

# Access to *Hospice Care*

## EXPANDING BOUNDARIES, OVERCOMING BARRIERS

### A SUMMARY

of the comprehensive report prepared by The Hastings Center and the National Hospice Work Group, April 2003

In recent years, widely publicized research studies have documented a litany of seemingly intractable problems with the quality of care given to Americans at the end of their lives—inadequate pain control, inadequate counseling and family support, inadequate compassion or human presence. A comprehensive new report issued by The Hastings Center, a leading bioethics research center in Garrison, N.Y., confirms those previous findings while identifying new opportunities for overcoming high levels of preventable suffering at the end of life. A major thrust of its recommended solutions lies in a surprising but familiar direction: making greater use of America's 3,400 existing providers of hospice care.

**"People never forget and never forgive if they think a person has not been respectful of death."**

- Carol Hoffman, University of California-Berkeley

*Access to Hospice Care: Expanding Boundaries, Overcoming Barriers*, a report drawn from a three-year study of hospice access and values issues conducted by The Hastings Center and the National Hospice Work Group, a voluntary association of progressive hospices, was published as a Special Supplement accompanying the March/April 2003 issue of the bioethics journal, the *Hastings Center Report*.

The purpose of the study was to contribute to the broad goal of improving end-of-life care by addressing specific problems in access to and delivery of hospice care. Its distinctive contribution is to pay explicit attention to the human values involved in hospice care policy and practice. The report examines the problem of hospice access from the perspective of social justice, equity or fairness and makes an ethical case for equitable access on the basis of the vulnerability of the population served, the moral importance of meeting their needs and the values upon which comprehensive, high-quality hospice care is constructed (see pages S13-S17 of the full report).

The report also offers a new vision of hospice, one that holds firm to many of the traditions and values of the past but finds new and more flexible ways to deliver care. The model of traditional hospice care as an independent and specialized service will gradually be transformed into a more comprehensive model in which hospice becomes the coordinating center for a range of services and types of expertise that can be accessed by patients. In the authors' new vision, America's hospices will play an expanded role in addressing more of the supportive and symptom relief needs of patients confronting life-limiting illnesses and their families for longer periods and in a wider variety of settings and contexts.

To achieve this ambitious goal, policies must change and powerful cultural taboos surrounding death and dying must be overcome. What's needed are a national program of professional education about hospice and palliative care and a massive social marketing campaign regarding hospice programs' abilities to address and resolve many of the most widely held fears about the end of life.

### Challenges of End-of-Life Suffering

Death is an inevitable aspect of the human condition. Dying badly is not. But the problems of dying badly are often social in nature, reflecting the way America's health care system is organized and financed. While the acceptance

#### What Is Wrong with this Picture?

Martin, a 78-year-old former executive with CHF, experiences a dramatic role reversal when his 70-year-old wife is diagnosed with lung cancer that has aggressively metastasized. He must simultaneously support her and consider his own future survival needs without her. Her physician tells them: "It's time for outpatient radiotherapy, not hospice."

and utilization of hospice care has grown in recent years, more than a million Americans die each year of chronic, life-limiting illnesses without receiving hospice services.

Some of the “barriers” to hospice actually result from misunderstandings and misinformation, while others have sources that are structural, financial, regulatory, cultural and even “self-imposed” (by hospices themselves). The cultural issues—taboos, denial of death, avoidance of painful subjects—are major contributors to the problem, but so, too, are unfairly restrictive government policies. (See pages S27-S38 of the full report.)

*Specifically, the hospice access problem takes four forms:*

1. Some dying patients never get referred to hospice;
2. Other patients are referred to hospice only in the final days of their lives (nationally, more than a third of patients spend less than seven days enrolled in hospice);
3. Some aspects of hospice’s care management are needed much earlier than the last six months of life, and
4. Cultural differences and barriers contribute to an inequitable distribution of hospice services while hospices’ efforts to overcome these barriers have not been entirely successful (see pages S39-S43 of the full report).

**"(Hospice) is the form of health care that most explicitly acknowledges and makes manifest the interpersonal significance of health care—the bonds of empathy and compassion between the person cared for and the care-givers."**

- Bruce Jennings, et al., *Hastings Center Report Special Supplement 33*, March/April 2003

## Characteristics of Hospice Valued by Consumers

The success of the hospice movement is attributed to its demonstrations of *trustworthiness* to patients and families. Its nonprofit origins and early reliance on volunteers secured the support of community members, and its special value to those made vulnerable by profound illness was reinforced by the following characteristics of care:

**1. Responses to the human consequences of profound illness (palliative care management).** (See pages S44-S48 of the full report.) Hospice staff responds to the need for comfort, safety, choice and support experienced by dying patients and their families as their conditions change and they move from one care setting to another.

**2. Continuity of care-giving.** (See page S49 of the full report.) Hospice staff maintains a coherent vision of what is preferred by and effective for patients and their families as care shifts to new settings and providers.

**3. Response to evolving community needs.** (See pages S48-S49 of the full report.) Hospice leaders have expanded a philosophy of care originally based on the needs of white, middle-class adults with cancer. Hospices now serve people with many other diseases, as well as children, persons living in difficult service areas such as prisons and the rural “outback,” and the community’s bereaved.

### What Is Wrong with this Picture?

Maria, a 34-year-old mother of two, received a prenatal diagnosis that her baby has a lethal congenital anomaly and will only briefly live after birth. When Maria's physician tells her not to schedule more visits until just prior to her due date and sends her home, she reports great emotional distress being left to "wait for death" without any support. A local support group tells her of hospice but the hospice will not accept her until the baby is born alive and lives to go home.

The report recommends freeing America’s hospice providers from existing regulatory, financial and cultural constraints so that their expertise can be applied more broadly in new settings and contexts. The authors also note that new palliative care providers and innovative palliative demonstration projects have much to offer to the evolving landscape of end-of-life care in America, particularly in collaboration with hospices.

The existing organizational infrastructure of hospice programs is a national resource of continuing value and viability for patients and families as they move from

one setting to the next. But hospice must develop new organizational forms if it is to continue providing the essential components of trustworthiness: palliative care management, continuity of care-giving and responsiveness to the changing needs of its patients, families and community. The challenge is to find new practical approaches to hospice care, correcting policies and practices that have become unduly restrictive.

Dying persons, their families and loved ones, and society as a whole are diminished by the current failure to respect the autonomy and dignity of the person with a life-threatening illness, to respond to that person's suffering, or to offer care, compassion and vigilance at the end of life. When so many die without the support of good hospice or palliative care, America has not met its obligation to the most vulnerable in society, and has not kept faith with its highest moral ideals.

*A just increase in access to hospice care should take place principally in three ways:*

1. By making it easier for more chronically ill people to be eligible for hospice admission;
2. By lengthening the average time patients spend in hospice care, primarily through expanded services and earlier referral; and
3. By maintaining both high-quality palliative care and good stewardship of scarce resources through a rigorous care management system that follows patients at home and in institutions.

"When a son rather than a home health aide rubs his dying mother's back, he is doing something more than preventing the formation of decubitus ulcers—he is also conveying his love and concern. When a sister listens to and fleshes out her dying brother's reminiscences, she is helping him to make sense of his life, and perhaps to come to terms with his death. These goods of relationship are not fungible: they can only be provided by those with whom one's life is intertwined."

- Hilde Lindemann Nelson, "Pictures of Persons and the Good of Hospice Care," *Hastings Center Report Special Supplement* 33, March/April 2003

## Approaching Just Access: Recommendations

The recommendations contained in *Access to Hospice Care* (see pages S53-S56 of the full report) identify a realistic but challenging course for the future of hospice in America. They require patience, political leadership, broad debate, willingness to compromise and openness to new ideas. They also require further research and increased understanding of why the health care system behaves as it does and how various new practices may affect the needs and well-being of dying patients and their families. The report recommends:

- 1. Health care leaders, policymakers and key stakeholder groups must come to consensus on the definition of palliative care and develop a framework for greater accountability in palliative care delivery in concert with financing mechanisms.** As was done with hospices in the early 1980s, this consensus process would be achieved in part through a national field survey of services that call themselves "palliative care" to determine which elements the services have in common and how they qualitatively differ. A foundation for the process would come from the exhaustive NHPCO Standards of Hospice Care/Robert Wood Johnson Foundation Precepts of Palliative Care. A national forum would also be convened, bringing together key constituencies to establish a definition for palliative care to provide the framework for delivery, standards of care and reimbursement and to draft a position paper articulating the conclusions.
- 2. Public policy should expand the scope of hospice services.** Congress should approve a series of demonstration projects to advance hospice access for patients who do not yet qualify for traditional hospice care and to foster and promote access to hospice's palliative care management through innovative community relationships.
- 3. Policymakers should act immediately to bring about policy reform of the absolute application of an individual's prognosis as a primary criterion for reimbursement of services.** The federal Center for Medicare and Medicaid Services (CMS) and its contract fiscal intermediaries should take steps to protect hospices, referring physicians

and patients from regulatory misinterpretations by establishing a statistically accurate definition of terminal prognosis. Such a definition would recognize the relevance of prognosis as a population measure, not an individual one, consistent with the wide literature addressing the fallibility of medical prognostication on individual patients.

**4. Expand access and delivery of hospice to dying persons residing in long-term care facilities.** Modifying Medicare's Part A and RUG reimbursement systems could help support hospice care for residents of long-term care facilities without causing financial penalty to the nursing home or the resident/family unit. CMS and state departments of health should also adopt a common survey process for hospice patients in nursing homes so that patients' wishes for end-of-life care are not subordinated to clinically and personally harmful regulatory requirements such as the enforcement of feedings among dying patients.

**5. Leaders in the hospice community and in mainstream medicine must promote hospice-hospital partnerships in order to meet current and projected needs of the rapidly expanding volume of chronically and terminally ill patients.** Leadership groups in hospice and palliative care should work with palliative care physicians and administrators of hospices and hospitals to construct a regulatory reform agenda that would enable improved outcomes for hospitalized patients in need of hospice and palliative care. Ongoing studies of maturing hospital/hospice models are also needed, while a Surgeon General's report on the quality of dying in America could provide the proper venue for viewing care of the dying as a public health issue.

**6. Develop telemedicine to expand access to palliative care.** The imminent collision between the burgeoning senior population and decreasing numbers of health care providers will dramatically alter how care is provided to the chronically and terminally ill. Therefore, CMS or some other appropriate government agency should move quickly to fund multi-site telehospice demonstration projects in which centrally located palliative care specialists can interact at a moment's notice with rural hospice staff, family caregivers in varied geographical settings and staff in non-hospice inpatient settings.

**7. Engage the business community.** Good care of dying Americans is clearly a workforce issue because it relates to productivity of employees as patients and as caregivers. Therefore, the major national hospice foundations, in concert with community hospices, should assist the business community in understanding the economic value associated with support to employees who are caregivers as well as the benefits associated with proactive responses to employees who become chronically ill or bereaved.

**8. Develop educational programs to "reintroduce" hospice and palliative care to the public in light of their new capabilities, flexibility and accessibility.** Population-wide educational and outreach programs could emphasize that hospice is no longer just about death and dying, with more positive messages about the benefits of hospice programs: comfort, safety, choice and support in responding to the life consequences associated with illness and disability.

"The need for hospice care is very high. Relieving an agonizing death is as much a part of medicine as preventing a serious illness or preventing a premature one... The alternative to hospice is grim—the prospect of dying an agonizing death... (and) human flourishing is well-served if people do not die miserable deaths."

- Daniel P. Sulmasy, "Health Care Justice and Hospice Care," *Hastings Center Report Special Supplement* 33, 2003

**Note:** *Access to Hospice Care: Expanding Boundaries, Overcoming Barriers*, by Bruce Jennings, True Ryndes, Carol D'Onofrio, and Mary Ann Baily, is a special supplement to the *Hastings Center Report*, March-April 2003. To order copies of this report, contact the Membership Department of The Hastings Center, 21 Malcolm Gordon Rd., Garrison, NY 10524, (845) 424-4040, (845) 424-4545 fax, [publications@thehastingscenter.org](mailto:publications@thehastingscenter.org), [www.thehastingscenter.org](http://www.thehastingscenter.org). This report was produced with support from The Arthur Vining Davis Foundations and the Nathan Cummings Foundation and in association with the National Hospice and Palliative Care Organization of Alexandria, VA, [www.nhpc.org](http://www.nhpc.org).