, often of infectious diseases or unintentional injuries.\(^1\) Average life expectancy today is 77 years, and the leading causes of death are heart disease, cancer, stroke, lung disease, and degenerative neurological disorders.\(^2,3,4\) Chronic conditions such as these account for 75 percent of all deaths today.\(^5,6\) With the development of antibiotics, improvements in public health, and new technologies, the modern health care system aggressively fights illness and often postpones death. The prolonging of life means that people often live with chronic disease and disability for many years. Although there is variation in the definition of what constitutes end-of-life care, most research focuses on the last year or last six months of life as the time period when the quality of care provided can be substantially improved.
Despite the sophistication of our health care system, the United States does not have a highly integrated and supportive system for taking care of persons at the end of their lives. A landmark four-year Robert Wood Johnson Foundation (RWJF) study completed in 1994, SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment), showed substantial shortcomings in the care of patients with advanced fatal illness. In five of the top academic hospitals across the United States, researchers found that fewer than 50 percent of physicians were aware of “Do Not Resuscitate” (DNR) orders that were documented. Approximately 50 percent of DNR orders were written within two days of death, about 40 percent of patients who died spent at least ten days in an intensive care unit (ICU), and 50 percent of conscious patients were in moderate to severe pain during the last three days of life. These findings dramatically conflict with documented patient preferences for pain and symptom control, avoidance of inappropriate prolongation of the dying process, and a sense of control.

The goal of the study was to improve end-of-life decision-making and reduce the frequency of mechanically supported, painful, and prolonged experiences of dying. The intervention provided physicians with predictive information on future functional ability, survival probability, and patient preferences for end-of-life care; and added a nurse case manager to facilitate advance care planning and enable palliative care. Unfortunately, these interventions had no impact on the designated outcomes of the study. The reasons for this failure can be attributed to a lack of change in physician practice patterns, a lack of high-level support from the health care organizations, the need to study the intervention in a broad range of settings, the need to design interventions earlier on in the course of illness, and a lack of broad, system-wide interventions. The observations from the SUPPORT study have stimulated nationwide efforts to research and improve the quality of end-of-life care.

The World Health Organization defines palliative care as the “active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families.” Palliative interventions serve to address the needs of the “whole patient”; ideally these interventions occur in conjunction with curative care. Later, the balance between curative and palliative care may shift as the disease progresses. Thus, palliative care reduces both physical and emotional suffering. When the health care system embraces palliative care as an integral part of care in general, care for patients with chronic illness and limited life expectancy will improve.

An important component of palliative care is case management, because patients near the end-of-life are often transferred between settings for procedures or skilled care. Many individuals need care from a variety of resources, including families, friends, home health care workers, assisted living facilities, nursing homes, and hospitals. The system in the United States is very fragmented and costly, with little consistency in quality of care.

The following sections of this paper discuss the epidemiology (Section III) and cost (Section IV) associated with end-of-life care; the state of knowledge, diagnosis, treatment, and monitoring (Section V); the gaps between knowledge and treatment (Section VI); current efforts to close the gaps (Section VII); and opportunities/recommendations to improve the quality of end-of-life care. The paper focuses on persons 65 and older because three out of every four deaths occur in this population. In addition, significant attention is paid to hospitals because roughly half of all deaths occur in this setting.
II. Epidemiology

According to the California Department of Finance, roughly 225,000 Californians die each year. Given that 2.3 million Americans die each year, it can be inferred that 10 percent of all deaths occur in California. Nationwide, 80 percent of dying patients are covered by Medicare. In California, nine percent of Medi-Cal enrollees are elderly, which equates to about 557,000 individuals.

Patients requiring end-of-life care typically have multiple significant medical problems during the last year of life. According to Medicare claims data from 1993 to 1998, the typical Medicare decedent had almost four diseases, while the average survivor had only one. About three-quarters of decedents had some type of heart disease, about half had heart failure, and approximately one-third had cancer, stroke, chronic obstructive pulmonary disease, or pneumonia. More than a quarter of dying Medicare patients was demented.

End-of-life patients spend the last part of life in a variety of different settings, and sometimes in multiple settings during the last year. Nationwide, 57 percent of deaths occur in hospitals, 17 percent in nursing homes, and only 20 percent at home. In California, approximately 50 percent of deaths occur in a hospital, 26 percent in a nursing home, and 25 percent at home. Although there have been improvements and proportionately more patients are dying at home in California than nationwide, these data indicate that patients’ preferences are not systematically followed. Multiple studies have found that the majority of people would prefer to receive end-of-life care at home.

Hospitals

In California, although the majority of patients die in hospitals, only 2.3 percent of hospital patients die, representing a relatively small portion of the overall care that hospitals provide. This may partly explain why palliative care services and end-of-life care is a low priority for many hospitals.
Long-Term Care Facilities

Approximately one-third of all individuals in the United States will stay in a long-term facility, or nursing home, at some point before they die.\textsuperscript{31,32} About 40 percent of Medicare fee-for-service patients spend some time in a nursing home during the last year of life.\textsuperscript{33} In California, the average length of stay (LOS) is fewer than two months for more than 70 percent of residents.\textsuperscript{34} There are approximately 1,450 nursing homes in California with approximately 86,000 residents.\textsuperscript{35,36,37}

Compared to patients in hospices, patients who reside in long-term care facilities have a rather low prevalence of cancer diagnoses and a much higher prevalence of dementia. Approximately 60 percent of residents in long-term care facilities have mild, moderate, or severe dementia.\textsuperscript{38} Nursing home residents are also considered to be the most frail, requiring assistance with four out of five activities of daily living (ADLs) (bathing, dressing, getting in or out of a bed or chair, using the toilet, and eating).\textsuperscript{39,40,41,42} Although nursing homes are the site of death for many patients with advanced chronic illness, only one percent of the U.S. nursing home population enrolls in hospice care.\textsuperscript{43}

Hospices

The Medicare hospice benefit was introduced as a result of the Tax Equity and Fiscal Responsibility Act of 1982. The Medicare benefit provides reimbursement for hospice care in a variety of settings, including the home, hospice, hospital, or nursing home.\textsuperscript{44} The vast majority (97 percent) of hospice care is in the patient’s home.\textsuperscript{45} Hospice is typically used now by 10 to 15 percent of elderly Americans.\textsuperscript{46} Nationally, the mean age of hospice patients is around 79 years; about 82 to 90 percent of patients are Caucasian, and more than half have some type of cancer.\textsuperscript{47,48,49,50,51,52} Medicare claims data show a disparity in hospice use between decedents with cancer and decedents with non-malignant diseases; approximately fifty percent of patients with cancer compared to only 10 percent of patients with non-malignant diseases used hospice during the last year of life.\textsuperscript{53} In 2000, the average LOS was 48 days, and median LOS was 25 days. (The National Hospice and Palliative Care Organization states that median LOS is a more accurate measure of hospice experiences, i.e., high frequency of short stays.) About one-third of hospice patients died in seven days or fewer.\textsuperscript{54}

In 1998, there were 127 hospices in California serving in excess of 51,000 patients. In California hospices, approximately 60 percent of patients have some form of cancer, 12 percent have diseases of the circulatory system, and a small percentage have diseases of the respiratory system, nervous system, digestive system, and HIV.\textsuperscript{55} The average length of stay for hospice patients in California is 15 days, well below the national average of 48 days. The average LOS varies across the state, and is as low as five days in southern California.\textsuperscript{56}
III. Cost

The per-patient cost for end-of-life care is substantial; it may be financed completely or in part by a number of sources, including Medicare, Medicaid, out-of-pocket, and private long-term care insurance. Studies show that Medicare pays for about 61 percent of decedents’ overall costs during the last year of life, Medicaid pays for 10 percent, out-of-pocket costs account for about 18 percent, and other payers such as private insurers pay for 12 percent.57

**Medicare**

End-of-life care (defined here as care during the last year of life) accounts for 10 to 12 percent of the total health care budget and 27 percent of the Medicare budget.58,59,60 In 1998 the mean Medicare payment for patients in the final year of life was $26,300 compared to $4,400 for all other Medicare beneficiaries.61 In 1997, more than $115 billion was spent on long-term care in the United States.62

California accounts for close to 10 percent of the total Medicare enrollment in the United States.63 Expenditures for fee-for-service decedents in the last year of life are substantial. A recent study found that expenditures totaled $27,814 per decedent in California. Expenditures rose dramatically as death approached; expenditures in the last month of life accounted for more than 38 percent of total expenditures for the last year of life in California.64

**Trends in Medicare Payments**

In an attempt to control Medicare spending and provide incentives for efficiency, the federal government implemented a prospective payment system (PPS) for hospitals in 1983. The new program provided incentives to become administratively more efficient and to shorten hospital stays. Hospital lengths of stay declined dramatically in 1984, the first full year of the PPS, and hospital profits improved despite fewer hospital admissions and declining occupancy rates.65 Although the PPS has achieved some of its objectives, the shorter hospital stays and increased profitability are largely due to shifting the costs and burdens of care to families, home health agencies, and nursing homes. There have been three reports of increasing numbers of deaths in nursing homes that correspond with a decline in deaths in hospitals during the same time period (immediately following PPS implementation).66,67,68 Among different states, the degree of this
shift varied as a function of hospital length of stay and the degree of HMO penetration, i.e., the greatest shifts occurred in states with high HMO penetration, such as California.69,70

**Medicaid/Medi-Cal**

Of the two major government health care programs in the United States, Medicaid finances almost 40 percent of all long-term care expenses ($115 billion), including half the costs of nursing home care.71 In 1998, nursing home expenditures reached $100 million in the United States.72 The average annual cost of nursing home care is approximately $41,000, and most nursing home residents will rely on Medicaid (Medi-Cal) to meet these costs.73

In California, 64 percent of nursing facility residents rely solely on Medi-Cal to pay for their care. Medicare covers fewer than 8 percent, private insurance covers fewer than 2 percent, and out-of-pocket spending accounts for the remaining 26 percent.74,75 The average nursing facility costs ranged between $101 and $120 per patient per day ($36,865 to $43,800 per year) in 1998.76 Elderly Californians account for about one-fifth of the total Medi-Cal budget; these expenditures include acute and long-term care expenses.77

**Significant Out-of-Pocket Spending**

A significant proportion of the actual cost of providing end-of-life care is not reflected in the preceding figures because it is difficult to assign value to the services provided by families and friends. Similar to nationwide statistics, one in four families in California provides care to older adults.78,79 Out-of-pocket spending accounts for 26 percent of nursing facility costs in California.80 As a consequence of providing care, research shows that a significant number of patients and families suffer from financial devastation: In one study, 31 percent of families lost most of their savings, and another study found that 40 percent of families became impoverished.81 Thus, while the actual costs of end-of-life care for patients and their families cannot be determined, it is clear that these costs are significant and often devastating.

**Limited Role for Private Insurance**

Private insurance has a very limited role in the financing of long-term and end-of-life care services. One estimate is that private insurance covers less than six percent of nursing home and home health care costs.82 Moreover, only about seven percent of elderly persons own long-term care insurance policies primarily due to the high cost of purchasing these policies later in life.83,84

**Potential for Savings**

There is significant potential for more appropriate care to reduce costs to the overall health care system. A model of care that is based on thorough, open communication, careful planning, attention to peoples’ values and goals, and insistence on physical comfort will build confidence and enable patients to remain at home or in other settings of their choosing. Following this model can avoid unnecessary crisis interventions, unwanted hospitalizations, and tertiary care. Most research indicates that good palliative care will positively impact the quality of care including the utilization of resources, such as emergency room visits, ambulance transfers, hospitalizations, surgeries, and cardio-pulmonary resuscitation.85,86,87

**Hospice—Potential for Savings Not Yet Determined**

The Medicare program covers more than 75 percent of hospice payments, which accrue to more than $1.5 billion annually.88,89 Despite the belief that enrolling in hospice avoids costly, often...
futile health care expenditures, there is some controversy about this assumption.\textsuperscript{90,91,92,93} One study found that Medicare saved $1.52 in expenditures for every dollar spent on hospice, and a total of $3,192 per patient during the last month of life.\textsuperscript{94} Another study demonstrated that the use of hospice saved up to 10 percent in the last year of life, 10 to 17 percent in the last six months of life, and 25 to 40 percent in the patient’s final month.\textsuperscript{95} The most recent data suggest that expenditures for cancer patients who elected hospice care were 13 and 20 percent less than control groups in Massachusetts and California, respectively. Expenditures in the last month of life were about 40 percent lower in hospice, and these reduced expenditures extended to the third month before death. These savings, however, were only relevant to cancer patients.\textsuperscript{96}

It is difficult to assess cost savings given that most patients do not enroll in hospice until they reach an advanced stage of their illness. Early death in a hospice may indicate that the patient received costly and possibly unnecessarily aggressive care for too long prior to referral.\textsuperscript{97,98} Although short hospice stays mean that patients are sicker during the duration of their stay, hospice care is still less expensive than a stay in the hospital.\textsuperscript{99}
IV. State of Knowledge, Prevention, Diagnosis, Treatment, and Monitoring

Although a variety of care guidelines and quality measures are available, there is little consensus about which tools to use for end-of-life care. Collections of measures have been recommended by national organizations or recognized experts, but most of these measures have not been adopted in any standardized fashion.\textsuperscript{100} The reasons for the lack of consistent acceptance are: (1) research in the field of end-of-life care is relatively young and there are few controlled, randomized studies; and (2) data are difficult and time-intensive to collect due to fragmented care, a lack of administrative electronic data sets, and a heavy reliance on chart reviews and interviews.\textsuperscript{101,102}

Defining End-of-Life Care Quality

Measurements for end-of-life care should address a broad range of clinical and non-clinical indicators. There is general agreement regarding certain broad categories, including symptom management, pain management, quality of life, patient and family satisfaction, and psychospiritual and psychosocial care.\textsuperscript{103,104,105}

There has been some recent work in conceptualizing quality of care for dying patients and identifying the appropriate domains. The World Health Organization (WHO) and Institute of Medicine (IOM) define quality to include services that gain desired health outcomes as well as activities that affect the cognitive and emotional well being of elderly patients, such as treatment of depression or use of advance directives.\textsuperscript{106}

The Center to Improve Care of the Dying issued ten domains for capturing the quality of care provided to dying patients: physical and emotional symptoms; support of function and autonomy; advance care planning; aggressive care near death in terms of site of death, CPR, and hospitalization; patient and family satisfaction; global quality of life; family burden; survival time; provider continuity and skill; and bereavement. These domains were reviewed by more than 25 experts and presented to the IOM’s Committee on Care at the End-of-Life hearing in Washington, D.C. The domains are supported by at least 31 national organizations.\textsuperscript{107}
Recommended Guidelines


The Milbank Memorial Fund has issued a report with core principles for end-of-life care. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) participated in the development of these guidelines, and its standards on end-of-life care for hospitals and health care organizations are aligned with these principles. These principles have been formally adopted by many national societies, including the American Medical Association, the American Academy of Hospice and Palliative Medicine, the American Board of Hospice and Palliative Medicine, American Society of Clinical Oncology, and the American Pain Society. The core principles are listed in Appendix A.  

In January 2000, a statewide task force in conjunction with Sacramento Healthcare Decisions and the California Coalition for Compassionate Care issued the ECHO (Extreme Care, Humane Options) Nursing Facility Recommendations. These recommendations were field-tested in several nursing facilities and circulated statewide for review. The purpose of the recommendations is to facilitate institutional processes, enhance provider competence, and strengthen organizational relationships to improve advance care planning and palliative care services. Specifically, the ECHO recommendations emphasize the role of the patient or surrogate in the decision-making process, assure that patients receive care consistent with their wishes in a timely fashion, explain the legal and ethical issues around decision-making processes, and propose administrative and clinical changes to address barriers. The ECHO recommendations detail specific strategies for corporate and administrative leaders, health care professionals, and regulatory agencies. They include a comprehensive summary about goals of care, interventions, implementation, and resources for forms and materials.  

In another effort to stimulate quality improvement in end-of-life care, the RAND Center to Improve Care of the Dying proposed seven promises that a good care system should be able to make to patients throughout the stages of illness and death (see Appendix A). These promises emphasize quality of life for the whole patient. Consequently, the Institute for Healthcare Improvement (IHI), an organization devoted to quality improvement within health care systems, issued specific guidelines for meeting these promises.  

Public Reporting and Accountability

Unlike some conditions, there are few publicly reported quality measures for end-of-life care. The Department of Health and Human Services recently announced that it would be publishing a set of standards for comparing nursing homes (see Appendix A); although this is valuable information, it would not be specific to end-of-life care. Currently, there are a few indicators available on the Web site for the Centers for Medicare and Medicaid (CMS).  

The Joint Commission on Accreditation of Health Care Organizations (JCAHO) has done a lot of work to regulate pain control and long-term care quality. Effective January 2001, JCAHO added an accreditation requirement that hospitals and health care facilities must regularly assess, monitor, and manage pain in all patients. To facilitate compliance, JCAHO provides a tool for patients to rate their pain on a ten-point scale. JCAHO also recommends strong medication for
chronic, unrelenting pain. JCAHO drafted long-term care standards for the credentialing of licensed independent practitioners, as well as guidelines to promote resident safety and medical/health-care error reduction.

In 1999, the Foundation for Accountability (FACCT) issued a set of proposed standards for holding managed care organizations accountable for quality of medical care at the end of life (see Appendix A). These measures are still under development and require further refinement. At this point, these measures do not appear to have been adopted by California stakeholders.

The California Association of Health Facilities and the California Hospital Association issued indicators for quality in a SNF. These indicators include the documentation of pressure sores, weight loss, falls, employee satisfaction, customer satisfaction, abuse prohibition, and palliative care.

**Recommended Tools**

The most commonly used tool in the assessment of end-of-life care is the Minimum Data Set (MDS) used in SNFs. The MDS collects information such as activities of daily living (ADLs), documentation of advance directives, health status and treatments, and cognitive, emotional, physical, psychosocial, and communicative functioning. Although the collection of data is comprehensive, it is resource-intensive and required at multiple time points for Medicare reimbursement. The MDS produces a quality indicator report, but experts are not satisfied with the reported data. The concerns are that the MDS reports define compliance with regulations and some potential issues, but provide no mechanism for assessing or sustaining improvements in care. Moreover, the quality indicators are intended for the majority of residents in nursing homes where the goal is to restore function and are not as appropriate for patients who are dying.

There has been some recent progress in the dissemination and promulgation of measures and recommended tools for assessment. A few national entities have published toolkits, i.e., collections of tools for collecting end-of-life care measures. First, the Center for Gerontology and Health Care Research at Brown Medical School compiled an annotated bibliography of instruments to measure the quality of care at the end of life. These instruments are organized for assessment of the following categories: pain and other physical symptoms; depression and other emotional symptoms; functional status; survival time and aggressiveness of care; continuity of care; spirituality; grief; caregiver and family experience; and patient and family member satisfaction with the quality of care. The Center also drafted a set of instruments for monitoring system performance in end-of-life care. To accompany these tools, the Center provides a chart review instrument along with surrogate and patient questionnaires.

In 1999, the Promoting Excellence grant, funded by the Robert Wood Johnson Foundation, assembled the Promoting Excellence Toolkit, a 10-inch-thick book of instruments used in its 22 participating research projects. These tools can be organized into categories, including advance care planning, care management and coordination, cost utilization, provider education, grief and bereavement, pain and symptom management, quality of life, and satisfaction of patient and family (see Appendix A for 18 categories). The Promoting Excellence evaluation committee will soon publish a list of the tools determined to be most valuable.
V. Gaps Between Knowledge and Treatment

Fragmentation and Focus on Acute Care Obstructs Quality End-of-Life Care

Most Americans will live for months or years with a chronic disease that eventually kills them, and most will suffer from the inadequacies of a health care system that was never designed for people with chronic diseases. Debates about paying for acute illness, such as basic services and surgeries, shaped the current system at the time of its conception. Thus, the U.S. health care system ensures that surgery is readily available, but it does not consider the needs of people who require medications and skilled care as they face an eventually fatal chronic illness.126

Priorities for people with fatal, chronic illness include living well within constraints; preventing unnecessary disability; providing comfort, spiritual peace, life closure, and preparation for death; and continuity of care for what is often several chronic conditions. In general, our health care system suffers from the following shortcomings: inadequate utilization of pain medications, inadequate symptom management and palliative care, payment disincentives for continuity and coordination of services, absence of standard guidelines for advance care planning, and inadequate training of physicians, nurses, and staff in end-of-life care.

Urban Dwellers Receive More Intense Services

Care at the end of life is often determined by the geographic location of a patient. End-of-life treatment decisions are often influenced by the available supply of acute care hospital resources and by individual physicians’ practice styles instead of by patients’ wishes. The percentage of Medicare beneficiaries admitted to an ICU during the hospitalization in which they died varied from 4 to 31.2 percent among California’s hospital service areas. The highest rates were around Los Angeles and the lowest were around the San Francisco Bay Area and other areas of northern California. Further data show enormous variation in visits to medical specialists during the last six months of life. Specialist visit rates varied almost thirty-fold across California hospital service areas, from an average of 1.1 visits to 33.3 visits per enrollee. Once again, the highest rates were located in southern California and the lowest in northern California. For end-of-life care, it is probable that receiving more services is an indicator of unwanted care and unnecessary expenditures, but further research is warranted to explain these variations.127
Despite Legislation, Pain Management Remains a Significant Problem

Substantial research demonstrates that many patients with limited life expectancy experience severe pain. Several sources document between 40 and 80 percent of conscious patients had moderate to severe pain during the last three days of life. An estimated 70 to 90 percent of cancer patients experience significant pain at some point, and 42 percent never receive adequate pain control.

Barriers to effective pain control have been identified at the level of the health care system, the physician, and the patient. Health care systems may discourage effective pain control by over-regulating analgesic use, focusing on curing disease rather than managing pain and symptoms, and giving low priority to palliative care. Physicians often lack relevant training and experience or are fearful of prescribing narcotics. Finally, patients may be reluctant to discuss pain and symptoms due to misconceptions about addiction and exaggerated risks of adverse effects or may be unable to communicate, especially if demented. Caregivers are also often reluctant to heavily medicate their loved ones.

Fortunately, California has seen some significant progress in addressing some of these barriers. Legislative efforts have focused on reducing barriers to writing and filling pain prescriptions, mandating the inclusion of palliative care curriculum in medical training programs, and requiring pain as the fifth vital sign taken in hospitals and SNFs. For example, AB 2018, effective January 1, 2001, reduces some of the administrative obstacles that physicians and patients face using triplicate prescriptions for potent pain killing medications and removes the cap on the number of triplicates that can be issued to a particular physician.

Effective January 1, 2001, AB 791 adds pain management and end-of-life care to medical school curriculum requirements for any person entering medical school on or after June 1, 2000, as a condition of California physician licensure. This legislation also requires health facilities to include pain as a fifth vital sign as a condition of State of California licensure.

Effective July 1, 2002, AB 487 requires physicians to take continuing education course in pain management and treatment of terminally ill and dying patients. This will be a one-time requirement of twelve credit hours that must be completed within the next four years. This bill also requires the State Medical Board to investigate and report complaints regarding pain treatment. The passage of these pieces of legislation should result in significant improvements in pain management throughout the health care system. Implementation, however, will take several years, as will an assessment of results.

Professional Education Lacking

Although the problem of poor-quality end-of-life care is multifaceted, insufficient training of medical professionals plays a significant role. Professional education about end-of-life care and training in clinical communication is minimal during any level of training. As a result, clinicians receive little training in pain and symptom management and have little experience with advance directives.

When surveyed by the American Medical Association in 1997–98, only four of the 126 U.S. medical schools required a separate course in the care of the dying. In 1995, only 26 percent of residency programs in the United States offered a course on care at the end-of-life. Only eight
percent included a required hospice rotation and only nine percent offered an elective hospice rotation. In general, there are relatively few role models to help students handle end-of-life care, and patient contact is extremely limited. Teaching about palliative care is generally incorporated into scattered courses in various areas, training is mostly elective, and teaching focuses primarily on knowledge rather than attitudes and skills.140

Compounding this problem is the lack of information about good palliative care in mainstream textbooks. Recent research identified major deficiencies in 50 best-selling medical textbooks, including six of the top oncology and hematology texts. In addition, it was rare to find even one chapter that dealt with death and dying in these books.141 The typical textbook discussed prognostication and possible medical treatments to alter the course of a disease. There was very little content about advance care planning, decision-making, the effect of death and dying on the family, or symptom management. Textbooks rarely even characterized the dying process for specific diseases.142 In sum, textbooks focused on how to save patients and fix abnormalities without addressing how to serve patients with limited life expectancy.

There is also a dire need for education about legal and ethical issues around end-of-life care. Recent legislation and court decisions give patients the legal right to decide whether to receive medical treatment, even when refusal of treatment could lead to death. Translating this legal right into actual practice is a complicated undertaking. The Milbank Memorial Fund issued a report that cites physician concerns about the legal implications of decisions and lack of knowledge about institutional policies around decision-making. The report advocates for hospital counsel to educate physicians and provide assistance during end-of-life decision-making.143

Patients’ Wishes and Advance Care Planning Have Limited Role

A major barrier to the provision of quality end-of-life care is the paucity of decision-making discussions between providers and patients. A fundamental part of caring for patients with limited life expectancy is communicating about illness and death, and then documenting patients’ preferences for care. Patients often lack sufficient knowledge of health states, interventions, and prognoses to make informed treatment choices.144,145,146 Advance directives have been advocated as a means for eliciting patients’ wishes and following them when a patient is incapacitated. Unfortunately, research has found that advance directives are not used effectively in clinical practice and have a limited role in end-of-life decision-making.147,148,149,150 Common pitfalls are the failure to even begin advance care planning, the proxy not being present for discussions, documentation of ambiguous and unclear patient preferences, a narrow focus of discussions about prognoses and options, rare documentation about discussions, negligence in reading advance directive documents, and beliefs that the document’s directives are not yet applicable.151,152,153,154 Experts recommend that experienced providers discuss options with patients in an open, direct, and candid manner. Providers need to hold more comprehensive and informative discussions in order for patients to make meaningful decisions.155,156

Effective July 1, 2000, AB 891, the new Health Care Decision Law, allows a person to appoint a durable power of attorney for health care, delineates the roles of surrogate decision-makers, and specifies that a copy of the advance directive must be kept in the medical record. The law also states that a provider must comply with a patient’s advance directive and document all information pertaining to its existence or revocation. The provider must also document the degree of a patient’s decision-making capacity, any oral directives, and any appointment of a surrogate.157,158 Compared to the Patient Self-Determination Act of 1990, this law adds important
requirements for documentation of preferences and discussions. Previous law merely required that health care facilities provide written information about patients’ rights regarding health care decision-making and relevant facility-specific policies.

**Nursing Home Reimbursement, Staffing Lead to Overuse of Hospitals**

There are several barriers to providing quality care in a nursing home. The current Medicare per diem reimbursement method for SNFs is based on resource utilization groups (RUGs), or number of services provided to patients. These data are captured using the Minimum Data Set (MDS), a national assessment tool that has recently evolved into a reimbursement tool for Medicare. Unfortunately, the RUGs that are captured do not adequately reflect complex medical needs or ancillary services, such as drugs, infusion therapy, respiratory therapy, lab tests, imaging services, and transportation. Moreover, the RUGs do not adequately reimburse the level of skilled care that is required for a resident in the end-stage of life. Therefore, some SNFs are not willing to admit patients with certain high-cost needs, such as patients with end-stage renal disease or who require a ventilator.

Often there is an over reliance on hospitals. Some residents will be transferred back and forth to receive certain high-cost treatments for which Medicare will reimburse the hospital only. Moreover, patients with complex and extremely high-cost needs (e.g., total parenteral nutrition) who are near death are often discharged to hospitals. Two independent studies estimated that about 200,000 nursing home residents experience avoidable hospital stays at a cost of $1 billion each year. Many of these admissions would not occur if physician and other costly services were more available in the nursing home, if SNF staff were better prepared to take care of dying patients in acute situations, and if end-of-life discussions were held in advance of the acute event.

In addition to the problem of low reimbursement rates, most nursing home staff are less technically sophisticated than those in a hospital or office setting. Workforce issues, such as a shrinking number of workers willing to do this work and high turnover (70 to 100 percent annually), make it difficult to improve the quality of care in nursing homes. Nursing staff, such as nurses’ aides and orderlies, provide the majority (80 to 90 percent) of direct care in a nursing home. While the demand for nursing homes is growing, staff are faced with poor wages, stress, burnout, little training, poor working conditions (due to understaffing and the third-highest injury rate of all occupations in the country), little autonomy, and lack of benefits.

Inadequate use of pain medications also compromises care in SNFs. One in seven nursing home residents experiences persistent pain. Few facilities have a pharmacy available twenty-four hours a day, and most have a limited variety of analgesics on hand. Most institutions have restrictive policies about administering pain medications as needed due to fear of unfavorable regulatory review or addiction. Similarly, some SNFs discourage palliative care because administrators fear that regulators may cite facilities for not instituting restorative measures.

**Hospices Are Promising, Yet Barriers to Entry Limit Full Use**

Hospice is the most dramatic and useful innovation in end-of-life care. More than half of cancer patients who die while covered by Medicare use hospice. They are treated to unusually coordinated and comprehensive care. Although the quality of care provided by hospices is not well documented, surveys among patients and caregivers indicate extraordinarily high
There are, however, barriers in access to hospice care. Medicare regulations state that a beneficiary is eligible for the hospice benefit only if the patient’s doctor and the hospice medical director both certify that the patient is terminally ill. Until very recently, criteria specified a medical prognosis of life expectancy of six months or less, but this time limit was eliminated in 2000. Nevertheless, the majority of patients with limited life expectancy is not eligible for hospice because their prognosis is too uncertain until the last few days of life, when death is obviously inevitable. In many cases, physicians are too conservative or optimistic with prognostication. Therefore, fewer than twenty percent of terminally ill patients receive hospice care.

As with palliative care in any other setting, hospice is often introduced too late to be effective. While the ideal length of stay depends on the condition and needs of the patient, most dying persons need at least a few months to come to terms with death, and achieve closure in the many different parts of their lives. Plus, patients benefit from well-managed pain and symptom control while under hospice care. Unfortunately, the median LOS in hospice is only 25 days, and 33 percent of these patients die within 7 days of admission. Aside from the loss of potential benefits mentioned previously, shorter lengths of stay compromise the financial viability of hospice programs. Per-day expenses are typically higher for the first and last few days of hospice stays; thus, shorter lengths of stay mean that hospices have a greater proportion of higher-cost days that all receive the same per diem reimbursement.

In addition to the uncertainties surrounding prognosis, other barriers in the referral process to hospice result in an unnecessarily small number of terminally ill patients receiving hospice care. First, patients may resist referral due to fear of managing death at home, reluctance to stop curative therapy, or fear of being abandoned by the medical establishment. With the advent of managed care, there are often concerns that cost issues rather than the patient’s best interests may determine medical decisions. These feelings are especially prevalent among racial and ethnic minorities. Second, research shows that only one in ten Americans knows that Medicare pays for hospice care. Third, physicians often avoid discussing the imminence of death (see above). Fourth, physicians often lack knowledge about hospice eligibility and protocols for referrals, especially when it comes to patients with non-cancer diagnoses.

Fifth, hospices may avoid or physicians may be reluctant to refer patients with certain financial and logistic problems. Since hospice per diem rates average about $100, it is difficult for hospices to provide expensive medications, procedures such as palliative radiation or chemotherapy, certain types of durable medical equipment, and blood transfusions. When the hospice reimbursement model was created in 1983, prescription drugs accounted for about two percent of daily hospice expenses, but that factor has increased to thirteen percent today. Moreover, room and board for hospice patients are not covered, and the current reimbursement rate is insufficient to provide high levels of nursing care for homebound patients.

**Medicare Reimbursement Overall Presents Significant Barrier**

Reimbursement issues cause some of the greatest barriers to providing quality end-of-life care. Outside of hospice reimbursement, there is no explicit financing framework to pay for palliative care. Medicare covers only short-term, skilled nursing facility care and limited home health care related to post-acute care. While Medicare pays reasonably well for diagnostic tests, procedures,
and hospitalizations, it usually does not pay for patient/family education for self-care, medications, caregiver support, or care coordination.\textsuperscript{186}

The current system does not provide payment for the management and coordination of care for patients with complex needs. For example, a 1997 IOM report suggests that physicians may be encouraged to limit time spent with terminally ill patients because the current payment system does not recognize the resources, such as longer evaluation and management time, needed to provide high-quality palliative care.\textsuperscript{187} Moreover, patients who are terribly sick may not be eligible for Medicare home care if they are not homebound or do not need skilled-care services.\textsuperscript{188} Therefore, patients are often lost in a huge gap between acute care and hospice in the current system.

Hospitals lose money on palliative care services because there is little or no reimbursement. The Medicare payment policy may encourage hospitals to discharge older, dying patients to less costly hospital units or to nursing homes, hospice, or other types of less costly care.\textsuperscript{189} Since nursing homes and hospices lack adequate reimbursement for certain high-cost procedures, patients near death are often shuttled back and forth between settings. Ironically, when doctors resort to aggressive, futile treatments in a hospital, these life-prolonging attempts are reimbursed better than palliative care although such care is significantly more costly.\textsuperscript{190,191}
VI. Current Efforts to Close the Gaps

There are some significant efforts to improve the quality of the end-of-life care system in California. The most comprehensive efforts involving multiple stakeholders or multiple demonstration sites are discussed first, followed by examples of promising initiatives by single health care organizations, such as health plans and provider organizations. Although end-of-life care is a young field, these initiatives demonstrate that organized efforts can greatly improve the access to and quality of palliative care in many settings. Moreover, several projects demonstrate potential savings in conjunction with improved quality of care.

The California Coalition for Compassionate Care

The California Coalition for Compassionate Care (henceforth called the Coalition) was formed by Sacramento Healthcare Decisions and more than 30 health care and community organizations in early 1998. The Coalition is housed within the California Healthcare Association (CHA), which provides in-kind support for the Coalition’s twenty-percent-time Executive Director. Sponsored by a $450,000 RWJF grant, the Coalition is dedicated to the advancement of palliative medicine and end-of-life care in California. The Coalition sponsors five main initiatives: nursing facility training, California Hospital Initiative in Palliative Services (CHIPS), professional education, public policy, and public engagement. Each of the programs is described below. The breadth of the Coalition’s membership is considerable, reaching public and private organizations, government agencies, statewide associations, and health care institutions.

Nursing Facility Training

The Coalition sponsors intensive two-day training programs for SNF administrative and professional staff in leadership positions. The curriculum includes the following topics: communication skills for facilitating advance care planning, legal and ethical considerations, managing pain and other symptoms, and hydration and nutrition. The programs also help participants develop an action plan to implement these new and improved practices. One year later, the participants meet for a reunion conference to discuss overall success; some data are collected via survey by each facility. During the past two years, the program has trained 259 staff from 96 nursing facilities across California. The Coalition also produced the ECHO (Extreme Care, Humane Options) Nursing Facility Recommendations (see Section V above), which were
field-tested in 1999, and then used extensively in the year 2000 training program. The ECHO manual can also be used by SNFs to evaluate their policies and learn how to begin institutional reform.

California Hospital Initiative in Palliative Services (CHIPS)

The CHIPS program is funded by the Center to Advance Palliative Care (CAPC) at Mount Sinai School of Medicine in New York and sponsored by the Coalition. During the past two years, the CHIPS program has involved representatives of 40 hospitals to facilitate the development or expansion of palliative care services. Participating hospitals send a multidisciplinary team to learn the basics of palliative care program development. To ensure high-level organizational support, the signature of the hospital’s CEO is required. Many different types of hospitals have participated, including urban, rural, non-profit, academic, government-owned, and veteran’s administration facilities from areas all over the state.

Whereas the Coalition’s SNF training programs focus on clinical issues, the CHIPS program emphasizes needs assessment, business planning, and reimbursement issues. After the initial training, designated mentors provide ongoing support via site visits, conference calls, materials, and technical assistance. As with the SNF training program, participants meet for a reunion conference after one year to discuss challenges and assess development. The first reunion conference was held in May 2002. At this point, the CHIPS program lacks a strong evaluation component, but the structure of the program allows for the collection of data before and after implementation of new palliative services. The intent of the participants’ action plans ranges widely, from adding assigned beds or dedicated units to creating outpatient clinics and floating consultation teams. The CHIPS leadership hopes to use feedback gathered during the reunion to better understand what institutional changes work well in palliative care.

Professional Education

The Coalition’s philosophy regarding professional education is to focus on identifying and establishing innovative training programs in California with the hope that, once the process is established, another organization will take over the program. Thus far, the Coalition has sponsored training courses based on the national Education for Physicians in End-of-Life Care (EPEC) model. The EPEC curriculum is designed to educate physicians to appropriately care for patients with limited life expectancy and includes fundamental skills in communication, ethical decision-making, whole patient assessment, multidimensional aspects of suffering, palliative care, and pain and symptom management. EPEC is designed to be a two-and-a-half-day train-the-trainer program that gives participants the necessary materials to teach the curriculum in their own setting. The Coalition has held two EPEC training courses to date, one in Sacramento with 58 participants, and one in San Diego with 125 participants. In 2002, the Coalition plans to hold two more EPEC courses in the Sonoma and Yosemite areas. The Coalition Web site also advertises other opportunities for EPEC training.

Along with Kaiser Permanente Northern California, the Coalition is co-sponsoring a course to integrate end-of-life care into internal medicine residency programs. Designed to complement the EPEC curriculum, the course trained a cohort of thirty residency programs.

The Coalition also sponsors a local program for End-of-Life Nursing Education Consortium (ELNEC) training, which is a comprehensive, national education program to improve palliative care by nurses. The national program is designed to meet the needs of several types of nursing
educators: baccalaureate and associate-degree program faculty, continuing education faculty, and representatives of state boards of nursing. The content includes pain and symptom management, ethical and legal issues, cultural considerations, communication skills, and preparation and care for the time of death.201 To date, approximately 40 nursing school educators have completed the training, and the next group will be composed of continuing education teachers.202

Public Policy
The goal of the Coalition is to provide a resource that identifies and describes recent and pending legislation in the areas of end-of-life and palliative care. The Web site also describes how to write a letter of support to government representatives.203

Public Engagement
One of the major initiatives of the Coalition is to bring advance care planning activities into communities throughout the state. The Coalition developed a Community Education Kit for use by both laypersons and professionals. The Coalition has also conducted 11 training programs for a total of 320 participants across the state to help interested speakers and meeting facilitators discuss end-of-life issues. The Coalition is also working to reach ethnic and cultural communities through linguistically and culturally appropriate educational materials, outreach plans for targeted populations, and support of outside organizations with similar goals. To date, the Coalition has specifically targeted the Hispanic/Latino community throughout the state, and the Filipino and Chinese communities in the San Francisco Bay Area.204

Promoting Excellence in End-of-Life Care Projects
The Promoting Excellence in End-of-Life Care national program is a $15 million RWJF-sponsored grant that supports 22 demonstration sites across the country, four of which are in California. The Promoting Excellence grant began in 1999. All projects completed their funding cycles by the spring of 2002. The overarching mission of the grant is to test models of palliative care that apply the best of hospice care practices to settings and patients that are not typically served well by hospices. Hospice programs lead some projects, and others work collaboratively to create broader continuums of end-of-life care. In order to ensure that projects have the greatest potential to create institutional quality improvements, projects were chosen based on the following criteria: demonstrated commitment of clinical and administrative staff; evidence of the applicant’s ability to provide the full range of clinical and supportive care needed by dying patients and their families; degree of innovation; strength of the business plan and administrative structure; and the extent to which the proposal could be used to leverage broader change in the health care system.205 Each of the four California sites is described in Appendix B.

Emerging Trends from the Promoting Excellence Project and Next Steps
Although the final data from the Promoting Excellence demonstration sites are not yet available, certain trends have emerged in terms of best practices. Researchers emphasize the importance of care coordination within the delivery system. Case management is a powerful intervention because the dying process occurs in multiple settings, each of which is often new to the patient and family. Preliminary research shows that attentive care management will result in patient and family satisfaction as well as cost containment. Another finding was the direct correlation between the degree of financial risk and the success of the palliative care programs among organizations. Because capitated organizations can realize potential savings from palliative care within some part of the system, they are more willing to embrace it. Next, system changes are
important to facilitate the practice of quality palliative care. Lastly, the role of a high-level champion is critical to organizational buy-in and programmatic success.

The Promoting Excellence project is now focusing on how to export the lessons learned at the demonstration sites to a national level. Discussions are currently underway with the National Cancer Policy Board and the Department of Health and Human Services’ Health Research and Services Administration. Now that grantees have built new models, the National Program Office (NPO) plans to test them through regional, federal demonstration projects. The NPO is planning a national finance meeting in the fall to look at how to elevate the work of the Promoting Excellence project and embed what they have learned into how palliative care is delivered nationwide. Last summer, the NPO convened national conferences for comprehensive cancer centers and Veterans Health Administration medical centers. Furthermore, the National Program Office has arranged for the publication of a special edition in the *Journal of Palliative Medicine* that will feature articles from each demonstration site. The NPO will also work with each grantee to facilitate individual publications and will publish its own synopsis article.

**Health Plan and Provider Group Initiatives in California**

Most health plans and medical groups have not implemented specific care management programs for end-of-life care. With a few exceptions, the programs that do exist appear to be limited largely to traditional case management. The success of these programs often suffers from a lack of adequate triggers to identify dying patients. There are, however, considerable opportunities for developing coordinated care management across delivery sites, interdisciplinary teams within an organization, innovative care programs, and accountability for care standards in managed care organizations. Managed care plans, with their emphasis on prevention, clinical guidelines, patient education, cost efficiency, service coordination, and integrated provider networks, are positioned well to provide high quality, cost-effective palliative care. (See Appendix B for descriptions of Kaiser Permanente, PacifiCare, HealthCare Partners Medical Group, Sutter Health System, Catholic Healthcare West, and other plan and provider organization initiatives in California.)
VII. Opportunities and Recommendations

The field of end-of-life care is relatively young, and barriers to quality care are numerous and pervasive. Thus, there are many opportunities to improve palliative care for patients with limited life expectancy. As discussed above, while hospice incorporates all of the elements of palliative care and has been a highly effective means of delivering excellent care at the end-of-life, significant barriers for getting patients into this setting remain. Moreover, not all patients wish to relinquish curative treatments and receive care through hospice. And, while the majority of patients die in hospitals, this population constitutes a relatively small percentage of total inpatient volume, meaning insufficient attention is devoted to end-of-life care issues.

Below are seven recommendations for how CHCF and others can invest in end-of-life care quality improvement in California, taking into consideration current efforts underway and recent legislation. The first recommendation is broad, suggesting that CHCF help to institutionalize a model for coordinated care with particular focus on hospitals and skilled nursing facilities and their affiliated professionals. This can be accomplished by building upon several initiatives housed under the Coalition for Compassionate Care that bring together stakeholders in these settings. The remaining recommendations focus on discrete areas that experts on end-of-life care consistently raised, including making more widespread advance planning for end-of-life care and death, implementing portable physician’s orders that reflect patient care plans, improving pain management, obtaining consensus on quality metrics for end-of-life care, advancing research on the relative cost of hospice and palliative care, and revamping reimbursement to support palliative care.

**Recommendation #1: Work with the Coalition on Compassionate Care to implement the elements of a coordinated care model to improve quality at the end of life.**

Fortunately, given the significant investments of RWJF in end-of-life care, as well as other noteworthy stakeholder efforts, California offers fertile ground upon which to use a coordinated care model to effect lasting change. Moreover, since the RWJF future direction in end-of-life care focuses on technical assistance rather than funding for specific programs, the timing is ripe to support specific comprehensive QI programs within the state.
The collaborative efforts of the Coalition for Compassionate Care offer promising opportunities to create more coordinated care delivery. Specifically, the CHIPS and SNF initiatives could be enhanced and more closely integrated with professionals who are trained under the Coalition’s EPEC program.

An example approach for this recommendation would be for CHCF (and/or other interested stakeholders) and the Coalition to issue an RFP and award grants to hospitals or SNFs that meet generally accepted criteria for a model of coordinated care, such as the following:

- The specification of systematic changes, such as distributing care paths (like those in Kaiser’s Elder Care Sourcebook), supportive care pathways (like those of the Alliance for Catholic Health Care), easily accessible DNR forms, or pre-printed physician orders for medications and discontinuing medications;
- Distribution of guidelines, such as for managing pain, other symptoms, and hospice triage;
- Discussion of necessary and relevant policies such as DNR orders and advance care planning, or documentation of an action plan to develop such policies;
- A list of physicians who would attend EPEC training and an action plan for follow-up training for a reasonable number of physicians in the hospital, or other staff in the SNF;
- Discussion of identification of patient population and timing of interventions;
- Discussion of how the proposed program would facilitate patient self-management;
- Discussion of psychosocial services, such as helping patients and families deal with emotions surrounding disease and death, support and planning for future caregiving needs, referrals to support groups, and other resources;
- Description of the model of care delivery and the team that will deliver the care, such as an inpatient palliative care consultation service, a dedicated inpatient palliative care unit, a combined hospice/palliative care unit, an outpatient palliative care intervention, or a home-based palliative care program; this description should include:
  - Discussion of how the proposed program would create incentives for physicians or other staff to spend time discussing values with patients and accommodate the associated time commitment;
  - Demonstration of the potential to develop interdisciplinary teams (including a physician, a nurse, and a social worker at a minimum; may also include a bereavement and pastoral care counselor, pharmacist, patient advocate, anesthesia pain expert, rehabilitation therapist, or a psychiatry consultant) on-site; consideration should be given to the following roles of team members:
    - Medical evaluation and decision-making
- Pain and symptom management
- Communication
- Ability to address difficult decisions about the goals of care
- Discussion of spiritual issues
- Sophisticated discharge planning
- Ability to access community resources, possibly including a list of support services that would be included in the program’s network
- Ability to deliver care continuity and access.

- Discussion of the availability of staff, beds, and clinic space, if applicable;
- Documentation about current information systems or plans to enhance systems for state-of-the-art care management protocols;
- Evidence of high-level organizational support.

Another important component of this effort would be a standardized evaluation of outcomes across participating hospitals or SNFs, which could be used for continuous quality improvement. It is important to assess whether palliative care services improve care for patients by looking at the following data:

- Patient and family satisfaction
- Quality of care, such as improved pain and symptom management
- Completion of advance directives and compliance with wishes
- Identification and documentation of health care proxy
- Frequency and timing of DNR orders
- Performance of psychosocial assessment
- Number of medical errors, pressure sores, falls
- Services received before death
- Length of stay, utilization patterns (ICU vs ER vs palliative care unit, readmissions), time spent using aggressive treatment before death, medical care during last 48 hours of life (chart review and survey)
- Actual and preferred site of death

Ideally, such assessments would take place within a compressed time frame in order to support continued change.
In addition to working with the Coalition on Compassionate Care, CHCF could partner with California provider organizations, notably Catholic HealthCare West and Health Care Partners, that are demonstrating successful approaches to improving quality in this area.

**Recommendation #2: Improve advance care planning through public and professional education.**

The first step toward increasing the utilization of hospice care, as well as improving quality care at the end of life overall, is to ensure that patients’ wishes are known and documented before the patients reach an advanced state of terminal illness. The importance of understanding patients’ desires came to the forefront last summer when the California Supreme Court ruled on the Wendland case.\(^{210,211}\) The Court’s decision to place new limits on circumstances under which life support may be withdrawn has caused advocates to realize that efforts to educate both patients and professionals on advance planning must be expanded. This is true despite the fact that the Health Care Decision Law requires documentation of and compliance with advance directives.

Other funders may be best suited to support grassroots community education campaigns on planning for chronic illness and death. Initiative ideas in line with CHCF’s interests are (1) to dovetail efforts with community campaigns by educating professionals in the geographies in which they are conducted. For example, if churches in the Oakland-Berkeley area conduct small group meetings to educate members about advance directives, CHCF could simultaneously fund professional education efforts at Highland, Summit, Alta Bates, and area nursing homes to facilitate a dialogue with their patients; (2) to target specific populations, such as persons with AIDS or breast cancer, within select delivery systems/organizations, to boost the completion of advance directives; (3) to expand the work of the Coalition to increase access to end-of-life care as well as completion of advance directives by minority populations, including specific programs for providers and communities that address cultural issues and outreach programs. Working with both professionals and the patients they serve in a specific geography, as opposed to a more scattershot approach, could help to improve the choice of setting and treatment options for end-of-life care.

**Recommendation #3: Establish statewide education initiative to improve documentation and compliance with patients’ wishes**

Implementation of a standardized form for physician documentation of patients’ wishes is a proven way to systematically facilitate compliance with patients’ wishes and promote comfort care. A group of long-term care physicians, along with the California Medical Association (CMA), the Nursing Home Association, and the Department of Health Services (DHS) created a task force to draft and implement the Preferred Intensity of Treatment (PIT) form for completion by long-term or acute care facility staff. The form is easily recognized, has a standardized format, and centralizes information pertinent to a patient’s care.

The PIT form translates patients’ wishes for care into medical orders. The form contains information about capacity determination, interventions (including resuscitation, antibiotics, and artificial feedings), and goals of care (curative or comfort measures). Once the patient completes the form, it is signed by a physician. When a patient if transferred from one health care facility to another, the form travels with the patient. The PIT enables a system for communicating patient wishes among various providers and across health care settings.\(^{212}\)
The PIT form is similar to the Physician’s Orders for Life-Sustaining Treatment (POLST) program in Oregon, which was launched as a voluntary, statewide protocol in 1995. At present most Oregon nursing homes and hospices are using POLST, along with several major managed care systems, including Kaiser Permanente. Research in Oregon supports the efficacy of the POLST form; one study found that POLST instructions for CPR, antibiotics, fluids, and feeding tubes were followed more closely than advance directive instructions, and another study demonstrated over 95 percent compliance with patients’ wishes for care during a serious medical event.

The adoption rate in California is significantly lower than Oregon due to a lack of awareness and education among physicians. Fortunately, the development, revision, and implementation of the PIT form has been a serious and explicit focus by leaders of a statewide consensus group, and there is considerable interest in establishing a statewide education initiative. The California task force has already developed a protocol for educating physicians about end-of-life decision making and the use of the PIT form. This protocol was piloted in the Oakland area with approximately three evening training sessions and two lunchtime sessions during grand rounds at local hospitals. This protocol could be employed for a statewide education initiative to improve decision-making discussion skills among physicians and bolster the use of the standardized PIT form.

Recommendation #4: Assist with pain management education.

As discussed above, a priority consistently mentioned by interviewed stakeholders is the need to improve pain management. Recent legislation provides the impetus for improvements, but knowledge of these laws is not widespread. For example, surprisingly, many experts were unaware of the California statute, AB 2018, effective January 2001, that eased the state requirements surrounding the triplicate forms that were necessary to prescribe narcotics.

Given these legislative changes, there is a role for CHCF or others to conduct a communications campaign to heighten awareness about new policy changes and effective strategies for monitoring pain. Incorporating recent laws, court cases, and other information into the EPEC and SNF training sessions and other courses that will meet newly mandated professional education requirements would also help to improve quality of pain management care.

Another way to improve pain management within hospitals and facilities would be to disseminate and promote the use of guidelines, such as those developed by WHO and the Agency for Healthcare Research and Quality.

Another idea is to educate patients and their families to evaluate and advocate for pain and symptom treatment. Possible educational venues include seminars on chronic disease/pain self-management, support groups, and articles in newsletters.

Recommendation #5: Obtain consensus on end-of-life care metrics.

Despite the fact that experts and practitioners generally agree on categories for quality of care for end-of-life patients, there is no standard set of metrics in use in California or nationwide. Obtaining consensus on quality metrics would provide both a statewide and organization-specific gauge for improvement. In addition, common metrics could be used to shift reimbursement from rewarding acute services to including those related to palliative care.
Recommendation #6: Advance research on the relative costs of hospice and palliative care services.

As described above, findings from research on the total costs of Medicare hospice benefits versus traditional care are mixed and often limited (e.g., focused only on patients with cancer). Innovators of programs to improve quality in this area claim overall savings; however, there are few published studies to substantiate them. Although the potential to save money should not be the sole driver of the movement toward hospice and palliative care (and in fact could arouse patient suspicion), in an era of fiscal constraint such studies could serve as a contributing factor to managers who are considering improving care in this area.

Recommendation #7: Import innovative demonstrations related to reimbursement for end-of-life care into California.

Two of the Promoting Excellence projects (see Appendix B for description of projects) outside of California represent collaborations between state agencies, insurers, and local hospitals and hospice agencies. Both of these projects offer models of increased access to palliative care through partnerships with public sector agencies. Due to the collaborative nature of these projects, there have been changes to the state Medicaid reimbursement strategies to better support reimbursement of case management for patients with limited life expectancy. CHCF could partner with state agencies and local insurers to import these models to California. Specifically, CHCF could conduct a study to evaluate the current payment structure for end-of-life care and make recommendations for improvements in the reimbursement of palliative care, pain and symptom management, case management, consultations, assessments, skilled care, and the operations of multidisciplinary teams. The involvement of the state health and Medi-Cal agencies will serve to validate the need for improvement and better ensure that their reimbursement strategies are revised.
VIII. Conclusion

As the size of the elderly population grows and the majority of dying patients suffers from chronic illnesses, the quality of end-of-life care has become increasingly important. Patients requiring end-of-life care typically have multiple significant medical problems, and spend the last part of life in several settings as their needs change. The U.S. health care system suffers from many shortcomings that impede the provision of supportive, coordinated palliative care. There is optimism, however, that quality palliative care will positively impact the utilization of expensive resources, reducing unnecessary hospitalizations and the use of undesirable life-sustaining interventions. Most important, it will allow the majority of patients to die according to their wishes.
Appendix A: Recommendations, Guidelines, and Standards

Recommendations and Future Directions. (From Approaching Death: Improving Care at the End of Life [Institute of Medicine, 1997])

1. People with advanced, potentially fatal illnesses and those close to them should be able to expect and receive reliable, skillful, and supportive care.

2. Physicians, nurses, social workers, and other health professionals must commit themselves to improving care for dying patients and to using existing knowledge effectively to prevent and relieve pain and other symptoms.

3. Because many problems in care stem from system problems, policymakers, consumer groups, and purchasers of health care should work with health care practitioners, organizations, and researchers to:
   a. Strengthen methods for measuring the quality of life and other outcomes of care for dying patients and those close to them;
   b. Develop better tools and strategies for improving the quality of care and holding health care organizations accountable for care at the end of life;
   c. Revise mechanisms for financing care so that they encourage rather than impede good end-of-life care and sustain rather than frustrate coordinated systems of excellent care; and
   d. Reform drug prescription laws, burdensome regulations, and state medical board policies and practices that impede effective use of opioids to relieve pain and suffering.

4. Educators and other health professionals should initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have relevant attitudes, knowledge, and skills to care well for dying patients.

5. Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and research.

6. The nation’s research establishment should define and implement priorities for strengthening the knowledge base for end-of-life care.

7. A continuing public discussion is essential to develop a better understanding of the modern experience of dying, the options available to patients and families, and the obligations of communities to those approaching death.}\textsuperscript{218}
Core principles for end-of-life care issued by the Milbank Memorial Fund.

The core principles state that clinical policy of care at the end of life and the professional practice it guides should:

1. Respect the dignity of both the patient and caregivers;
2. Be sensitive to and respectful of the patient’s and family’s wishes;
3. Use the most appropriate measures that are consistent with patient choices;
4. Encompass alleviation of pain and other physical symptoms;
5. Assess and manage psychological, social, and spiritual/religious problems;
6. Offer continuity (the patient should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers);
7. Provide access to any therapy which may realistically be expected to improve the patient's quality of life, including alternative or nontraditional treatments;
8. Provide access to palliative care and hospice care;
9. Respect the right to refuse treatment;
10. Respect the physician's professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preferences;
11. Promote clinical and evidence-based research on providing care at the end of life.219

RAND Center to Improve Care of the Dying

Promises for Patients: A Vision of a Better System

1. Good medical treatment
2. Never overwhelmed by symptoms
3. Continuity and comprehensiveness
4. Planning ahead, no surprises
5. Customized care, reflecting your preferences
6. Family is part of care
7. Make the best of every day220
Nursing Home Standards from the Department of Health and Human Services

The new criteria will include seven measures of chronic care quality: use of physical restraints, prevalence of pressure sores, weight loss, infections, pain management, declines in daily activity, and use of anti-psychotic drugs without a psychiatric diagnosis. The remaining four criteria will measure post-acute care quality: managing delirium, managing pain, improvement in walking, and re-hospitalizations. These quality measures will be tested in the states of Colorado, Ohio, Rhode Island, and Washington; nationwide data should be available by October 2002.\textsuperscript{221}

Foundation for Accountability (FACCT)

Proposed standards for holding managed care organizations accountable for quality of medical care at the end of life. For the assessment of the patient, the following measures are proposed:

- Steps to Good Care – Advance Care Planning (advance directives, preferences, caregiver assessment),
- Results of Care – Pain and Symptom Management (pain management, physical and emotional functional status, symptom control), and
- Experience of Care – Provider Communication and Health Care Setting (patient involvement in treatment, spiritual and emotional support, and continuity).

For assessment of surrogates, the following measures are proposed:

- Experience of Care – Advance Care Planning (advance directives, wishes and preferences),
- Experience of Care – Pain and Symptom Management (pain distress, symptom control), and
- Experience of Care – Provider Communication and Health Care Setting (family involvement in care and treatment, family spiritual and emotional support, coordination/continuity, and caregiver experience).\textsuperscript{222}

Promoting Excellence in End-of-Life Care Toolkit Categories

Advance Care Planning—Patient Preferences
Instruments for eliciting and documenting patient preferences regarding treatment

Care Management and Coordination
Tools for assuring and evaluating continuity of care

Chart Review
Tools for auditing charts for palliative care information

Cost Utilization
Tools for determining costs of care and or service utilization
Education
Instruments for assessing knowledge, attitudes, skills and behaviors before and after an educational intervention

Focus Group/Interview Tools
Includes introductory statements, consent forms, discussion questions, and interview items used for focus groups or individual interviews about end-of-life care

Grief and Bereavement Care
Tools that measure grief reactions; used to assess bereavement needs and outcomes

Needs Assessment/Community and Education
Includes instruments for assessing educational needs among professionals and perceived community resources and needs regarding end-of-life care

Organizational Assessment
Instruments for organizational needs assessment and self-evaluation

Pain Management
Instruments to assess pain

Patient Identification
Tools used to identify or screen patients for an end-of-life care program

Patient/Surrogate Interviews & Questionnaires
Interviews or questionnaires used to assess patients and/or to measure perception of care. This group includes instruments that cover multiple topics and therefore could not be assigned exclusively to another group. Questionnaires that cover only one topic are found under that topic area.

Psychosocial Care
Tools for assessing social and psychological status and needs

Psychospiritual Care
Instruments that assess needs and outcomes of spiritual care

Quality of Life
Tools designed to measure quality of life for patients with advanced disease

Satisfaction/Perception of Care—Family
Instruments that assess the experience of the patient and/or family with respect to end-of-life care

Satisfaction/Perception of Care—Patient
Instruments that assess the experience of the patient with respect to end-of-life care

Symptom Management
Tools for assessing and tracking the level of symptoms (some are patient reported)
Appendix B: Stakeholder Projects

Promoting Excellence in End-of-Life Care Projects

The West Coast Center for Palliative Education at the University of California, Davis School of Medicine

The UC Davis Simultaneous Care Program introduces palliative care to patients who are usually ineligible for hospice services because they are receiving potentially life-prolonging treatment. Specifically, patients involved in investigatory therapy are not usually eligible for hospice until completion of clinical trials, but this program allows patients to receive palliative care during the therapy. One of the major barriers in quality end-of-life care is that patients do not receive palliative services soon enough to truly benefit; experts are working to promote a continuum of services that overlaps with curative treatments. In response to this need, the UC Davis project is breaking ground by offering palliative care services while patients are undergoing investigative treatments.

Preliminary data show improvements in the quality of life and quality of care for participating patients. More specifically, the intervention appears to improve the coordination of care and respect patients’ wishes. There has also been a greater adherence to chemotherapy protocols, a higher percentage of referrals to hospice, and improved lengths of stays in hospice. In terms of cost, preliminary data indicate that offering simultaneous care will either be cost-neutral or allow for substantial savings. Case management by a nurse or social worker is the program’s primary source of expenditures, but these costs are offset by the savings from managing the patient at home or in a hospice instead of a hospital. This research supports a widespread belief that investing in patients earlier in their illness will ultimately save money for the health care system. Further research will determine whether the model is exportable, i.e., whether it can be validated in a broader setting.

The principal investigators are currently seeking support for a multi-institutional cancer trial. Part of the multi-institutional trial is designed to support caregivers. Research shows that approximately 50 percent of caregivers suffer from a medical condition or crisis during the year following a loved one’s death. The COPE (Creativity, Optimism, Planning, and Expert Information) model provides on-call services to help family members hold informed discussions and make educated decisions. This information resource is intended to facilitate care coordination by providing pain, symptom, treatment, and logistical information to the patient and family, thus facilitating conversations with physicians.

University of California, San Francisco and the Hospice of the Bay

The Comprehensive Care Team (CCT) project is an outpatient program for patients with serious illnesses such as cancer, CHF, and chronic obstructive pulmonary disease. Similar to other models that emphasize a continuum of care, the CCT program offers palliation of symptoms and reasonable curative treatments simultaneously. Comfort care is not viewed as an all-or-nothing choice because patients with chronic illness need many levels of support even when death does not appear to be imminent. This study expanded its criteria for introduction of palliative care services to patients who were expected to die within two to five years. (An interesting side note is that approximately 20 percent of these patients died within the first year, further supporting the notion that prognoses regarding the timing of death are uncertain and doctors are often
optimistic.) These patients receive intensive case management and access to the services of CCT, which include a social worker, chaplain, pharmacist, psychological assessment, caregiver training courses, caregiver emotional support, and various support groups. The program draws heavily on local volunteers, faith communities, and social agencies. Identifying the services for patients and facilitating their application were significant benefits that did not require additional sources of funding.228

The CCT model emphasized the psychosocial, non-clinical components of end-of-life care, and preliminary survey data show improved patient satisfaction, anxiety levels, and spiritual well-being. Despite the introduction of palliative care services much earlier in the course of illness than usual, 70 percent of patients would have access to the CCT even earlier. Other data demonstrate effective and timely pain and symptom control, as well as earlier completion of advance directives.229 Health care utilization and cost data will also be analyzed. However, researchers doubt that the project will be sustainable due to the deteriorating operating environment of the hospital. Recently, the general medical practice cut its social work staff in half and totally eliminated its pharmaceutical staff. Therefore, it will be difficult to persuade the hospital to invest in a project within a practice that is not financially viable.230

U.S. Department of Veterans Affairs, West Los Angeles Medical Center
The “Critical Pathways for Poor-Prognosis Conditions: The Veteran’s Affairs (VA) Center for Patient-Focused Care” project integrates palliative care into its continuum of services for specific groups of veterans, such as those with lung cancer, advanced congestive heart failure, chronic pulmonary disease, and cirrhosis. The program entitles patients to meet with a case manager who coordinates services with a palliative care team. The team customizes a “critical pathway,” which becomes part of the patient’s electronic medical record and is available throughout the VA medical system. The program also emphasizes the importance of monthly palliative care seminars for doctors, nurses, and ancillary staff.231

The response of the national VA administration has been quite impressive. The West Los Angeles VA has continued to hire more case managers in order to expand this model to reach more patients. The VA system also sponsored a national conference to highlight various palliative care models, including the West LA Medical Center’s, which has served to promote and heighten interest in developing similar programs nationwide.232

Sutter Visiting Nurse Association and Hospice and North American Medical Management
The Comprehensive Home-Based Options for Informed Consent about End-Stage Services (CHOICES) program is premised on the principle that physicians can refer patients for palliative care without terminating curative or life-prolonging treatments. A nurse practitioner and a social worker coordinate care in each patient’s home. Central to the case management program is the discussion and documentation of comprehensive advance care planning, including individualized plans of care and preparation for potential crises. The CHOICES team is on call 24 hours a day to respond to, avert, or control problems that could otherwise result in emergency room visits and hospitalizations.233 Preliminary findings demonstrate cost savings as well as improved access and quality of palliative care services.234
Health Plan and Provider Group Initiatives in California

Kaiser Permanente

The Kaiser Permanente Care Management Institute (CMI) has promoted multiple projects to improve end-of-life care for its population. First, CMI produced comprehensive manuals for the provision of palliative care. These manuals describe best practices, instruct hospitals and facilities about how to implement institutional improvements, and provide supporting materials such as guidelines, care paths for commonly treated conditions in nursing facilities, educational resources, assessment tools, and clinical forms. As part of its palliative care initiative, Kaiser is allocating internal resources to support new proposals for the development of palliative care services. Kaiser also co-developed an end-of-life care module with the Bayer Institute to facilitate patient-physician conversations. After it was tested and refined, it was disseminated through Kaiser’s CME training program.235

Kaiser Permanente Bellflower Medical Center in Los Angeles pioneered a program in hospice and palliative care that works closely with their heart failure program. In 1996, patients with heart and lung failure accounted for 40 percent of deaths in the ICU and 29 percent of deaths in the medical-surgical unit at Kaiser Bellflower. Administrators found that outpatient care was not well orchestrated among multiple specialists, which contributed to acute exacerbations of illness, repeated inpatient admissions, and home health care requirements. The new program taught patients to manage their symptoms (shortness of breath, swelling) at home, and provided 24-hour access to a nurse care manager or physician. By learning how to manage their illness, patients took charge of their health, became more independent, and reduced or eliminated unnecessary emergency room visits and hospitalizations. Once again, this study has important implications for the importance of patient empowerment during chronic illness and the end of life.236

In addition, Kaiser Permanente Bellflower enhanced its hospice program to include a palliative care program for patients not yet eligible for hospice. The care team includes physicians, nurses, and social workers who assist patients and families with ongoing physical, psychosocial, and spiritual issues. Later, Kaiser Bellflower participated in an Institute for Healthcare Improvement (IHI) Breakthrough Series, which supported the implementation and evaluation of additional institutional changes for patients during the last week of life. The team invited physicians to a training session aimed at increasing hospice and palliative care referrals earlier in the illness. The team also implemented three changes in the delivery system to help physicians provide quality care: a checklist of conversation topics for the medical binder kept at patients’ homes, guidelines with the specifics of care and corresponding timelines, and an electronic medical record in order to prevent medical errors. The team achieved dramatic results, including earlier referral to hospice and decreased emergency room visits. Researchers at Kaiser Bellflower are currently seeking funding to support a randomized study.

Kaiser also launched a Tri-Central home-based palliative care program in 1998. Intended to promote timely referrals, hospice criteria were relaxed to allow patients to enroll who were still receiving potentially life-prolonging treatments and whose life expectancy was expected to be twelve months or less. This program uses an interdisciplinary team approach, a customized care plan, in-home supportive and medical care, advance care planning, and ongoing care management. Once again, Kaiser realized savings due to decreases in acute care services.

In conjunction with researchers in the state of New York, researchers in California Kaiser facilities are seeking funding for a multi-site randomized field trial of the Advanced Illness
Coordinated Care Program (AICCP). The AICCP includes a standardized format for six case management meetings. The overarching goal is to promote patient autonomy and control of the dying process by facilitating open and candid conversations with providers. Recent evaluations of the model found greater completion of advance directives, more documentation of end-of-life discussions, and inpatient cost savings for study subjects compared to controls. The AICCP has not been widely adopted throughout Kaiser Permanente, but Kaiser leaders hope to fund studies in a few sites to determine the generalizability of its efficacy.

**PacifiCare**

PacifiCare’s program for end-of-life care identifies members with a broad range of terminal illnesses. The program initially relied on claims for identification, but soon changed their strategy to use four referral sources in order to collect more real-time data. These referral sources include reports from hospital and telephonic concurrent review nurses, medical group utilization management departments, the PacifiCare case management program, and PacifiCare’s four disease management programs (coronary artery failure, end-stage renal disease, CHF, and chronic lung disease). Case managers (primarily social workers) contact the patient and family to conduct health risk and needs assessments and then coordinate referrals to health care resources. Case managers will also provide information and support in terms of reconciling spiritual and psychosocial issues, managing pain and other symptoms, and writing advance directives. Specific goals of the program are to discuss durable power of attorney, advance directives, and hospice referral. PacifiCare evaluates its programs by looking at the following measures:

- documentation of end-of-life discussions with PCP;
- discussion and documentation of durable power of attorney;
- percent and timeliness of hospice referrals;
- percent of deaths in each setting;
- average LOS in hospice/hospital;
- cost per death, across last 12 months of patient’s life;
- and cost of most recent hospitalization.

At this point, neither patient/family satisfaction nor pain management is assessed, but these will probably be added in the future. Preliminary data demonstrate reductions in deaths occurring in the acute hospital setting. Also, there has been a consistently impressive rate of advance directive completion that is greater than 50 percent for PacifiCare senior members.

**Blue Shield**

Blue Shield provides a care management program for hospice patients. The majority of case managers are registered nurses. Case managers work with patients to coordinate services across various settings and relevant agencies. In terms of efficacy, case management also ensures that a patient’s needs are met using in-network agencies and are in compliance with benefit design. Patients are identified when the physician or hospital contacts Blue Shield.
Physician and Other Organizations

*HealthCare Partners Medical Group* launched the Options Program for patients with terminal illness in 1993. The program offers a comprehensive range of medical and support services at no cost to patients. The Options Program can complement or be chosen in lieu of hospice; the critical difference is that patients can enroll in the Options Program to receive similar support and palliative care to patients without withdrawing curative treatment. The program identifies patients when they experience a hospitalization, an urgent care visit, or a visit by a home health nurse or social worker. Once the primary care provider refers the patient to the program, a social worker reviews the case, conducts a psychosocial assessment, and determines the needs for specific services. If necessary, the social worker will coordinate referrals for other assistance, such as home health nursing or physical therapy. Throughout the duration of each patient’s care, the Options committee will review cases every three weeks to revise care plans, ensure that the patient and caregivers fully understand the clinical situation and range of options, and confirm that the PCP has discussed advance directives. When a patient dies, a sympathy card is generated and the primary caregiver is later contacted to obtain feedback about the program.

Although created to improve the quality of patient care, the Options Program has realized significant savings due to reduced emergency room visits and crisis hospitalizations. Only 15 percent of patients in the program die in the hospital because most patients would prefer to die at home and choose less-intensive interventions when given the choice. Moreover, personnel costs have remained constant.

In order to facilitate better advance care planning, *Sutter Health System* has assembled a packet of information on advance directives for physicians to distribute in their offices. Sutter also convened a physician-led task force that evolved out of their participation in the development of the “Extreme Care, Humane Options (ECHO)” recommendations. The task force aspired to better understand public preferences with respect to end-of-life care. For example, one problem that Sutter is addressing is the lack of clarity among physicians regarding what constitutes appropriate comfort care. Another goal is to better coordinate the care between the multiple physicians involved in end-of-life care, particularly in the intensive care unit (ICU) or across care settings such as the ICU, the regular ward, the skilled nursing facility, and the home. Physicians in the Sutter IPA have also formalized their participation in community-based train-the-trainer sessions for end-of-life curriculum.

*On Lok* is a non-profit managed care plan that provides medical, long-term, and end-of-life care to elderly persons who are eligible for nursing home care. Begun in San Francisco, the program obtained waivers from Medicare and Medi-Cal in 1983 to provide a comprehensive range of health and long-term care services under risk-based, capitated reimbursement. Each enrollee’s care is planned and managed by an interdisciplinary team of physicians, nurses, social workers, therapists, dietitians, and transportation and home care workers. Assessments include rankings on a pain scale that can be customized for assessing pain in patients with dementia. There is a comprehensive effort to hold discussions regarding clients’ preference regarding end-of-life care, and more than 90 percent of enrollees have advance directives.

*Catholic Healthcare West* (part of the Alliance for Catholic Healthcare mentioned below) has four types of system-wide programs. Their programs include: education about management and governance; protocols for pain management and reports about best practices; analyses of patient migration across settings; and assessment of quality via patient surveys.
Other Projects in California
Consistent with its mission to improve end-of-life care, the Alliance of Catholic Healthcare, the primary advocacy arm for 65 Catholic hospitals in the state (15 percent of all California hospitals), has historically taken a leadership position in this field. The Alliance developed Supportive Care Pathways, which have been implemented in the Alliance’s Sacramento-based hospitals. These pathways identify benchmarks and suggest protocols for each stage of dying. Generally, the pathways provide guidelines about comfort care and palliative care services to physicians and staff. Instead of aggressive treatment, these pathways advocate for aggressive comfort care. In order to support physicians, the pathways include pre-printed physician orders for palliative medicines and discontinuing other medications. They also include training materials for all levels of support staff, such as nutrition technologists, nurses, and ancillary staff.249

Another project at UC Davis recently evaluated the effect of an individualized education and coaching intervention on pain outcomes and pain-related knowledge among outpatients with cancer. Participants received customized information about pain self-management, coaches addressed misconceptions about pain treatment, and patients rehearsed individually scripted patient-physician conversations about pain control. Two weeks later, average pain severity improved significantly in the experimental group, but this intervention had little impact on functional impairment as a result of pain or pain frequency. It is hypothesized that the intervention helped patients to effectively interact with their doctors and discuss mutually agreeable treatment plans. This study has important implications for operationalizing patient empowerment and helping doctors to discuss and follow patients’ wishes. Researchers are seeking support to validate these effects and elucidate their mechanisms.250

The City of Hope (COH) is one of 40 National Cancer Institute-designated comprehensive cancer centers in the U.S. COH sponsors research, treatment, and patient care for patients with cancer and other life-threatening diagnoses. COH created a clinical training curriculum about palliative/hospice medicine for nurses. The program, called HOPE (Home Care Outreach for Palliative Care Education), includes evaluation tools, general information, and modules on pain management, symptom control, communication with dying patients and families, and information about the death process.251

End-of-Life Articles in JAMA. In order to promote inclusion of end-of-life care content in leading medical journals, researchers at UCSF are coordinating and editing a new bimonthly series in JAMA devoted to case studies about patients near the end of life. The goal of each article is to present practical, clinically useful, authoritative recommendations to clinicians of various specialties who care for patients at the end of life.252

The California State Hospice Association is currently seeking support for a study of the effectiveness of bereavement and grief support for caregivers. Medicare rules mandate that hospice provide services to family members for up to one year following a death. The Hospice Association would like to quantify the impact on the health care system that results from medical problems and loss of work during that year with and without support services.253

Select Out-of-State Promoting Excellence Projects
The Children’s Hospital and Regional Medical Center in Seattle, WA, collaborated with the area’s two largest insurers, the Washington Department of Health, and eight local and state
hospice organizations to develop flexible insurance benefits. The project implemented protocols for pain and symptom management and a decision-making tool that includes patient/family perspectives in care planning. The project connects hospice-trained care coordinators with phone-based case managers at insurance plans. The success of the program has also spurred the formation of a palliative care case management option at Regence Blue Shield.\(^{254}\)

The second project established a partnership between the Massachusetts Department of Mental Health, the state’s Medicaid Bureau, and two local hospice programs. The program focused on patients with chronic, severe mental illness because of the extraordinary complexity involved in end-of-life care for this population. Despite the 1991 Self-Determination Act, the vast majority of individuals did not have health care proxies because it is difficult to assess whether they are capable of selecting a proxy. Researchers found that most providers assume that mentally ill patients are not capable of choosing a health care proxy or feel uncomfortable discussing death with these patients due to their particularly volatile mental states. Therefore, the partnership worked to establish advance care planning practices for this population of dying patients.\(^{255}\) The program used specific tools to assess competency to select a proxy and care preferences, and also educated mental health professionals about hospice and hospice workers about caring for the mentally ill patient.\(^{256}\)

**MediCaring: National Managed Care Program**

The MediCaring program is designed to provide palliative care within a managed care structure to patients nearing the end of life. The emphasis on prevention, patient education, cost efficiency, and service coordination positions managed care delivery systems to deliver quality end-of-life care. Yet, the reimbursement structure of capitated systems creates strong incentives for providers to avoid patients with limited life expectancy. The MediCaring program seeks to revise Medicare and Medicaid fee structures to encourage managed care systems to provide enhanced palliative care services. The goal of MediCaring is to extend hospice-type services to a broader array of terminally ill individuals; eligibility criteria would be based on severity of illness. The program focuses on patient preferences, the use of interdisciplinary teams, symptom management, and counseling, and provides both medical and palliative services. To pay for these services, MediCaring plans to bring a team of health professionals, specialists, and supportive services together under one management and capitated payment structure.\(^{257}\) Pricing would be based on a package of services, and a patient’s capitation rate would be increased to reflect this new structure once a person reaches an advanced stage of illness. (Consequently, the base rate for the remaining population would slightly decrease to reflect the relatively lower illness risk.)\(^{258}\)
Endnotes


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