

Palliative Care: Innovation in Care at the End of Life

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What is Wrong with Healthcare at the End of Life?

Americans benefit from rapid innovation in medical therapies to prolong life and ameliorate disease, but innovation in care of dying patients has not kept pace. When efforts to cure or to manage diseases reach their inevitable limits, patients, families, physicians, and nurses question continued use of treatments designed to prolong life. Many physicians and nurses recall using life-sustaining treatments for terminally ill patients—treatments that they considered to be inappropriate at the time.¹ In extreme cases, beginning with the court battle over life support treatment for Karen Ann Quinlan, these poignant personal decisions have become public narratives of suffering. When chances for cure and survival diminish, most dying patients and their families prefer an approach to medical treatment that emphasizes comfort and quality of life. Discerning and then communicating this transition is one of the central dilemmas of end-of-life care.

Good care at the end of life is not accomplished by simply stopping traditional modes of treatment. The alleviation of suffering is one of the primary goals of medicine, yet emerging research in the care of dying patients demonstrates high rates of untreated pain and other physical symptoms. New forms of treatment and care are needed to control symptoms associated with dying. Decisions to withhold or withdraw life-sustaining treatments do not address the needs for effective treatment for pain and other symptoms. The crisis of impending mortality triggers additional emotional and spiritual suffering.² Forty percent of conscious patients have moderate-to-severe pain and more than half have moderate-to-severe dyspnea during the last two-to-three days

of life.³ Patients dying in hospitals and nursing homes have high rates of unmet needs for physical symptoms, emotional suffering, personal care services, and communication about treatment options.^{4,5} Patients do not suffer alone; during the dying process and after a death, family caregivers experience significant emotional, physical, and financial stress.^{6,7,8} Patients, families, and healthcare providers acknowledge pro-

found deficiencies in current end-of-life care, and the need for improved palliative care services that are well matched to the needs of dying patients.

Palliative care is an emerging field in United States healthcare. Palliative care is comprehensive, interdisciplinary care designed to promote quality of life for patients and families living with a serious or incurable illness.⁹ Because it is a comprehensive approach to care, providers of palliative care offer expert pain and symptom management, sup-

portive care for emotional and spiritual distress, and bereavement support for surviving family. Palliative care includes and expands on the expert care of dying patients found in hospice services.

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How Do Americans Die?

More than two million deaths occur in the United States each year. Depending on the underlying cause of death, a dying patient’s “death trajectory,” or their functional decline prior to death, may follow a brief or prolonged course. The trajectory of illness before death may have a recognizable terminal phase, or a more uncertain and unpredictable course prior to death. The underlying cause of death and resulting death trajectory strongly influence the quality of the dying experience, the certainty that a patient is dying, and the physician’s ability to discuss options for medical treatment.^{10,11,12}

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Progressive chronic diseases—heart disease, cancer, stroke, chronic lung disease, and neurodegenerative disease such as Alzheimer's and other dementias—cause the majority of adult deaths. Among these causes, cancer patients have a more precipitous functional decline near death, which may facilitate recognition of a terminal phase of illness. Patients with chronic heart or lung disease have a more uncertain trajectory of worsening and remitting symptoms over months to years prior to death. Elderly nursing home residents with neurologic diseases and varied other chronic illnesses may have a very slow functional decline for many years, with no recognizable terminal phase. These individuals often die of an acute illness such as pneumonia or hip fracture. In the context of advanced dementia, these treatable acute illnesses have a 50% mortality risk at six months.^{13,14}

Because Americans expect to live into old age, deaths early in life are especially painful. Premature deaths among children and teens are more often caused by relatively sudden events such as accidental injury, homicide, suicide, or complications of HIV infection or congenital abnormalities.¹⁶ Racial and ethnic minority groups have higher rates of death at younger ages from these traumatic or sudden causes. The national Institute of Medicine's report, *Approaching Death: Improving Care at the End of Life*, emphasizes the need for overall improvements in end-of-life care and lends attention to the diverse needs of these subgroups of dying patients.^{15,16}

Where Do People Die?

The site of death may be one of the most important structural determinants of the experience of dying.^{5,17} Patients and their families say they prefer terminal care at home,¹⁸ but four of five deaths in the United States take place in hospitals and nursing homes. After-death interviews with bereaved families show an association between site of death and satisfaction with terminal care. Surviving family are consistently more satisfied with hospice and are least satisfied with conventional nursing home and hospital care.^{5,17,19} Hospice services, which can be provided in private homes or long-term care facilities, now support one-in-five dying Americans. In 1989 the Medicare hospice benefit was extended to nursing home residents. Hospice has since been added to usual nursing home care for 5.6% of deaths in long-term care facilities.²⁰ The site of death and use of hospice care varies by state. Oregon, after its highly publicized debate on assisted suicide legislation, has achieved the highest rate of hospice enrollment in the nation (31% of all deaths), and is able to provide terminal care at home for 42% of its citizens who die. North Carolinians' healthcare experiences at the end of life are very similar to the majority of decedents in the nation (See Table 1).

Table 1.
Site of Death in North Carolina, 2001

	NC	US
Site of death		
Hospital	54%	49%
Nursing home	22%	24%
Home	25%	23%
With Hospice	21%	19%

As the population ages, and as economic pressures cause reduced hospital lengths of stay, nursing homes are becoming a more common site of death. Data from the National Mortality Followback Survey, a representative sample of United States deaths in 1986 and 1993, show that the proportion of deaths that occur in hospitals decreased from 65% to 56%, while the proportion of deaths in nursing homes increased from 17% to 19%. By helping frail elders receive treatment and supportive care outside of hospitals, community-based, integrated elder-care programs such as the Programs of All-Inclusive Care for the Elderly (PACE)²² can result in increased use of nursing homes (34%) and private homes (45%) as sites of death.²³ The availability of services within one's local health system, including readily available hospital beds, nursing home beds, and hospice services are likely to influence where people die, perhaps more than their own preferences about site of terminal care.^{24,25}

How Do Patients and Families Define a Good Death?

Most medical treatments are judged to be effective if they are proven to prolong life or to reduce the risk of adverse health events or functional impairments. Good end-of-life care can only be defined by its ability to promote a "good death," or good dying experience for patients. As the potential for medical treatment to improve function and survival diminishes, patient- and family-centered outcomes become paramount. An expert consensus panel convened by the national Institute of Medicine has defined a good death as "one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards."¹⁵

Several well-designed studies explore domains defined as important to seriously ill and dying patients and their professional and family caregivers (See Table 2).^{26,27,28,29,30,31} Dying patients and those who provide their care consistently value: (a) relief from pain and other physical symptoms, (b) attention to emotional, psychological, and spiritual needs, (c) compassionate communication, (d) involvement in critical healthcare decisions, (e) affirmation of personhood and dignity, (f) support for family caregivers, and (g) coordination and continuity of care.^{32,33}

Innovations in End-of-Life Care

Public demand for appropriate care at the end of life emerged in the controversy surrounding dramatic "right-to-die" court cases. It has been fuelled by the debate over assisted suicide, and by descriptive studies of pain and suffering experienced by dying patients and their families. These problems are well defined, and new approaches to the delivery of medical care to seriously ill and dying patients are beginning to improve care.

Strategies to improve end-of-life care can be conceived as targeted or comprehensive interventions. Targeted interventions

Table 2.
Patient and Caregiver Perceptions of Quality in End-of-Life Care

Study Population	How do patients, family, and healthcare providers define a "good death"?
<i>N = 126 chronically ill patients (Singer, 1999)</i>	Receiving adequate pain and symptom management Avoiding inappropriate prolongation of dying Achieving a sense of control Relieving burden on loved ones Strengthening relationships
<i>N = 137 chronically ill patients, family members, and healthcare providers (Curtis, 2001)</i>	Physician access and continuity Team coordination Communication with patients Patient education Inclusion of family Medical competence Pain and symptom management Emotional support Personalization Attention to patient values Respect and humility Support of patient decision making
<i>N = 75 healthcare providers, patients, and family caregivers (Steinhauser, 2000)</i>	Pain and symptom management Clear decision making Preparation for death Completion of spiritual or meaningful final tasks Contribution to others Affirmation of the whole person

are designed to influence one aspect of the dying experience. Examples could include programs to improve physician communication skills, to implement pain management protocols, or to provide grief counselling for parents of dying children. Comprehensive clinical services such as hospice or palliative care units are designed to improve the overall quality of care for dying patients and their families. These comprehensive services typically include healthcare providers who can address a wide range of communication and symptom management needs for dying patients and their families.

Making Advance Directives Work

Given evidence that patients and families were dissatisfied with current end-of-life care, concerned clinicians and bioethicists reasoned that increasing patient control over major clinical decisions would result in more appropriate forms of treatment. Advance directive documents emerged, in which a patient gave prior direction about who could make decisions on his or her behalf (Healthcare Power of Attorney) and how life-sustaining treatments were to be used in the event of terminal or incurable illness (Living Will). Research on advance directives has shown that education and provision of advance directive forms can increase documentation of patient preferences. Patients generally welcome these conversations, and many are willing to record their wishes in some form.

Unfortunately, advance directives may be necessary but not sufficient to change the experience of care at the end of life. Living wills and other advance directive documents have not had a significant impact on the medical care received by dying patients.³⁴ In 1995, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment randomized seriously ill patients with limited life expectancy to a nurse-facilitated, written communication of prognosis and treatment preferences. The aim of the intervention was to inform and facilitate decision-making by patients and physicians. This intervention, like similar smaller studies, had no impact on pain treatment, life-sustaining treatment use, or cost of care.³⁵ Advance directives have the potential to promote communication among patient, family, and provider, but are not sufficient to change care at the end of life.

In retrospect, it is not surprising that advance directives alone are not sufficiently powerful to change care at the end of life. These documents may not be immediately available when patients become acutely ill and are unable to speak for themselves. Living wills are subject to interpretation and may be difficult to apply to specific clinical circumstances. Is a patient with advanced Alzheimer's and a hip fracture "terminally ill"? Is the treatment of pneumonia in a patient with end-stage cancer "life-sustaining treatment"? Another limitation is that traditional advance directives focus on withholding or withdrawing treatments, rather than a positive choice for an overall plan of care.

Advance directive documents are most useful when they serve as an invitation to conversations about patients' real concerns and values, goals of treatment, and a plan of care serving those goals. Some newer advance directives promote more comprehensive advance care planning. One example, The Medical Directive, requires a median time of 14 minutes to discuss, and allows the physician and patient to cover a broad range of health scenarios and treatment options.³⁶ In the mid-1990s Oregon adopted a portable physician order form which promotes discussion of preferences for resuscitation, overall level of medical treatment, and use of antibiotics, feeding tubes, and intravenous fluids. The form, Physician Orders for Life-Sustaining Treatment (POLST), is a physician order that is portable between healthcare sites.³⁷ The POLST has been widely accepted in Oregon, and evaluations suggest that it lowers the use of

life-sustaining treatments and hospital admission among nursing home residents. A randomized controlled trial of a similar comprehensive advance directive in six Ontario nursing homes had a marked effect on hospital use and cost of treatment at the end of life.³⁸

Improving Communication

Meaningful and compassionate communication is the core skill in end-of-life care. Absent this skill, physicians will be unable to help patients decide on appropriate treatments, assess physical symptoms, or address emotional and spiritual suffering. Patients facing the crisis of their own mortality require time to express fears and to seek reassurance of continuing physician attention to their spiritual and emotional needs, in addition to medical aspects of their care.

Family perspectives on the quality of the dying experience are independently important. While the patient lives, physicians must be skilled in communication with family members who make decisions for incapacitated patients, and serve as physical and emotional caregivers. Although they may not accurately represent patient treatment preferences or symptoms, family members are the ethical surrogate for incapable patients, and they will evaluate the quality of care after the patient's death.^{39,40} In one study of recently bereaved family members in North Carolina, their most common recommendation for improved care at the end of life was to improve physician communication skills.¹⁷ Their recommendations emphasized the need for communication beyond medical treatment choices, including a desire to talk more about prognosis, and about the humanity and dignity of the patient.

Communication of prognosis is essential if patients and families are to participate in informed decision-making. Prognostic models are accurate for populations, but challenging to communicate to individual patients. In the SUPPORT study population, a patient with a 50% chance of living two weeks also had a 20% chance of living six months.⁴¹ Physicians and patients alike respond to prognostic information with optimism born of hope for survival. Physicians systematically overestimate their patients' life expectancies, and communicate even more optimistic data than they believe.⁴² Patients who have cancer and an average life expectancy of six months will nearly all expect to live longer than six months.⁴³

Compassionate communication about prognosis seeks to balance optimism with a gentle respect for patients' right to know the truth about their illness. Probabilities are confusing, but physicians can often tell patients whether life expectancy is measured in days to weeks, weeks to months, or months to a year or two. Patients and physicians can travel a careful middle ground together, where they "hope for the best, and prepare for the worst."⁴⁴ Prognosis is not simply a question of communicating life expectancy. Patients and family members also need information about what is likely to happen during the dying experience. Their ability to understand and anticipate the natural history of disease, its symptoms, and possible treatments will allow time for practical and spiritual preparation for more serious

illness or death. It may also relieve unspoken fears.

Physician training includes little experiential learning about these essential communication skills. However, physicians who have worked to become expert in this aspect of medical practice are demonstrably more capable of comprehensive, patient-centered communication. This communication can be accomplished even within the time constraints of an office visit.⁴⁵ Experts in end-of-life communication have published useful examples of the words and approaches they use to promote continued practice of this vital skill.^{44,46,47,48,49,50} Innovative continuing education programs that expand didactic education to include experiential learning techniques have a positive effect on physicians' communication skills.^{51,52}

Communication about end-of-life treatment decisions may also be improved using ethics consultations for intensive care unit (ICU) patients. In a multi-site randomized controlled trial, ethics consultants led family meetings when value-laden treatment decisions were imminent. These consultations result in high levels of satisfaction, reduced use of life-sustaining treatment and ICU days, and yet had no adverse effect on the length of patient survival.^{53,54}

Individualizing Care for Diverse Populations

End-of-life care varies for patients of minority, ethnic, and cultural backgrounds. Terminally ill African-American or Hispanic patients are less likely to receive effective pain treatment or to enroll in hospice than their white counterparts, and are more likely to die in hospitals.^{55,56} Physicians seeking to provide excellent care for dying patients must consider whether these differences in treatment are driven by patient values, or by failed access to or understanding of treatment options. Knowing that African-American patients generally enroll less often in hospice should not lead physicians to assume an individual patient's preference, but it may allow for more sensitivity in discussions of treatment decisions.

Patient characteristics such as education, race, and cultural or religious background may also influence values about patient and family involvement in medical treatment decisions. For example, traditional Navajos may perceive that speaking of potential bad outcomes may cause them to occur; a value quite distinct from a Western European emphasis on truth telling.⁵⁷ Patients from some cultural traditions, including African American, Hispanic, and some Asian countries, may place a greater emphasis on the importance of family involvement in medical treatment decisions even when the patient is capable of making his or her own choices.⁵⁸ Use of written advance directives and orders to limit life-sustaining treatment vary by patient insurance status, educational attainment, and racial background.^{59,60} Dying patients and their caregivers desire spiritual care, and this aspect may engender particular concern among patients from minority, ethnic, or religious backgrounds.⁶¹ Spiritual care, when available for dying patients and their families, needs to be consistent with individual faith traditions and cultural expression of spiritual practices.⁶² Understanding these patterns of historical differences may allow for more

nuanced communication with patients who do not share the physician's cultural heritage.⁶³

Comprehensive Strategies: Hospice

Palliative care is comprehensive, interdisciplinary care designed to promote quality of life for patients and families living with a terminal or incurable illness. Hospice agencies, modelled on the inpatient treatment approach pioneered by Dame Cicely Saunders in Britain, have delivered palliative care in private homes in the United States since the creation of the Medicare hospice benefit in the 1980s. In 1989 Medicare expanded this benefit to nursing home residents, and hospice is now offered under most state Medicaid programs and many forms of private health insurance.

Patients are eligible for hospice if a physician certifies that they have a life expectancy of six months or less "if the disease follows its expected course." Patients are also expected to agree to forgo "curative treatment for their terminal illness." Patients with uncertain disease trajectories may find it difficult to meet the six-month criterion, although non-cancer diagnoses are increasingly represented within the hospice population. For many diseases, curative and palliative treatments overlap and access to specific treatments may vary by provider. For example, patients with cancer may or may not be able to continue transfusions for anemia and patients with chronic obstructive pulmonary disease (COPD) may or may not be able to continue intravenous antibiotics for pneumonia.

For patients who can qualify, hospice improves satisfaction with end-of-life care. After death, family caregivers rate hospice services more positively than any other aspect of terminal care.^{5,17} In early studies, hospice inpatient units showed improved satisfaction despite modest impact on symptom scores.^{64,65} In nursing homes, family caregivers believe that adding hospice care improves the quality of care for physical symptoms and emotional needs.⁶⁶ Comparison of nursing home decedents who do or do not receive hospice care shows increased use of pain medication and decreased use of tube feeding and hospitalization for those enrolled in hospice.⁶⁷ Hospice delivered in private homes can reduce the total cost of care for younger patients and those who die from cancer, but not for other dying patients.⁶⁸

Many patients who might benefit from palliative care do not currently access hospice, or do so within only days of death. The length of stay in hospice has slowly decreased over the past decade. Patients may deny they are nearing death, or have an uncertain trajectory of illness that does not fit the

six-month criterion. They may be unwilling to forego treatments, such as palliative radiation, that are prohibitively costly to include in the hospice per diem payment. Many individuals may face terrible pain and suffering, but have a cultural or personal imperative to "fight until the end." Hospices and other healthcare organizations are creating newer forms of palliative care services to match the needs of these patients.

Comprehensive Strategies: Palliative Care Programs

New model palliative care programs have increased significantly during the past decade, in response to needs for palliative care outside the traditional hospice enrollment population. Palliative care programs may be affiliated with an acute care hospital, a hospice agency, or with innovative elder care services that provide a continuum of health services.⁶⁹

The number of physicians seeking palliative care certification is rising rapidly. The American Board of Hospice and Palliative Medicine incorporated in 1995, and began administration of its board exam in 1996. By August 2003, there were 43 active or emerging United States fellowships in Palliative Medicine, and over 1,200 physicians have met qualifications for certification in this field.⁷⁰

Seventeen percent of United States hospitals currently house a palliative care service. Unlike hospice, palliative care programs do not yet offer a standardized array of clinical services. Hospital-based palliative care may include a variety of healthcare providers who offer inpatient consultation, outpatient consultation, dedicated inpatient beds, or bereavement programs for families. For example, the Pain and Symptom Care Program at UNC Hospitals, initiated in 2001, now provides inpatient care on 23 different hospital units. Using a consultation model, this interdisciplinary service reaches a diverse patient population; half are under age 65, one-third are African American, and one-third have terminal illnesses other than advanced cancer. Patients' average ratings of pain and other symptoms improve, and 80% of patients and families receive counselling about end-of-life issues.

Table 3.
Internet Resources for Palliative Care

Organization	Website
American Academy of Hospice and Palliative Medicine	www.aahpm.org
American Board of Hospice and Palliative Medicine	www.abhpm.org
Carolinas Center for Hospice and End-of-Life Care	www.carolinasendoflife.org
Center for the Advancement of Palliative Care	www.capc.org
Duke Institute on Care at the End of Life	www.iceol.duke.edu
End-of-Life Palliative Education Resource Center	www.eperc.mcw.edu
Last Acts Partnership	www.lastacts.org
Midwest Bioethics Center	www.midbio.org
National Hospice and Palliative Care Organization	www.nhpco.org
National Resource Center on Diversity in End-of-Life Care	www.nrcd.com

Because palliative care programs are changing rapidly and are not yet standardized, studies of its impact on care quality and cost are just beginning. One systematic review of 16 relatively well-established services found that these hospital-based inpatient services improved family satisfaction, reduced symptoms of distress, and decreased the intensity or cost of inpatient services for the patients they serve.⁷¹ Like many labor-intensive healthcare services that do not emphasize procedures, palliative care is valued for its ability to reduce costs while improving quality of care.

Conclusion

For several decades, the medical literature has been filled with evidence of shortcomings in end-of-life care. Patients who have

acquired the disease that will cause their death receive the same approach to medical care in early and advanced stages of incurable disease. Physicians fail to discuss prognosis, and patients retain hope for cure rather than hope for comfort and quality of life during their remaining days. In recent years palliative care practice and research have stimulated new programs and new clinical approaches to the care of dying patients and their families. Hospice, long the only repository of expertise in palliative care, is now joined by physicians, nurses, and other healthcare providers who have made a career commitment to excellence in healthcare for patients in the final phase of life. **NCMJ**

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