

# A Quarter Century of Hospice Care: The Southern California Kaiser Permanente Experience

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## Abstract

Kaiser Permanente (KP) has been a pioneer in the development of hospice services in the United States. Since 1978, when hospice services were introduced in the KP Southern California Region, they have been gradually expanded to benefit thousands of patients and their families. However, important barriers to timely, appropriate utilization of hospice care remain. A pilot project conducted in our TriCentral Service Area has shown that palliative care—a newer development in end-of-life care—can be cost-effective in addition to being beneficial for patients and their families. Efforts are underway to emulate this model of care at other KP facilities. Availability of both home-based and inpatient palliative care services can expand the number and type of patients who, as they near the end of life, can benefit from effective symptom control and other support.

## Introduction

In 1978, jointly with the National Cancer Institute, Kaiser Permanente (KP) began a demonstration project designed to elucidate whether the British model of hospice care could function within the US health care system. Now, 26 years later, we reflect on how that experiment promoted hospice care as an important benefit for KP members in Southern California. We also take this opportunity to look ahead and consider how to make services more comprehensive for patients with advanced or terminal disease and for their families. This goal is particularly important because our member population (along with the general US population) is getting older and can therefore be expected to have an increasing number of chronic, incurable conditions.

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## Historical Development of the Hospice Model of Care

### Beginnings in England

Cicely Saunders, MD, is credited with originating the modern hospice movement in England in the 1960s. A former nurse and social worker, she became a physician (she was her own multidisciplinary team!) and was inspired to develop a better way to treat terminally ill patients. Then (and, arguably, now to an even greater extent), patients with cancer were aggressively treated in an attempt to achieve cure or remission; little attention was paid to relieving pain or other symptoms, and little emotional or spiritual support was given, particularly after the disease was designated as terminal. Dr Saunders developed the concept of addressing “total pain,”<sup>1</sup> ie, the physical, mental, social, and spiritual/existential factors affecting those faced with advanced/terminal illness. This concept eventually led to the 1967 founding of the celebrated St Christopher’s Hospice outside London and spread, worldwide, a care philosophy emphasizing comfort, quality of life, and enhancement of function for whatever time the patient had left to live.<sup>2</sup> This hospice concept also redefined the unit of care, which now would include relevant family members or caregivers in addition to the patient. The concept emphasized dignity and choice and downplayed efforts to keep the person alive “at all costs,” especially when doing so would introduce a high risk of adverse side effects without any appreciable possibility of extending longevity.

While St Christopher’s and other similar freestanding hospice facilities offered inpatient care, most patients remained at home, cared for by family members, friends, or hired caregivers supervised by a hospice nurse, physician, and social worker and sometimes supplemented by a home health aide, homemaker, chaplain, volunteer, and various therapists (eg, physical, occupational, speech, music).



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### Hospice Care in the United States

Hospice care in the United States began as a volunteer function which gradually became professionalized. By the late 1970s, enough interest had developed to fund demonstration projects. T Hart Baker, MD, who was then Medical Director of the Southern California Permanente Medical Group (SCPMG), personally helped to apply for such funds, which were subsequently granted along with funds for three other sites around the country. George Espe, MD, was placed in charge at a Norwalk site (formerly a nursing home) that featured patient rooms with direct access to a garden; a large activities room; a playroom for visiting children; and even a viewing room for use by family members and friends. Then, as now, most patients remained at home; only a minority required short stays in the inpatient facility for symptom control or (more often) to provide respite for the caregivers. The grant money was exhausted in 1980, but KP decided to continue the service.

By the early 1980s, the momentum propelling provision of hospice care prompted expansion of Medicare coverage, and hospice legislation was enacted providing comprehensive hospice services—primarily to people aged 65 years and over with a life expectancy of six months or less. For a daily reimbursement rate (approximately \$135 a day in mid-2005), hospice programs give all terminal-phase care, including medication, durable medical equipment, treatments (eg, oxygen), supplies, and visits by the multidisciplinary members of the hospice team. The care includes short inpatient stays, which are sometimes reimbursed at a higher daily rate. Palliative measures, such as chemotherapy, radiotherapy, intravenous administration of fluids and antibiotics, and total parenteral nutrition can be provided when the aim is comfort and not prolongation of life; however, hospice programs have an economic disincentive to offer these palliative measures, because they must be covered financially by the fixed daily rate of reimbursement. For patients without Medicare coverage, hospice care is financed by Medicaid, by private insurance, or by private donations.

### Hospice Care for KP Members in Southern California

In the mid 1980s, the KP Southern California Region (KPSC) began offering a hospice benefit for all KP members. This introduction led to expansion of the region's hospice programs, which have been established in five Southern California geographic areas: TriCentral/Orange County, San Diego, Fontana/Riverside, Metro Los Angeles, and the San Fernando Valley.<sup>3</sup> None of KP's ex-

pansion hospices offered a dedicated inpatient facility but instead offered inpatient care in acute hospitals and increasingly in contracted skilled nursing facilities. Norwalk eventually closed its inpatient facility when its retention became increasingly difficult to justify. Surveys show that “86% of terminally ill want to be cared for at home.”<sup>4</sup>

The five SCPMG Regional hospice programs have served many thousands of terminally ill patients and their loved ones. Primarily in the home setting, where patients can retain at least a modicum of control, they have generally been helped to achieve a “good death”<sup>5</sup> by means of pain management and symptom control (thus alleviating much suffering and agony) by giving them time to arrange their affairs, say their goodbyes, and, for some, to enable participation in significant family events or even long-awaited travel. Our follow-up surveys show generally high satisfaction with the interventions and service that the hospice program has provided. Commonly, we receive comments such as, “I wish we had known about hospice earlier,” or “I wish we had been referred earlier to hospice so he could have had the services longer.”

A unique feature of our hospice programs is the substantial involvement by Continuing Care physicians, who visit patients (either at their home or in the nursing home or board-and-care facility where they reside) during the first week of hospice service and on an as-needed basis thereafter (often every 30-60 days). We thus can become the patient's *de facto* attending physicians, although we do not restrict patients' access to their own primary care or specialist physicians. Most patients are grateful they need not travel to a medical office.

### Barriers to Hospice Care

Substantial barriers to appropriate utilization of hospice services remain. Nationally, only about 50% of patients with cancer or other terminal conditions are referred to hospice.<sup>6</sup> Pediatric referrals are particularly scarce. Patients are referred late; nationally in 2002, the mean length of stay was 48 to 51 days, whereas the median length of stay was only 26 days.<sup>7</sup> In SCPMG, we are probably doing better: The mean length of stay for patients in the Metro Los Angeles hospice program is 74 days; however, a survey conducted a few years ago showed that approximately a third of the patients died within two weeks after starting hospice service.

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Thus, although Medicare states that the prognostic criteria should be a life expectancy of six months or less “if the disease runs its normal course,”<sup>8</sup> most patients receive hospice care for much shorter timespans.

The prognostic criteria themselves are part of the problem. All of us working in a hospice program have taken care of patients with advanced disease (eg, lung, breast, prostate, and even pancreatic cancer) who have lived considerably longer than six months. And non-malignant disease (eg, congestive heart failure, chronic obstructive pulmonary disease, or dementia) can have a particularly unpredictable and variable course. Physicians—both in primary care and in specialties, are reluctant to discuss realistic options as the disease advances and as the patient’s condition becomes more clearly terminal. Even though chemotherapy was clearly ineffective in a particular case, the oncologist for the patient once told one of us: “I can’t stop the chemotherapy. I would be taking away hope.”

Because this hope looks for a remission or cure that will not occur, the day of reckoning comes sooner or later—and we miss the chance to switch the terms of hope so that we instead focus on avoiding suffering and promoting maximal independence. Because of this missed opportunity, some patients and families feel betrayed and angry despite their own aversion to asking probing questions or accepting the limitations of medicine. Many patients and families seek second and third medical opinions before coming to hospice and refuse to issue—or even discuss—advance directives. Moreover, at least in the inpatient setting, clinicians tend to ignore advance directives in the infrequent case where such a directive has been executed.<sup>9</sup>

### **Growth and Benefits of Palliative Care**

Gradually, a parallel concept of care—palliative care—has developed, defined as “comprehensive, specialized care provided by an interdisciplinary team to patients and families living with a life-threatening or severe advanced illness expected to progress toward dying and where care is particularly focused on alleviating suffering and promoting quality of life. Major concerns are pain and symptom management, information sharing and advance care planning, psychosocial and spiritual support, and coordination of care.”<sup>10</sup>

In other words, palliation emphasizes comprehensive, symptom-relieving supportive service. It is the type of care offered to those for whom hospice admission is inappropriate, either because the prognosis is too

uncertain or (more often) because referral is not given (by the physician) or not accepted (by the patient or significant others).

To identify patients who are good candidates for palliation, a useful concept has been to ask referring physicians, “Which patient’s death would not surprise you if it occurred in the next 12 months?”<sup>11</sup> Because palliative care is rendered under the criteria developed for the Medicare Home Health benefit, patients may receive this care only if they are homebound, whereas hospice patients may be fully ambulatory. Palliative care requires a documented need for skilled services, which may primarily consist of care management for monitoring and treating of symptoms at home, along with support services for patients and their significant others. Patients receiving palliative care or hospice services receive all professional visits free of charge; however, whereas hospice patients obtain medications and most durable medical equipment and supplies (including oxygen) at no cost, patients receiving palliative care must pay for these services at rates set by their health plan coverage, and their need for oxygen must be documented.

The KP TriCentral Service Area’s Home-Based Palliative Care Program won the 2003 Vohs Award for Quality.<sup>12</sup> The program clearly engendered great satisfaction with the services rendered to patients diagnosed with cancer, congestive heart failure, and chronic obstructive pulmonary disease. The program also led to substantial savings, primarily by avoiding unnecessary and unwanted trips to the emergency department and hospitalization. Costs of palliative care were approximately 45% lower than for “usual care.”<sup>13</sup> Switching the focus of care from the inpatient setting to the home setting was accomplished by providing 24-hour availability of services either by phone (primarily) or by home visits whenever needed. Replication of the KP Palliative Care Program beyond the TriCentral Service Area is actively being fostered, including demonstration projects underway in the KP Hawaii and Colorado Regions.

Several initiatives also are underway to promote implementation of an Inpatient Palliative Care Service, which would prospectively evaluate patients with terminal or advanced disease and thus facilitate and encourage treatment that would maximize their comfort. The service would also seek advance directives where none exist and would promote communication among patients, family members, and professionals so that available options and choices could be appropriately discussed.

The Inpatient Palliative Care Service functions also as a consultation service, helping to give advice on

obtaining adequate pain management and symptom control. The service also helps facilitate appropriate discharge planning, including referral to hospice or to other types of nonacute care.

## Conclusion

In the past 26 years, much has been accomplished to promote optimal end-of-life care, and a “good death” is now, for many patients, more often the norm than the exception. However, too many patients are still not receiving the benefit of hospice and palliative care services and expertise as they approach death. We therefore urge a redoubling of efforts to make this care available to all our members who can benefit from it. ❖

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## To Be Happy

... all we need to make us really happy is something to be enthusiastic about.

— Charles Kingsley, 1819-1875, English author and clergyman