



ACCESS TO
Hospice Care
EXPANDING BOUNDARIES, OVERCOMING BARRIERS

The Project on Increasing Access to Hospice Care

In January 2000 The Hastings Center and the National Hospice Work Group, in collaboration with the National Hospice and Palliative Care Organization, began a project on Increasing Access to Hospice Care, with support from The Arthur Vining Davis Foundations of Jacksonville, Florida, and the Nathan Cummings Foundation of New York, New York. A preliminary planning grant from the Nathan Cummings Foundation helped to launch the project with a meeting of hospice and palliative care leaders in September 1999.

The work of the project was organized around the deliberations of a national task force of distinguished experts on hospice, palliative care, and end of life care. Working with numerous other experts on health policy from around the country, the task force comprised a multidisciplinary group of researchers, scholars, policy analysts, health care executives, and health care providers from medicine, nursing, philosophy, theology, the social sciences, and hospice. The task force met four times during the period 2000-2002 to review hospice policy and practice, engage in discussion of the ethical and social values served by hospice care, investigate the barriers to greater access and earlier access to these services, and hear presentations on many facets of care of the dying and health policy. Many of our discussions and much of our analysis were oriented around the perspectives and viewpoints of several stakeholder groups, including: (1) consumer and patient groups, (2) health professionals, (3) the hospice community, (4) policymakers from both the public and the private sector, and (5) the community of professional ethicists and other scholars in the area of health policy and health systems research. In between project meetings, discussion and debate continued through a lively forum set up on a special web site made possible through the support and technical assistance of Bondware, Inc.

This special supplement grows out of the project as a whole and the work of the task force. The lead article, "Access to Hospice Care: Expanding Boundaries, Overcoming Barriers," written by the project co-directors, provides a comprehensive report on the deliberations and conclusions of the project. It is not a consensus document in the sense that each member of the task force endorses it in all details, but we have done our best to present an accurate and faithful reflection of the group's thinking,

and this analysis certainly would not have been possible without the benefit of their insight and expertise. The accompanying essays by task force members Ira Byock, Stephen Connor (writing with Jocelia Adams), Carol D'Onofrio, Linda Emanuel, Bruce Jennings, Hilde Nelson, True Ryndes, Jack Stanley, and Daniel Sulmasy discuss in more detail several key issues that surfaced during the course of our deliberations but could only be touched on briefly in the project report. These thoughtful essays also reflect the breadth and complexity of the issues with which the project as a whole had to grapple.

In addition to the Task Force members and other project participants, this supplement and the project on which it is based would not have been possible without the extraordinary support and assistance of many people. We would like to thank, first, colleagues at The Hastings Center for their contributions, encouragement, and support. An equal measure of credit and gratitude should go to the members of the National Hospice Work Group. They have been more than good colleagues and collaborators throughout the project; they have been constructively critical friends who have kept us on track and kept us close to the practical realities of care for the dying and their families. We are indebted, too, to the board and executive staff of the National Hospice and Palliative Care Organization (NHPCO), especially former president and chief executive officer Karen Davie. Stephen Connor and Chris Cody provided invaluable advice and technical assistance. The current president and chief executive officer of NHPCO, Donald Schumacher, was also an active member of the task force throughout the project in his capacity as president of the Center for Hospice and Palliative Care in Cheektowaga, New York. We thank Tammy Choate and her colleagues at Bondware for providing invaluable web-site support and services, which greatly facilitated the work of our project.

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ILLUSTRATION CREDITS

Diedre Scherer's fabric and thread images on aging have appeared in many shows throughout the United States and the world. She was also the recipient of a Fine Arts Fellowship from the Open Society Institute's Project on Death in America. For more information, visit www.dscherer.com.

The work of Adele Schtern and Judith Selby appears courtesy of OATH, the Organization for Artists Trained in Health Care, located in Philadelphia. For more information, contact muze@erols.com.

Authors

Jocelia Adams, is the founder/clinical director of The Center for Caregiver Training in San Francisco, Calif.

Mary Ann Bailly is associate for health policy and ethics at The Hastings Center.

Ira Byock, is a palliative care physician and Research Professor of Philosophy at the University of Montana.

Stephen Connor, is vice president for research at the National Hospice and Palliative Care Organization in Alexandria, Va.

Carol D'Onofrio is professor, emerita at the School of Public Health, University of California, Berkeley, and has served as consultant to many organizations, including the National Hospice Work Group.

Linda L. Emanuel directs the Interdisciplinary Program for Professionalism and Human Rights at Northwestern University Medical School.

Bruce Jennings is senior research scholar at The Hastings Center and teaches at the Yale School of Public Health.

Hilde Lindemann Nelson is an associate professor in the department of philosophy, and associate faculty at the Center for Ethics and Humanities in the Life Sciences, at Michigan State University

True Ryndes is president of the National Hospice Work Group and vice president of mission and policy for San Diego Hospice.

John M. Stanley is professor of philosophy, emeritus at Lawrence University, Appleton, Wis., and is the former president of American Health Decisions.

Daniel Sulmasy is Sisters of Charity Chair in Ethics at St. Vincent's Hospital Manhattan and director of the Bioethics Institute of New York Medical College.

ACCESS TO

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BY BRUCE JENNINGS, TRUE RYNDES, CAROL D'ONOFRIO,
AND MARY ANN BAILY

Too many Americans approach death without adequate medical, nursing, social, and spiritual support.¹ In the last stage of a long struggle with incurable, progressive diseases such as cancer, heart or lung disease, AIDS, Alzheimer's, Parkinson's, or amyotrophic lateral sclerosis, their pain is untreated or inadequately controlled. Their depression or other mental health problems are not addressed. Debilitating physical symptoms rob them of energy, dignity, and sometimes the will to carry on. Family members who provide care are stressed, inadequately supported by professionals, and often rendered ill themselves by the ordeal. Patients who wish to remain in familiar surroundings at home are often forced to spend their final days or weeks in a hospital or nursing home. Neither dying patients nor their families are provided with the kind of emotional and spiritual support they desire and need.

In sum, too many Americans die unnecessarily bad deaths—deaths with inadequate palliative support, inadequate compassion, and inadequate human presence and witness. Deaths preceded by a dying marked by fear, anxiety, loneliness, and isolation. Deaths that efface dignity and deny individual self-control and choice. And too many Americans have their access to better care and services, through hospice and other forms of palliative care, blocked by a lack of information, misunderstandings, ambivalence about treatment options, unfairly restrictive governmental policies, financial limitations, and other factors that can and must be changed.

Death is an inevitable aspect of the human condition. Dying badly is not. Yet it usually cannot be avoided by single individuals and families acting alone. Dying badly is a social problem that requires a social solution. It is an artifact of the way our health care system is organized and fi-

nanced. And it is a product of our societal failure to perceive the ethical and human cost of limited access to, and inadequate provision of, hospice care. Although the acceptance and utilization of palliative and hospice care have grown, there are still over one million Americans who die each year without receiving the hospice or hospice-type services that would have benefited them and their families.

These are difficult, even daunting, problems in the American health care system today. Who opposes improvements in palliative and end of life care in the abstract? The challenge is to find new practical approaches to hospice care, building on the strengths that this movement has developed over the years and correcting those policies and practices that have shown themselves to be unduly restrictive, unworkable, or unwise.

The challenge of end of life care will grow more serious over the next three decades. The population of seniors in the United States is projected to more than double over the next 30 years, rising from 34 million in 1997 to over 69 million by 2030. At that time, one in five Americans will be age 65 or older. One in nine baby boomers is expected to live to age 90, and by 2040, the number of Americans over age 85 will be nearly four times greater than today.² The United States already struggles to provide basic primary care to its population; more than 40 million Americans are without consistent or adequate health insurance coverage. Either they do not have access to health care at all, or they do not get it in a timely or efficient way. Out-of-pocket expenses for prescription drugs are a significant burden to many, and families must shoulder most of the financial and emotional burden for long-term care. We have been remarkably slow to acknowledge the impending health care crisis that looms ahead, much less the serious problems already with us. Health insurance reform has failed several times since the end of World War II, despite the bipartisan efforts of several presidents. Some incremental efforts are under way, but there is no public or governmental vision of a just health care system as a whole.

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And there is certainly no vision of a health care system adequate to meet our growing needs for chronic and palliative care. Americans are talking and worrying quietly about this, as focus group and opinion survey studies reveal.³

A redesign of the end of life care system must be accomplished in this decade if the nation is to have time to prepare for the challenges ahead. It has taken decades to build the present system of hospice care, and efforts to improve palliative care in hospital settings are only just beginning, yet these achievements will soon have to be substantially improved and augmented.

The purpose of this report is to contribute to the broad goal of improving end of life care by addressing specific problems in access to and delivery of hospice care. Several groups are addressing these problems from various points of view.⁴ The distinctive contribution of our study is that we pay explicit attention to the human values involved in hospice care policy and practice. The report examines the problem of access from the perspective of social justice and equity, or fairness, and we make an ethical case for equitable access on the basis of the moral importance of the needs met and the values served by comprehensive, high-quality hospice care.

We also offer a new vision of hospice, one that holds firmly to many of the traditions and values of the past, but finds new and more flexible organizational forms through which to express those values. The vision we offer is based on the notions of condition-management, community-responsiveness, and continuity-oriented practices. The new organizational forms appropriate to this vision are the model of the “community hospice” and the “comprehensive hospice center.” The past emphasis eligibility must be replaced by a focus on continuity and appropriateness of services given changes in the patient’s and the family’s condition over time. And the model of traditional hospice as a spe-

cialized service and an independent agency with a limited mission 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 various ways as the patient’s underlying condition evolves from diagnosis to death.

Providing access to hospice care is not simply a question of expanding a given service to more people who could benefit from it. The nature and goals of the service itself need to be redefined. We must envision hospice as a potentially new paradigm of social health care for an aging society. If we can learn how to define, organize, finance, and deliver hospice care properly, then we may have found the key to coping with the major problem of caring for staggering numbers of persons with chronic, degenerative disease—the number one problem of the health care systems of the developed world for the next fifty years. Chronic, degenerative disease requires patients and families to make difficult adjustments and transitions in their lives as they pass through various stages and phases of their disease. The experience of chronic disease blends gradually into the experience of dying. The flow and rhythms of hospice, as well as its goals and care plans, must be allowed to match the rhythms of chronic illness, as chronic illness becomes an increasingly widespread social condition. Of all the existing structures and specialties in health care today, hospice has the best chance of successfully transforming itself into this chronic care social medicine of the future.

The promise for a larger mission in the future, perhaps as much as the end of life care that many people lack access to today, is the principal reason for being urgently and deeply concerned about policy reforms in the finance and delivery of hospice.

A Course for Reform

There are two broad approaches to reforming and restructuring hospice and palliative care financing and delivery systems. First, we might supplement existing hospice services with enhanced, high-quality palliative care integrated into non-hospice care settings to form a continuum of care, of which hospice is a part. Second, we might expand the scope and mission of hospices, which have proved their capacity to provide effective palliative care, beyond their current confines to serve populations of patients who have longer to live and who are in various health care settings.⁵ These approaches are not mutually exclusive; in fact, both are needed. In order to further both, we must return to the issue of organizing the financing and delivery of hospice care so as to provide “equitable access.” For the purposes of this report, we define equitable access in the following way: equitable access to health care requires that all citizens can secure an adequate level of care without excessive burdens.⁶

This conception of just or equitable access leads to the following claims:

- Equitable access to hospice services does not exist in the United States, and this constitutes a violation of justice and fairness in our society that should be rectified.
- Many factors limit access to and utilization of hospice services, but governmental policies and professional practices are especially significant. Understanding what steps are appropriate to increase access to and utilization of hospice care services will reveal why we should not define the mission of hospice care narrowly.
- Steps taken to increase access to hospice care and to design the new system should be driven, first and foremost, by an explicit discussion of the ethical values that the end of

life caregiving system should embody.

Beyond justice, when individuals who are dying or who are in the later stages of an incurable illness do not attain access to hospice care services, fundamental social values are not fulfilled. The dying persons, their families and loved ones, and society as a whole are diminished by this failure to respect the autonomy and dignity of the person, to respond to the person's suffering, and to offer care, compassion, and vigilance at the end of life. When so many die without the support of good hospice or palliative care, we have not met our obligation to the most vulnerable in our society, and we have not kept faith with our highest moral ideals.

The nation has the technical expertise and financial resources to provide universal access to much higher-quality hospice care today. A just increase in access should take place principally in three ways: first, by making more people eligible for hospice admission and insurance coverage; second, by lengthening the average time spent in hospice, primarily through earlier referral; and third, by

maintaining both high-quality care and good stewardship of scarce resources through a professionally rigorous case management system within hospice programs.

Each of these three elements of access is ethically important. Justice pertains not only to getting in and staying in, but also to what types of services a patient and family receive once they are in a hospice program. It would do little good overall to expand hospice admission or length of stay while cutting services so drastically that they are of poor quality or little benefit to dying persons. Thinning the soup—"hospice lite," as it is sometimes referred to—is not the answer to the challenge of just or equitable access.

At the same time, justice does not require the provision of all services that patients and families want—indeed, not even all services that they might marginally benefit from—since there are always other ethically important claims on scarce resources, even in the richest countries. Hence, justice requires that hospices be given sufficient funds to provide adequate care, not a blank check. Historically hospice has operated under a system

of fiscal discipline that has worked reasonably well, at least in terms of its case management system and the efficiency of its professional staff. We expect this commitment to case management and quality improvement to continue in the future forms that hospice takes. If the expansion of hospice access we call for here turns out to require a large additional expenditure of Medicare funds, for example, the increase will not be—and should not be permitted by policymakers to be—undisciplined.

In fact, it is not clear how much more money should be spent on hospice, nor what the net increase might be after we take into consideration other health care cost savings produced by broader, better hospice care. We are not in a position to estimate such costs in this study.

In any case, we do not begin this study with a dollar amount. We begin with a description of the system our society needs and should have. We first ask what justice and other ethical values call on us to do in hospice care, and for whom. There will be time enough to devise an efficient way to pay for what ought to be done.

I. What Is Hospice Care?

When the first hospice program in the United States was started in Connecticut in 1973, end of life care was an orphan field of little interest to mainstream medicine, which was busy fighting President Nixon's war on cancer. Death and dying were such socially and culturally taboo subjects that even clergy were uncomfortable discussing them, let alone physicians, family, and friends.

Pioneered in England, hospice took root in the United States during the 1970s and was added as a benefit to the Medicare program in the early 1980s. Its origins lie in a grassroots movement that lay outside the medical mainstream and was informed by an ethic of compassion, dignity, and service. More or less self-consciously, hospice care was initially designed for people who were dying of cancer, and who had a functional family support system and a home where they could be cared for away from the high-tech hospital environment.⁷ Over time, the vision and the values of the hospice movement have developed and matured.

The Spectrum of Hospice Services and the Hospice Philosophy

In the view of most practitioners today, hospice is not limited to any single disease or to any one set of life circumstances for its patients and families. Accordingly, hospice has been expanding in recent years to reach people dying of something other than cancer, who lack family support systems, and who live in institutional settings. Its growth and its capacity to assist dying patients and their families demonstrate the health care and human benefit hospice offers. And although it is still a separate and distinct system in many ways, hospice has become a component of standard of end of life care and a part

of accepted medical practice. Hospice cannot rightfully be a matter of optional purchase for the affluent. If nothing else, the landmark public policy decision in 1983 to include hospice care in the Medicare program put an end to such thinking. Whatever unfairly or unreasonably limits access to hospice care should be seen as a moral problem.

In the past, ignorance about hospice and about appropriate palliative measures has also been viewed as an educational problem. Over the past six years, the Robert Wood Johnson Foundation and other foundations have dedicated tremendous resources to advancing professional and community education initiatives in support of improved end of life care. It is hard to imagine a North American health care provider that has not had the opportunity to learn more about hospice.

"Hospice" is both a concept (that is, a philosophy and a paradigm of care) and an organizational form of health care delivery. Hospice services include professional nursing care, personal assistance with activities of daily living, various forms of rehabilitation therapy, dietary counseling, psychological and spiritual counseling for both patient and family, volunteer services, respite care, provision of medical drugs and devices necessary for palliative care, and family bereavement services following the patient's death. Hospice care is provided by an interdisciplinary care team comprised of nurses, social workers, pastoral counselors, nursing assistants, and other health professionals under the management of a physician, who may be the patient's own primary care physician or may be affiliated directly with the hospice program. Caring for the dying is a complex social enterprise that must involve the families of the dying, religious organizations, the health care system, and the community at large,

from the very local to the national level.

The specific needs of dying persons to which care must respond can be grouped under the headings of physical, emotional, and social well-being. Within each category, the health care system plays an important role in meeting these needs but is never the only actor and not always even the chief actor. Physical needs include a safe, clean, and comfortable place for dying; control of pain and symptoms; appropriate food and nutrition; personal care (aid with bathing, feeding, dressing, and other activities of daily living); information about how best to manage the physical condition of the dying person; and information about the changes in physical condition to be expected over time. Emotional needs include respect for the dying person's dignity as a human being; respect for the dying person's wishes, to the extent possible; information about the emotional changes to expect; counseling to help the patient come to terms with what is happening; assistance with advance planning for death; and attending to spiritual concerns. Social needs include companionship; maintenance of social functioning, to the extent possible; assistance in "telling one's life story" to others; and help in resolving relationships and taking care of other "unfinished business."

Responding to these needs requires access to a complex continuum of care. As a group, people who are dying make use of virtually the entire array of health care goods and services, including acute care, long-term care, mental health care, and health education. Managing pain and other distressing symptoms may require sophisticated treatment regimens and technologies, ranging from carefully tailored drug regimens to palliative radiation and surgery to mechanical ventilation. Feeding and

hydration issues may be addressed by special diets or supportive counseling when patients stop eating. Careful nursing care is required, including bathing, feeding, skin care, and other personal care activities that make a great difference to a sick person's comfort. Health education is necessary to provide information about the physical and emotional changes to expect and to explain what the patient and family can do about them. Mental health services may also be needed, including counseling and the treatment of depression. Patients' symptoms vary tremendously, and with them the appropriate pattern of care.

Some of the care needed must be provided by highly skilled health care workers, but much of it can and should be undertaken by families, friends, and members of the dying person's faith community. Family caregivers may take care of the patient's home, provide meals, help with personal care, offer companionship, and help the patient maintain social functioning. Friends and community organizations may help family members with these caregiving activities. Religious organizations may provide spiritual support to the patient. There is no sharp line separating the care provided by the health care system and the care provided by others; the division of labor depends on the patient's situation and community resources.

Family members themselves also need care and support from the health care system, religious organizations, and the community. Family members are usually the front-line providers of daily care, working in tandem with professional health care providers. To perform their caregiving role well, they need information and training. At the same time, they are themselves patients of the health care system. They need care to prevent and, if necessary, to treat the physical and mental health problems that can be associated with caregiving and bereavement. Again, there is no bright line separating care for family

members and care for the dying themselves; their well-being is profoundly interdependent. What hospice care offers family members includes: information about how to provide care to the dying patient; caregiver support, emotional support, and practical assistance; caregiver respite; help with preparation and advance planning for death; resolution of relationships; and grief counseling.

The subjective preferences of patients vary widely. The objective situation of patients also varies with age, diagnosis, income, family circumstances (some have many caring family members while others have none), social class, type of residence (home, nursing home, hospital, board and care facility, prison, or the streets), race/ethnicity/culture, religion, and geographic location. Therefore, someone must manage the patient's access so the patient can receive care that is compassionate, timely, and in accord with individual needs and preferences. The patient and family members can do some of the coordination, but the task is too complicated for them to handle alone. Given the importance of health care in the care mix and the specialized knowledge it requires, the health care system reasonably takes on the role of integrating the care provided by health care providers with the care provided by family and community.

The Distinction between Hospice and Palliative Care

What is the relationship between hospice care and palliative care? It is a more complicated question than may at first appear. The two labels are often thought to be virtually synonymous, particularly if one bears in mind that the hospice philosophy (if not the Medicare Hospice benefit) has been expanding its ambit over time to include persons who are dying not only of cancer but of many other fatal diseases as well, and not only those who are thought to have less than six months to live but those whose dying process may

follow a longer, more chronic and unpredictable course—who may be referred to as the “chronically dying” or the “chronically terminally ill.” This perspective is consistent with the definition of palliative care formulated by the World Health Organization, which makes it virtually identical with hospice: “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.”⁸

From another perspective, however, the two terms are often taken to refer to different caregiving orientations, time frames, institutional settings. WHO's definition of palliative care goes on to add that “Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anti-cancer treatment.” From a medical perspective, then, palliative care may be taken as the broader term, covering all forms of the prevention and treatment of suffering, while “hospice,” in a narrow medical sense, has been viewed as a subset of palliative care especially targeted to the needs of those near death. This usage seems consistent with the Medicare program, which after all is a hospice benefit and not a palliative care benefit. Palliative care is appropriate whenever symptoms causing pain and suffering are present, and good counsel regarding the consequences of illness and treatment is required, regardless of the underlying medical condition and prognosis of the patient. A child receiving chemotherapy for leukemia, with an excellent chance for recovery and long life, should still receive palliative care as a component of the care plan. Traditional hospice care, on the other hand, has always included addressing the patient's impending death and the reaction to that prospect, whatever additional medical and nursing services it might also involve.

Caregiving at the End of Life

BY STEPHEN CONNOR AND JOCELIA ADAMS

Chances are that as you age, you will either be a caregiver or will need someone to care for you. The amount of care provided by informal caregivers in the United States is staggering. Estimates of the value of these services are \$196 billion annually.¹

We care for grandparents, parents, spouses, friends and neighbors, and children. The average caregiver provides four and a half years of care. Three out of four caregivers are women, who themselves are less likely to be cared for by a family member than their male counterparts. With rare exceptions, our health care economic system does not value or reward caregiving. Caring for a person who will not recover is one of the most stressful of human experiences. People can feel intense psychological suffering in response to caregiving and bereavement. Adverse psychological distress can continue for months and years. Those who report mental and emotional strain associated with the chronic stress of caregiving had a mortality risk 63 percent higher than non-caregiving controls.²

Caring for someone with advanced illness is fraught with hazards and opportunities. The impact of caregiving on health and well-being varies widely. Most who do so are motivated by love and concern. Giving to others can be very rewarding. It can also be very stressful. Many factors determine the extent to which caregiving is a burden and a blessing. Among these are the length and intensity of caregiving, the nature of the relationship with the person needing care, the amount of psychological, social, and physical support provided to the caregiver, the presence of professional caregivers, and the self-perception and emotional health of the caregiver.

The optimal period of caregiving appears to be months rather than years. Most of us can muster the inner resources to devote ourselves to the needs of someone we care about for a distinct period of time. But when caregiving responsibilities are considerable and no end is in sight, we feel more strain. This stress is both physical and financial. Over one-third of terminally ill patients have substantial care needs.³ Long-term, open-ended caregiving is often characteristic of the needs of the chronically ill with advanced disease.

We find it easier to care for someone who is an important part of our emotional life. The closer we are to the person we are caring for, the easier it is to be moti-

vated to provide care. However, closeness is not necessarily defined by familial relationships. One might have a close and intimate relationship with a spouse, for example, and be devoted to his or her care, or one might have an ambivalent, even abusive relationship and provide care resentfully.

Caring for a seriously ill person alone can be an overwhelming responsibility. If we know that there are others sharing the load, we can go on more easily. Also, many need care in order to give care.⁴ Professional caregivers should not supplant the family in the caregiver role, except where the family lacks the physical or emotional resources, knowledge, or desire to provide care. The provision of support and education to caregivers is essential to the ongoing provision of care to the dying. None of us are born knowing how to provide personal care. Effective training programs for caregivers have been developed, but they need to be made more widely available.

How much support is needed to take care of a person in the final phase of illness? Those leaving the hospital have had the advantage of pharmacy services, transport aides, all the special supplies from a hospital bed right down to special cleansers, “24/7” surveillance and monitoring by a variety of nursing staff, dietary services, maintenance, housekeeping, and so on. We send people home who are very sick and do not make the correlation that an untrained person or family will have to do the work of an entire hospital staff. If they are fortunate, they will get hospice care or a limited “prescription” for home health care, which may come after they have already been providing care for a long time.

Many caregivers are ambivalent about their own needs.⁵ They may focus on the patient to the detriment of their own health. Prior history of depression and pessimism are linked to poor adjustment after death. Caregivers who are able to continue participation in valued activities and interests experience less emotional distress regardless of the amount of care provided.⁶

The provision of family caregiving to the dying may help mediate the bereavement process following death.⁷ The combination of family caregiving and professional support creates the opportunity for optimal care delivery. Family members, involved in the care of their loved ones, with the support of an interdisciplinary team, for a period of time, can find that they deal more effectively with their bereavement and have fewer physical symptoms in the year following the death.

The Medicare Hospice Benefit is unique in that it requires hospices to provide caregiver education, support,

Stephen Connor and Jocelia Adams, “Caregiving at the End of Life,” *Hastings Center Report Special Supplement* 33, no. 2 (2003), pp. S8-S9.

and round-the-clock availability for emergency advice or visits. Caregiver support systems such as hospice are likely to reduce caregiver strain and consequent utilization of health care resources. While they are currently unrecognized, reductions in caregiver morbidity and mortality should be factored into cost-benefit studies of hospice and palliative care services.

In a longitudinal study of caregiving partners of men with AIDS, Folkman found the co-occurrence of positive and negative psychological states in the midst of enduring and profoundly stressful circumstances.⁸ While these men felt the stress of caregiving and the painful emotions associated with impending loss, they also felt good about their role and the ability to deepen their relationship with the ill person. These positive psychological states were associated with the theme of having sought and found some positive meaning in the caregiving experience.

Four types of coping seemed to be related to the experience of positive meaning: (1) problem-focused coping, (2) positive reappraisal, (3) spiritual beliefs and practices, and (4) infusing ordinary events with positive meaning. Being able to focus on the day-to-day problems and challenges of caring can be rewarding, particularly if this work is seen as successful and enhancing to self-esteem. Finding a direct connection in the ordinary work of caregiving to this sense of personal meaning and to one's perception of spiritual meaning in life serves as a counterbalance to the negative emotional reactions usually associated with having to perform caregiver duties. Caregiving ought to be redefined as a noble and meaningful role in our society.

Since the need for caregivers is likely to explode in the next thirty years and our health care system is not positioned to be able to offer much assistance, we need to recognize the importance of finding and promoting caregiver support systems that honor and encourage caring for each other. Key to this change is a societal acknowl-

edgement of the ethical imperative to provide care for each other. The contributions of men and women who make the decision to become a giver of care to another person should be acknowledged and, when essential, compensated. Some states, for example, are currently piloting family caregiver reimbursement in an effort to help patients avoid institutionalization. New caregiver support systems need to be constructed and refined to reflect new knowledge about how best to survive and thrive in the role of caregiver. For those of us not yet in need of caregiving, in the end, what we are doing is preparing the way for a system that will assure us of care as we reach the end of life.

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2. R. Schulz et al., "Involvement in Caregiving and Adjustment to Death of a Spouse: Findings from the Caregiver Health Effects Study," *JAMA* 285 (2001), 3123-29.

3. E.J. Emanuel et al., "Understanding Economic and Other Burdens of Terminal Illness: The Experience of Patients and their Caregivers," *Annals of Internal Medicine* 132, no. 6 (2000), 451-59.

4. International Work Group on Death, Dying, and Bereavement, "A Statement of Assumptions and Principles Concerning Psychosocial Care of Dying Persons and their Families, in *Statements on Death, Dying, and Bereavement*, 43-52. Available from IWG Secretariat c/o Bob Bendiksen (Rbendiksen@aol.com).

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6. J.I. Cameron et al., "Lifestyle Interference and Emotional Distress in Family Caregivers of Advanced Cancer Patients," *Cancer* 94, no. 2 (2002): 521-27.

7. S. Connor, "Hospice, Bereavement Intervention, and Use of Health Care Resources by Surviving Spouses," *HMO Practice* 10, no. 1 (1996): 20-23; Schulz et al., "Involvement in Caregiving."

8. S. Folkman, "Positive Psychological States and Coping with Severe Stress," *Social Science Medicine*, 45, no. 8 (1997): 1207-21.

Hospices are rich and complex in virtually all of their facets—in the skills and services they provide, in the needs they meet, in the expectations that people have of them, and in the range of personal and social values they serve. Yet for twenty years, hospice care has been defined, both overtly and implicitly, in public policy and in social attitudes, as being appropriate only for those who are beyond the reach of hope or continued medical care.

This understanding of hospice care must be changed. It drives away

patients and families; it causes many physicians to delay hospice referral; it focuses attention on the grave medical condition and prognosis that accompanies a referral to hospice, and away from the positive nature and aspects of what a hospice program can achieve. People witness or hear about dying without appropriate hospice care and they come to regard that prospect as the expected course of affairs, as something that they must come to accept. Those most supportive of hospice are people who have experienced first hand what it can

achieve. Americans have very high expectations of health care, it would seem, except at the very end. Then their expectations are grim. It is little wonder that so many people have so much difficulty reconciling themselves to the incurable state of their disease or to the futility and likely burden of life-prolonging measures.

Palliative care and hospice are not the care of "last resort;" they are not something that comes after other forms of care have been tried and failed. Palliative care is an integral part of all health care, and should be

viewed in that light. It should be provided in a variety of modes and settings as the patient's condition and life situation call for. Hospice care involves much more than fast-acting pain relief medications; it has psychosocial and spiritual goals and dimensions that can be met only through the building of trust, communication, and relationships that touch the self of the patient and the system of the family, not just the body. It is not for the imminently dying only, but for those wrestling with the complex clinical and personal decisions associated with an eventually fatal illness.

In any case, neither palliative care nor hospice care should signal the end of the physician-patient relationship, but simply a new stage in that relationship, with new goals and new collaborating caregivers. Palliative care should not signal the cessation of various forms of medical treatment chosen by and potentially beneficial to the patient that might lengthen the duration of life or improve the quality of life. Above all, hospice should not—and does not—signal the cessation of hope, but simply a shift of its focus.

Finally, the term “palliative care” is sometimes used to refer to the addition of symptom control and pain management services with the mainstream health care system, whereas “hospice” is used to refer to a structurally and organizationally distinct subsystem that has grown up around the creation of hospice agencies.

This distinction raises a wider and more important systemic question. Should we attempt to expand access to palliative care and to improve the quality of end of life care by adding a new layer of care management system (called “palliative care”), separate from existing hospice programs? Or should we attempt to expand and build upon the existing infrastructure of hospice agencies to achieve the goal of expanded access and to meet the needs of those patients and families who are not well served by hospice as it has been defined in the past?

It is important to recognize that the structure and organizational form of hospice has already been changing over the past twenty years. Many hospices have evolved beyond direct patient care delivery. Some have become social change agents, promoting more than innovative medical approaches. They have become social institutions in which discourse about community values and life planning occurs. They have become educational centers, where health care professionals rekindle their role of caring for patients previously isolated and neglected. Some hospices have become a meeting place for artists, musicians, and others in pursuit of meaning. Many have become known for their expertise in grief, loss, and social reconstruction. In these instances, one might very well say that palliative care is only a subset of hospice; it is only one of the social and health care functions that hospice serves.

We argue for the second of these two approaches. The development of palliative skills and services in hospital, nursing home, and other non-hospice settings is very important and beneficial, to be sure. However, this must be done in conjunction with a hospice care management system. We need coordination and continuity of care, not duplication, rivalry, and competition. The main reason we devote this report primarily to the question of increasing access to hospice care because the existing infrastructure of hospice programs is a national resource of continuing value and viability. We do not need to abandon it and return to the drawing board. And we do not need to build a second, detached system of palliative care to fill the large gaps that hospice currently does not serve. Instead, we should build on the existing infrastructure of hospice agencies and promote their diversity and growth in several directions. In this way we can create a solid foundation upon which to expand access to comprehensive, holistic “hospice-palliative” care.

Patterns of Access to Hospice Care

What do current patterns of access to hospice care look like, and what about them seems problematic? Describing access is not a simple matter. What must be measured is not the extent to which people actually get hospice care, but the extent to which they are able to get it if they want it.

Clearly, information on the volume and distribution of hospice care resources by geographic area is relevant. Also relevant is information on the way these resources are organized, such as measures of the characteristics of providers, the particular services provided, and the process of entering into care. Finally, the ability to obtain care depends on the financial terms on which it is available, such as the prices charged for elements of care and the nature and extent of insurance coverage.

To determine whether people are able to obtain services, information on the availability of services must be compared to the size and geographical distribution of the population at risk and the characteristics of that population that determine whether hospice care services are desired. These include age, sex, race, and ethnicity, family structure, health care beliefs and information, education, income, and health status.

The desire for services combines with physical availability, organization, and financial terms to determine actual use. Although access is primarily about the ability of a member of the population at risk to obtain care, in practice, information on actual use—“realized access”—is very important in determining whether this ability really exists. Therefore, Aday and Anderson, pioneers in measuring access to health care, define access as “those dimensions which describe the potential and actual entry of a given population group to the health care delivery system.”⁹ A description of realized access requires measures of utilization—the type, site, purpose, timeliness, duration, and frequency of

services used—and measures of consumer satisfaction.

This framework contains many areas of ambiguity. For example, how should the “population at risk” be defined—that is, what is the population that is potentially medically suitable? What is the place of health beliefs and information? If a person who might be expected to benefit from hospice care services does not know of their existence, or knows but fails to appreciate their value, does this constitute a barrier to access? We believe that it should. If there are people who do not want the current package of services, but would want a slightly different package that is not available, is this a kind of barrier to access? Again, if their expectation is reasonable, then we believe restrictions of services offered can sometimes be a barrier to access.¹⁰

What is the current availability and utilization of hospice in the United States? Approximately 2.5 million deaths (both unexpected and anticipated) occur each year, and nationwide more than half of those take place in a hospital or other health care facility, although this percentage varies widely among regions of the country. In institutions, as many as 70 percent of the deaths come after some decision not to treat (including a do not resuscitate order). The hospice movement was originally seen by many in the medical community as a hostile counterculture opposed to mainstream medicine. The doctors were not entirely wrong. Nonetheless, with remarkable tenacity, hospice has flourished. Twenty-five years after its inception, an estimated 38 percent of those facing an anticipated death from cancer and from chronic diseases such as CHF and AIDS receive hospice care. Prior to hospice, however, profoundly ill patients in community hospitals and academically oriented metropolitan medical centers were often surrounded by the latest

technological advances to combat disease, yet when deemed “terminal,” they were given rudimentary forms of palliative care at best. They fell victim to medicine’s inability to resolve what Daniel Callahan has called the “conflict about the place and meaning of death in human life . . . a conflict that pits the underlying logic of the research imperative, which is to overcome death itself, against the newly emergent (although ancient) clinical imperative to accept death as a part of life in order to make dying as tolerable as possible.”¹¹

The number of hospice programs in the United States has grown from one in 1974 to some 3200 programs today, and the number of programs doubled between 1986 and 1998. In 1998 there were 540,000 hospice admissions, and in 2001 that figure is believed to be closer to 775,000.¹² The most rapid period of growth has occurred since the early 1990s. Hospice programs tend to be nonprofit (62 percent in 2000) and relatively small, with over half the programs having annual budgets of less than \$1 million, although perhaps 100 programs in the country have budgets of \$7-10 million. In 1995, 60 percent of admissions were for a primary diagnosis of cancer, and more recently, the growth of certain non-cancer admissions may be declining due to regulatory scrutiny. This is particularly troubling in light of the problem of just access.

Although the growth of hospice programs and admissions over the years is encouraging, serious problems remain in at least two of the three dimensions of access identified above—admissions and length of stay. The ethics of access is most easily illuminated by considering patients who



would benefit from hospice care but who are not receiving it at all, and patients who receive hospice care but for such a brief period before their death that they cannot obtain the full benefits of hospice care.

Assume that 50 percent of the estimated 775,000 annual hospice admissions—387,500—are patients with a non-cancer diagnosis. Yet 940,000 Americans die each year of heart disease, 113,000 of lung disease, 158,000 of cerebrovascular diseases, and 23,000 from Alzheimer’s.¹³ These rough figures, which admittedly include sudden and unanticipated deaths, suggest how far we have to go before everyone who could benefit from hospice care does.

But not just any access to hospice is sufficient. The holistic, psychosocial nature of hospice care is such that relationships of good communication, mutual understanding, trust, and empathy must be established between hospice caregivers and patients and families. This ordinarily takes several weeks or more. Hospice physicians and nurses may sometimes be able to get distressing physical symptoms under control within forty-eight hours, but such crisis-oriented care is a far cry from complete hospice care.

The picture presented by data on length of stay in hospice is not encouraging. According to a study conducted by the National Hospice and Palliative Care Organization, the average length of stay (ALOS) has been declining steadily since the early 1990s, which is precisely the same period as that of hospice's most significant growth. In 1992 the ALOS was 64 days. By 1995 it had declined slightly to 61.5 days, and by 1998 it

had dropped to 51.3 days. The range among reporting programs was from 12 to 186 days. Data for 1999 indicate that this trend has continued, with the ALOS dropping to 48 days. Crucially, the Medicare Hospice Benefit, which many consider too restrictive, is built on the expectation that patients may be enrolled in the program for up to six months (210 days) before their expected death.

Data on the median length of stay (MLOS) show a similar pattern. The national MLOS in 1998 was 25 days, with a range from 3.5 days to 112 days. The extraordinary difference between the 1998 ALOS of 51.3 and the MLOS of 25 suggests a very large number of programs and patients with an exceptionally brief enrollment in hospice. Anecdotal evidence from around the country tends to confirm that impression.

II. The Ethical Imperative for Access to Hospice Care

The nature of the care that dying patients and their families and loved ones receive is fundamentally a question of values and ends, not of technical details and means. It is fundamentally a statement about who we are as a nation and as a community, for our moral identity is nowhere better tested and tempered than in the respect and care we show to those in the twilight of life.

Diseases and frailty are essentially disorders of human being, involving physical, cognitive, emotional, social, and even spiritual aspects. They create discomfort and disability and may impair one's ability to lead a personally meaningful and desirable life. Diseases frequently cause profound personal, familial, and social consequences. Whether acute, chronic, or terminal, what we refer to as the patient's and family's "condition" represents the totality of their experience in reference to a disease.

It was medicine's failure to exercise its art in response to the patient's and family's condition that made the United States receptive to hospice. The preferences and values of most Americans are not always in synch with the aggressive life-prolonging treatment that mainstream medicine offers. Large public opinion surveys have for many years confirmed that Americans are concerned about the circumstances of dying and the end of life care they and their loved ones are likely to receive. Fear of loss of personal control, of being a burden, of being abandoned, and of suffering from unrelieved pain stand out among the most common worries.¹⁴ As much as we want, we cannot suppress the question of what counts as a "good death" (or, perhaps more accurately, "dying well") and what counts as good care near the end of life.

Values in Care of the Dying

All cultures consider the period when people are dying to have special significance, and America is no exception. Moreover, despite this country's tremendous diversity, research suggests that there is surprising agreement among Americans about what is important at the end of life.¹⁵ The strongest message that emerges from this research is the importance Americans attach to maintaining their independence and having their personal values and preferences respected as they are dying. They want information about what is happening to them and what their options are. Many fear "being hooked up to machines" in circumstances in which their quality of life is low, but they are not anti-technology per se. Rather, they see decisions about the use of life-extending technology as a matter of balancing benefits and burdens, and they want to be the ones to do the balancing and to decide when it is time to forgo the benefit. Once it is clear that death is inevitable, most people would prefer to die at home rather than in a hospital.

Americans value compassion in their caregivers, in the sense of empathy—the ability to sense what a patient and family are feeling and act accordingly. The most important act of compassion health care providers can perform is the alleviation of pain and control of suffering in all its forms. What many fear most about dying is the suffering and loss of dignity experienced by persons in severe and constant pain.

Trust is of paramount importance. People want to be able to trust health care providers and the system as a whole to act in their best interests. They want to be able to trust the information they receive about their condition and their treatment options. They want to be able to trust the health care system to respect the

decisions they make, or their families make, if they are no longer capable of decisionmaking.

People who are dying are often concerned with spiritual or existential issues and struggle to come to terms with the meaning of life in general and their own lives in particular. Some have an explicit faith in religion (organized or individual), and expect to be able to turn to it for support. Others may have a more generalized belief that the course of life and destiny are in the hands of a power or powers beyond human control.

Dying persons and their families have a strong sense of mutual obligation. The dying want to be surrounded by and cared for by family, and families normally attach great importance to being able to be with them and care for them. (The families of some persons with AIDS maybe an exception.) Family members believe they have a moral obligation to provide this care and support; at the same time, dying persons do not want to be a burden and believe they ought to be concerned about the well-being of their families. They believe they should take their families' financial, mental, and emotional well-being into account in the decisions they make about end of life care, and they try to clarify their wishes to their families to lessen the burden of decisionmaking in case they become unable to make decisions.

Americans also recognize a societal obligation toward those who are dying. Dying is the ultimate private event, but it is also a profound social event; the community is automatically and inherently involved. Most Americans consider dying alone and in pain to be a tragedy. They believe that the community has an obligation to act when a dying person has no family, or his family is unable or unwilling to meet its obligations of care at the end of life. In a society as rich in resources as the United States, it

Health Care Justice and Hospice Care

BY DANIEL P. SULMASY

Most theories of health care justice account inadequately for hospice. They tend to regard death as an external force rather than as something to be integrated into an overall theory of care. They tend to be very individualistic. And they tend to assume relationships of equal power among independent agents whose conception of justice is the delineation of fair rules.

Yet for most of health care, and especially for the care of the dying, these assumptions make no sense. First, as hospice workers know well, death can be a friend. Second, health care is consummately about relationships. Hospice workers also understand this clearly. Third, health care relationships, especially in attending to the dying, are characterized by profound inequality, dependence, and loss of control. And in the face of sickness and death, the ultimate question is whether life itself, not any rule, is really fair.

To account for these clinical realities, an adequate theory of health care justice must have something substantive to say about human beings. Here, I will merely assert that human beings are characterized by three features that are especially relevant. First, as Aristotle insists, human beings are naturally social. This is sometimes referred to as a principle of social solidarity. Second, human beings are finite. Death is an intrinsic element of our humanity. Theories of health care justice must take human finitude seriously. Third, human beings have a radically equal intrinsic worth or dignity that commands the respect of others, independent of our preferences.

A human need may be defined as something required for human flourishing. Indisputably, the finitude of the body of each and every human being is both the limiting term of all possible individual human flourishing and also precisely the need that medicine, nursing, and the other health care professions serve. Health care professionals all profess publicly to serve the needs of those whose bodily finitude renders them vulnerable, diminished in power and control, and unable to help themselves. Health care professionals recognize the claims made on them by the dignity of the sick and by their own solidarity with them.

The finitude that the health professions address manifests itself in three ways—death, disease or injury, and symptoms. These correspond (roughly) to the traditional

Medieval aphorism about the goals of medicine—“To cure sometimes, to relieve often, and to comfort always.”

Meeting these needs requires resources. But the resources human beings may use to serve each other in their unequal bodily finitude and their equal human dignity are always scarce. By what criteria can one judge how best to apportion scarce health care resources in order to promote human flourishing? This is a question of justice, and justice requires criteria by which to make such judgments. I suggest six material considerations. The first five are commonly invoked in discussions of scarce medical resources, but are not usually considered in the context of human finitude, dignity, and solidarity. The sixth is almost never considered except as the sum of the other five. These material considerations are: (1) individual need, (2) prevalence, (3) prospect of success, (4) alternatives, (5) cost, and (6) contribution to the common good. For the sake of illustration, let us compare flu shots, liver transplants, and hospice according to these material considerations.

Need. The need for hospice care is very high. Symptoms diminish human flourishing, not just death. The dignity of the dying is never less than that of the surviving. Relieving an agonizing death is as much a part of medicine as is preventing a serious illness or preventing a premature one.

Prevalence. As many as 70 percent of Americans will have needs that could be addressed by hospice. By contrast, only about 1 percent of vaccinated persons individually benefit from vaccines, and fewer than 0.1 percent of persons will ever be eligible to benefit from a liver transplant.

Success. The prospect of success for hospice is extremely high. Well over 90 percent of persons achieve satisfactory symptom relief with appropriate palliative care. By contrast, even excellent flu vaccination programs achieve only about 75 percent success. And liver transplants carry a 50 percent five-year mortality rate.

Alternatives. The alternative to hospice is grim—the prospect of dying an agonizing death. By contrast, the alternative to flu vaccines is reasonable—treating influenza cases as they arise—either symptomatically or even with anti-viral drugs. But what is the alternative to liver transplant? A rational person would hope that it would be hospice. Many who need a liver will not receive one, and those who are transplanted will still die. And they could all benefit from hospice. In other words, it may actually be unjust to offer liver transplantation *unless* one can offer a program like hospice.

Daniel P. Sulmasy, “Health Care Justice and Hospice Care,” *Hastings Center Report Special Supplement* 33, no. 2 (2003), pp. S14-S15.

Cost. The cost of transplant is extremely high, the cost of flu shots very low, and the cost of hospice low to moderate.

Common Good. The common good is clearly served by flu vaccines. But hospice arguably not only serves a prevalent human need, but also accomplishes much on the interpersonal level that enhances the common good. The opportunities for interpersonal reconciliation, caring, and solidarity that are afforded by hospice redound quite substantially to the common good. In a robust understanding of the common good, the flourishing of each person is partly constituted by the flourishing of others. This means that we all benefit when the dying are treated well. By contrast, liver transplantation helps very few persons and contributes minimally to the common good.

This exercise suggests that, weighing all these material considerations, hospice compares well with prevention

and high-tech medicine. Hospice can claim, in justice, significant medical resources vis-à-vis other medical interventions. Human flourishing is well served if people do not die miserable deaths, both for the individuals themselves and the community with which those individuals are in solidarity.

As evidence, one need only look to the poorest of poor nations. Those with *no* resources palliate, as best they can, their dying kinspeople. Ask any clinician what he or she would take to a desert island. I suspect the list might include aspirin, morphine, two antibiotics, a few vaccines, and a textbook of surgery. These are the fundamentals. To palliate the dying is to give them their due. This is what we owe each other, out of mutual respect for our common dignity and in solidarity with each other as fellow mortals. As a matter of justice, hospice is the least we can do.

would not be right to let people “die in the gutter.” There is mutuality in this obligation, as there is in the obligations of dying persons and their families toward each other. People consider it appropriate that both individuals and the health care system have a sense of responsibility toward society as a whole and manage end of life care so that resources are not wasted on over-treatment.

These are the values implicit in discussions of end of life care in America. These values are essentially moral values; together, they constitute a moral framework with important implications for the content and characteristics of care and for the distribution of responsibility for the caring.

Equitable Access to Health Care at the End of Life

Society's obligation to provide end of life care plainly encompasses an obligation to provide equitable access to health care at the end of life. Yet this obligation is linked to a larger issue, that of equitable access to health care in general. Health itself, insofar as it is the absence of pain, suffering, and serious disability, is a “primary good”—something that is good for a person whatever his or her other ends, values and preferences.

Health care contributes directly to health and therefore to personal well-being by preventing or relieving pain, suffering, and disability, and by restoring lost function. In these ways, it facilitates the continued capacity of a person to act, to maintain dignity and integrity, to retain the capacity, in short, to have a life, instead of merely being alive.

Health care also expands the range of opportunities available to a person by helping to maintain the ability to function as normally as possible despite disease or disability. Even when all it can offer is information, health care can make a person better off; it can reassure or provide guidance on how to adjust.

Finally, health care—at least ideally and potentially—has profound interpersonal significance; it nurtures bonds of empathy and compassion in a society and providing a concrete expression of community solidarity in the face of suffering and death.

In recognition of this special importance, most countries throughout the world, including the United States, acknowledge a societal moral obligation to achieve fairness, or equity, in access to health care for all their citizens. Translating this moral commitment into practical policy is a critical social and political task. How should the term “equitable access to

health care” be interpreted? Access to what? At what cost? In this country, the interpretation that best reflects American values as expressed in health policy debates over the years is “access to an adequate level of care without excessive burden.” An adequate level of care is also referred to as a basic level, or a decent minimum.

The key characteristic of the concept of an adequate level is its explicit acknowledgement of limits on the extent of the societal moral obligation, limits that arise out of the inherent scarcity of the resources a society has available to it. The concept is most easily appreciated by comparing it with other ways to define a morally required level of care. For example, equitable access could be defined as access to whatever care would be of benefit. This definition ignores the reality that the benefits of health care vary in importance, from the preservation of life to the elimination of minor inconvenience, and some highly beneficial care is extremely costly. To guarantee universal access to all care of any benefit would be prohibitively expensive and would compromise the ability to spend resources on other important social goods.

Another alternative is to define equitable access as equal access. What

matters, in this view, is not what everyone gets, but that everyone gets the same. (Equality is, of course, interpreted relative to health state; if anyone with a certain liver disease can get a liver transplant, everyone with that disease should be able to get one.) This approach seeks to avoid specifying the guaranteed level; however, it cannot succeed. Given the inevitable differences in incomes and personal preferences, people in the same health state are likely to opt for different levels of care. Maintaining equality would require leveling up to the highest amount chosen or down to some lower amount. Leveling up takes society back to everything of benefit, or worse (since some people may use care that is not medically beneficial). Leveling down requires society to choose the level that will be guaranteed and then to prohibit people from buying more with their own resources. This would be considered an unacceptable restriction on liberty in the United States and probably could not be enforced.

So, one returns to defining equity as access to an “adequate level”—a level of care that may be less than all beneficial care but is enough to achieve sufficient well-being, opportunity, information, and evidence of interpersonal concern to allow a reasonably satisfying life and peaceful death. Care above this level has no special moral status. People who want more than the adequate level can get it, but society has no moral obligation to help them get it (although there are practical reasons a society might want to encourage the consumption of particular health services, just as for other consumer goods).

This analysis identifies a central question for health policy: How should a society determine the content of the adequate level? This is a question which countries around the world are struggling with. The logic of the argument for basing health policy on this concept does not give a definitive answer, but it does indicate

some characteristics the adequate level must have.

For example, the adequate level varies with the availability of resources in the society. Since the benefits of health care must be weighed against the benefits of the competing uses for resources, rich societies can be expected to set a higher standard of adequacy than poor societies. In adjusting the definition of adequacy to available resources, the values and priorities of society’s members are important in guiding the trade-offs among different kinds of health benefits and between health benefits and other social goods.

Therefore, the adequate level’s content cannot be determined solely by health professionals. Moreover, since the adequate level depends on technology, resource availability, and individual and societal values and preferences, it cannot be settled once and for all. Rather, it must be allowed to evolve over time in response to changes in technology, resources, and preferences.

The importance of health care (that is, the extent to which it is a special good) depends on an individual’s health state or condition; therefore, adequacy must be defined in relation to health state. Defining adequate care for a health condition requires specification of both the amount and the quality of health care to be received. An adequate level is best understood as an entire standard of care, not an insurance benefit package that merely lists the categories of services covered. In hospice practice, it would pertain not only to admission and recertification decisions, but also to the ongoing case management and care planning process.

Finally, the adequate level does not include all potentially beneficial care, but it can allow for choice. A range of cost-worthy treatment options for a condition can be included in the guaranteed standard of care to accommodate different patient preferences.

The companion concept of excessive burden refers to the cost of meeting the societal obligation to achieve equitable access. Guaranteeing access to adequate care does not mean providing care for free. On the other hand, expecting people to sacrifice everything else important in order to obtain health care would be inconsistent with the reasons for accepting the existence of a societal obligation to ensure access. The intermediate position is: People should be able to obtain an adequate level of care without having to bear an excessive burden, whether in money or in other costs such as waiting and travel time.

Given the unequal distribution of income and of ill health, ensuring that no one bears an excessive burden to obtain care will mean that some will pay less than the full cost of their own care and others will pay more. Equity requires that the final distribution of the total cost of guaranteeing access to an adequate level of care not impose an excessive burden on anyone. As with defining adequacy, deciding what “excessive” means is a difficult value judgment.

Given this definition of equitable access, the question for this report is the place of end of life care—in particular, the place of hospice care—within the level of care that all should be able to obtain without an excessive burden on themselves or their families. Some implicitly assume that care for the dying should be of low priority in defining the morally required level of care. This assumption can be seen in the repeated suggestions that the best place to look for cost savings in health care is in the care provided in the last year of life, and in statements that define the goal of a health care system as “maximization of the health of the population.” The focus naturally turns to those types of health care that can stop a life-threatening infection, rebuild a shattered leg, stave off the onset of a chronic disease, or restart and even replace a human heart. Of course access to these types of health care seems very important.

For many years it has been a standard feature of health policy analysis to assess various medical treatments in relation to their capacity to extend the life of the patient. While that rather crude mode of cost-benefit assessment has been superseded with the more discerning concept of “quality adjusted life years” (QALYs), the forward-looking bias remains. One influential philosophical theory of just distribution of health care is based on its role in maintaining normal human functioning and thereby fostering equality of opportunity for individuals to pursue their life plans and realize their goals.¹⁶ But what about those who have no future, only a present and a past? What argues in favor of expending resources on them?

Increasing individual opportunity is part of the story, but it is not the whole story. For much of human history, medicine was relatively powerless against disease and disability. People hoped to be made well, but in practice the medical practitioner’s main role was to explain what was happening, suggest simple palliative measures to ease the patient’s suffering, and, most importantly, be there to help the patient and family get through the experience. Yet despite their limited ability to cure, providers of health care had a special status and health care was considered to be of special moral importance.

In fact, we maintain that the connection of health care to death and dying—its role in easing a person’s passage from this world—is at least as important as its preventive and curative functions in explaining the universal moral significance attached to its distribution. In the words of a Presidential Commission charged with examining the ethical implications of differences in the availability of health care:

Since all human beings are vulnerable to disease and all die, health care has a special interpersonal significance: it expresses and nurtures bonds of empathy and compas-

sion. The depth of a society’s concern about health care can be seen as a measure of its sense of solidarity in the face of suffering and death. In spite of all the advances in the scientific understanding of birth, disease, and death, these profound and universal experiences remain shared mysteries that touch the spiritual side of human nature. For these reasons a society’s commitment to health care reflects some of its most basic attitudes about what it is to be a member of the human community.¹⁷

Since relieving pain and suffering is a primary goal of health care and the “specialness” of health care is closely related to the special vulnerability of the sick and the dying, hospice care is surely among the most basic of health services. In the current health care system, hospice comes the closest to providing the kind of services that conform to the values outlined above. It 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 caregivers, and the extent to which the manner of dying of a person concerns not only the person who dies, but family, friends, and the entire community.

The content of the adequate level should reflect the priorities of the members of the community. Consumer surveys and focus group studies such as *The Quest to Die with Dignity* provide evidence that Americans place a high priority on compassionate care for the dying.¹⁸ Additional evidence comes from the community meetings held to determine health care priorities for Oregon’s Medicaid reform, in which participants placed a high priority on palliative care for the dying. Even stronger evidence is provided implicitly by the very existence of the Medicare program and the Medicare Hospice Benefit. As a nation, we have not succeeded in establishing a health care system that

provides universal access to adequate care, despite our shared recognition of a societal moral obligation. Yet we have chosen to guarantee health care to the elderly, those who are beyond their economically productive years and in the last phase of life. Medicare’s coverage structure is flawed and does not fully meet the societal moral obligation, however “adequacy” and “excessive burden” are defined. Nonetheless, one thing the program does include is explicit coverage of hospice care.

In sum, given American values, including community philanthropy and expressed views on priorities in the face of resource scarcity, we conclude that timely, compassionate and appropriate hospice care belongs in the morally required level of care. To say this is not, however, to say that hospice providers should receive a blank check to provide hospice care in whatever way they see fit. Wise use of health care resources is still required. Wise use entails cost-conscious organization and delivery of the services that are provided. It entails a division of responsibility for care between the health care system and the rest of the community (including family, friends, and religious organizations) so that the burden of care, and particularly emotional and social support, is shared. And finally, it entails the recognition that while the hospice care enterprise as a whole is of very high priority, some end of life care services will sometimes not be sufficiently beneficial to warrant their cost, given the other possible uses for the resources. Throughout this report, we discuss the ways in which the structure of hospice care should be brought under scrutiny and redesigned to remove barriers to access, improve coordination of care, and offer a morally acceptable but cost-conscious continuum of care.

Pictures of Persons and the Good of Hospice Care

BY HILDE LINDEMANN NELSON

What I will call “distributive models” of health care justice cannot supply a rationale for expanded access to hospice care. These models fail because they are based on two misleading pictures: the picture of the moral agent, who resembles few of us as we lie dying and doesn’t look much like the loved ones who care for us either, and the picture of the good to be distributed, which seriously misrepresents the kind of good that hospice care consists in.

The Picture of the Person

The distributive model of justice is predicated on a picture of persons who compete for their share of life’s goods by planning a course for their lives and then bringing the plan to fruition through hard work and self-discipline. Norman Daniels’s argument for regarding health care as one of the basic social goods, for example, is that health care prevents, maintains, restores, or compensates for departures from normal species functioning, and that normal species functioning is an important component of the opportunity range—the array of life plans—open to individuals in a society. Daniels’s argument, in effect, is that because ill health or disability threatens people’s ability to live according to the plans they have set for themselves, health care is owed to everyone as a matter of social justice.¹

Margaret Urban Walker has recently contended that the normative assumption that people have “life plans” is found in a cultural theme with a long history—“the idea of *each individual life as a career*.” The “career self” who lives out this life creates a plan that permits him to be

economically and socially productive. He sets himself a course of progressive achievement, which he navigates by being fit, industrious, law-abiding, and, above all, self-disciplined. “It is a picture,” remarks Walker, “of autonomy as energetic self-superintendence with a consistent track record over time to show for it.”²

The picture of the career self, however, far from being a neutral representation of persons as such, is a picture of only some people’s lives, and even then it is not a particularly accurate picture, because it leaves out the times in the life trajectory when the career self could not yet, or can no longer, pursue the projects or goods that give his life meaning. The career self was never an option for those who are poor, chronically ill, severely disabled, or the object of others’ domination or control. And it was never intended for women. Women’s task was to play the supporting roles of homemaker, domestic servant, and care giver that both freed and compelled men to become career selves. Most importantly for present purposes, the career self is not an option for the dying person who is no longer economically and socially productive. “Life plans” aren’t doing the right kind of moral work here. At best, they are irrelevant, and at worst, the thought that they are required for personhood gets actively in the way of any useful analysis of access to hospice care.

The Picture of the Good

The language of “delivery” and “market,” and the examples running through the literature of cars, potato chips, or, in Daniels’s essay, coffee, suggests that the picture of the goods underlying distributive models of justice is that of commodities on a shelf, waiting to be parceled out equitably. To some extent, the goods of hospice are indeed the material goods the distributive para-

Hilde Lindemann Nelson, “Pictures of Persons and the Good of Hospice Care,” *Hastings Center Report Special Supplement* 33, no. 2 (2003), pp. S18-S19.

Locating Responsibility for Achieving Equitable Access to Health Care

If health care is assumed to have special importance to individual well-being, then one might argue that individuals can be expected to bear the responsibility for securing access to it themselves. Indeed, individuals bear some responsibility; however, given the often unpredictable nature of health and costly nature of health care, most people cannot ensure access to adequate care simply through

their own individual actions. Collective action, including political action, is required to achieve equitable access.

Health care, especially modern scientific health care, is a social product. Individuals cannot produce it for themselves. Moreover, unlike other basic needs, such as the need for food, clothing, and shelter, the need for health care is distributed unevenly and unpredictably across individuals, and the cost of securing care can be high relative to income. Individuals cannot completely control their

health status through their own efforts and thereby avoid this cost altogether. Individual behavior does have effects on health status, but the effects are complex and poorly understood, and behavior itself is not always the result of informed and voluntary choice. Given the potential cost, most people also cannot be sure of their ability to pay for adequate care for any health condition that might strike them unless there is some social mechanism to spread the cost.

digm represents them to be. There are drugs on the “commodity shelf”—likely a hospital bed, perhaps a supplemental oxygen machine, a morphine pump, other paraphernalia of the sickroom. And there are commodity-like services provided by paid professionals.

But these, presumably, are not the only “goods” that the dying have in mind when they express the wish to be cared for by members of their family. I suspect that they are thinking instead of the goods of relationship, not commodities on a shelf. 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 decubitous ulcers—he is also conveying his love and concern.³ 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.

Justice and Expanded Access to Hospice

While questions of distribution surely must have a place in any theory of justice, regarding them as paradigmatic overinflates their importance, as my corrected pictures of persons and goods is meant to show. A theory of justice that focuses primarily on the distribution of commodities misses too many of the other ways in which moral agents (and the societies that shape them) can be guilty of injustice.

It seems, then, that we need a better theory of justice. If we begin from the fact of human vulnerability, it might be possible to argue that health care is a universal right, not because it levels the playing field so that members of a society can compete on a more equal footing for the goods and services on offer there, but because of our shared vulnerability to pain, meaninglessness, trauma, disability, and death. On what we might call a responsibilities-to-the-vulnerable model of justice, expanded ac-

cess to hospice care is justified less by appeals to the centrality of such care for the array of life plans open to people in a society than by society’s responsibility to look after its most vulnerable citizens. It is a right, not because it fosters our ability to be productive workers and conscientious consumers, but because the protective membrane between any of us and unbearable suffering is often so thin.

On this model of justice, the dying have a claim against society to a basic minimum of care that falls under two headings. The first is relief from pain, nausea, and other forms of physical suffering—this is the palliative care arm of hospice. The second kind of care is whatever relief from spiritual and existential suffering the dying can take from their connections to something greater than themselves, whether this be God, their loved ones, the flourishing of their community, or some combination of these. This is the “home” arm of hospice.

I would have to say a good deal more about the responsibility-to-the-vulnerable model of justice before it could be made to serve as the basis of an argument for expanded access to hospice. If, however, I am right about the pictures of persons and goods that underlie the distributive model, correcting those pictures in the light of my criticisms might show us how such an argument could begin.

1. N. Daniels, “Equity of Access to Health Care: Some Conceptual and Ethical Issues,” in *Securing Access to Health Care: The Ethical Implications of Differences in the Availability of Health Services*, vol. 2: *Appendices, Sociocultural and Philosophical Studies*, by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (Washington, D.C.: U.S. Government Printing Office, 1983), 41.

2. M.U. Walker, “Getting Out of Line: Alternatives to Life as a Career,” in *Mother Time: Women, Aging, and Ethics*, ed. M.U. Walker (Lanham, Md.: Rowman & Littlefield, 1999), 100-102.

3. L.A. Blum, *Friendship, Altruism and Morality* (London: Routledge and Kegan Paul, 1980); H.L. Nelson and J.L. Nelson, *The Patient in the Family: An Ethics of Medicine and Families* (New York: Routledge, 1995).

There are private social mechanisms for spreading the cost, namely private health insurance and private charity, but they are inherently insufficient to achieve equity. There are many reasons a private health insurance market cannot achieve equitable access by itself. To give just two, in a private insurance market premiums cannot be adjusted in accord with income, and they will be adjusted in accord with individual risk (to the extent that risk can be predicted from information such as age and personal

and family health history). This results in lack of access to adequate care for some of the poor and for those at high risk, and excessive burdens to obtain care for others. Private charity can fill in some gaps, but it, too, has never been sufficient to ensure adequate care for all. Lack of generosity plays a role, but also important is the fact that charitable action requires the coordinated efforts of many people to be effective, especially if the goal is a stable guarantee of adequate care for all those who cannot obtain it for

themselves. Lacking assurance that the donations of others will be forthcoming, people may fail to express their generous impulses or may direct them to other causes.

For these reasons, the ultimate responsibility for ensuring that the societal moral obligation to ensure equitable access to health care is met falls upon government, which exists to serve as an instrument for collective action. In all countries, including the United States, the government plays a substantial role in the provision of ac-

cess to health care. Other industrialized countries have created organized health care systems, under government supervision, in which close to universal access is provided to a level of care that at least approximates an adequate level. As noted, all are struggling with the issue of how to determine whether the care provided is in fact adequate; however, the debate takes place in a comprehensive system in which a cost-conscious standard of care has already been established.

Unfortunately, the United States has not achieved this much. Our health care system remains a patchwork of uncoordinated public and private financing and delivery structures that fail to meet the equity standard, for any reasonable definition of “adequacy” and “excessive burden.” Some might argue that the lack of progress toward equitable access creates serious doubt as to whether Americans really believe in a societal moral obligation to achieve it. Yet both the rhetoric and the actual content of American health policy over the years demonstrate the existence and influence of this belief. The problem is a political stalemate on the appropriate means to achieve equitable access, one that seems to be very difficult to resolve. Thus it is within the context of an extremely flawed and inequitable overall health care system that we must, for the time being, consider access to hospice care.

Stakeholders in Hospice and Their Responsibilities

The moral responsibility for improving access to hospice care is best considered from the vantage point of key groups and institutions that play a role in it.

Individuals. Unfeeling though it may sound, individuals have a moral responsibility to face the prospect of their own deaths. There are psychological and cultural difficulties with upholding this responsibility. But the costs and consequences of a widespread failure to do so are too high. Facing one's impending death in a re-

alistic and mature way enables a person to engage in advance health care planning, thereby reducing the uncertainty and the anxiety of family and loved ones. And doing so may lead more persons with critical and terminal illness to prompt their physicians—to give them moral permission, so to speak, to refer them to hospice programs when appropriate. Patients wait for physicians to bring it up, physicians wait for patients; someone must break this vicious cycle.

Individuals also have a responsibility, as consumers of health care and as citizens, to support societal efforts to create a just end of life care system (and a just health care system as whole). Research suggests that Americans agree in principle that they ought to do this; however, the same research indicates that people are uncomfortable thinking about death and therefore find it difficult to live up to this responsibility. Some of the recommendations in this report address the educational and cultural challenge of overcoming widespread avoidance of the topic of death and dying.

Families. Research suggests that Americans recognize a moral obligation to care for family members who are dying, and most would like to fulfill this obligation. Given the changing structure of American families and changes in women's labor force participation, fulfilling this obligation is already difficult for some families; if current demographic and social trends continue, the difficulty is likely to worsen. When the dying process is prolonged, when the patient has a condition (such as Alzheimer's disease) that requires an exceptional level of care, when the available caregivers have other significant demands on their time and energy (such as young children or a demanding yet financially necessary job), and when financial resources are very limited—the family may be overwhelmed. A major goal of hospice care is to provide the support each family needs in order to provide care to the dying person

without suffering serious adverse consequences themselves—without, that is to say, undue or excessive burden.

Organized religion. Religious groups have always been sources of support for the dying and their families. Religion plays a major role in society's attitudes toward death and dying, and the work of the professional clergy and organized religious communities help terminally ill individuals with spiritual support and caregiving assistance. Given these traditional functions of churches and religious denominations, it is somewhat surprising that more attention is not paid to end of life care issues in the professional training of clergy and that more congregations do not feature educational programs to make fellow congregants aware of the planning they need to undertake, or the resources they need available, when faced with a serious illness. Clergy must become more knowledgeable about hospice in the years ahead, and the churches of America should be tapped as a resource for reaching large numbers of people with educational programs about hospice and about end of life care generally.

Physicians. Since antiquity, the profession of medicine has acknowledged the special moral obligation that makes medicine a profession, not simply an occupation: the obligation to do what is best for patients. To fulfill this obligation, physicians must do more than offer a routine set of services to all patients or passively provide whatever a particular patient asks for. Rather, the physician must actively help patients discover what is best for them. Physicians have a moral obligation to make hospice care part of this process so that patients can make informed decisions about the role these services should play in their care.

The physician's obligation to the individual patient generates a related obligation at the level of the profession. Physicians as a group exercise great influence on the content of medical practice through their control over medical education, entry

Hanover Hands
© Diedre Scherer, 1996, 27"x30",
fabric and thread

into the profession, and peer review of physician performance. If there is widespread dissatisfaction with end of life care, physicians have a responsibility to cooperate with one another to make the available care more responsive to patients' values and preferences. Physicians have long acknowledged this corporate obligation, although they have not always done all they should do to meet it. Significant change is already under way, but more effort is needed.

Finally, physicians have an obligation at the level of the entire health care system. The existence of this obligation is more controversial. Many physicians maintain that their responsibility is only to individual patients. Moreover, they argue, they have no control over the structure of the system and are themselves at the mercy of third-party payers and the government. It is true that physicians cannot dictate the structure of health care financing and delivery and so cannot be held responsible for it. But they can be held responsible as individuals and as a profession for cooperating with well-conceived efforts of others, including the government, to improve the health care system and make it more responsive to patient values.

Recently, there have been calls for "a new medical ethics"—one in which the focus of ethical obligations shifts from individuals to populations. Physicians do have moral obligations toward society as a whole, concerning public health and the health of populations. But these obligations are not new, and they are compatible with traditional understandings of medical ethics. We would argue instead for a broad understanding of that tradition. In our view, the obligation to cooperate in producing a



fairer and more responsive health care system is not in conflict with the physician's obligation to serve the interests of the individual patient; rather, it is an integral part of it when those interests are less narrowly conceived.

In this project, the health profession stakeholder group identified continuity of care as an important value in hospice care. Continuity of care is extraordinarily difficult to achieve in the current health care system. An individual physician cannot achieve it for his individual patient. What is really needed is structural change to overcome the reimbursement and organizational obstacles to continuity of care. Physicians have a moral obligation to highlight the importance of continuity of care and cooperate with others to bring about this change—not for the sake of an amorphous entity called a "population" or "society," but for the sake of their individual patients, whose care is compromised by the lack of continuity.

Organizations that provide and/or pay for health care. The belief that health care has special moral significance also shapes the responsibilities of the organizations that play important roles in the financing and delivery of health care, the provider and the payer organizations. These organizations have moral obligations to the people they serve and to the community at large. Even business and private industry share in this obligation for they play an important role in health care financing. For hospice care, private insurance is less significant than public insurance, since most individuals who become terminally ill are past retirement age and have shifted from employer-based private insurance to Medicare for the applicable coverage. Nonetheless, private hospice coverage is vital to many; private employers, private insurers, and managed care organizations share in the responsibility for working to improve access and quality, as well as efficiency, in hospice care.

Unfortunately, there are often serious conflicts between these expecta-

What the People Would Want If They Knew More About It: *A Case for the Social Marketing of Hospice Care*

BY JOHN M. STANLEY

If hospice-type end of life care is thought to be so good and so helpful by such a high percentage of both patients and families experiencing it, why don't more dying people make use of it and why don't those who use it do so sooner? Those questions were the starting point of the deliberations of a small study group of the Increasing Access to Hospice Care Project. The group had been asked to represent a consumer perspective of the issues surrounding some of the apparent conflicts between the social values our society endorses and our access to and utilization of hospice-type end of life care.

Ignorance of the Hospice Care

From the consumer's point of view, the first answer was obvious. Far too many potential consumers of such care don't even know of its existence. And, of those who do, too many have learned of it too late to make optimal use of its services.

Of course, for some patients, a short stay in hospice is appropriate. Patients with newly diagnosed catastrophic disease and patients experiencing sudden and acute exacerbations of recurrent chronic illness would indeed have brief stays. But many who could have benefited significantly from hospice services far earlier in the trajectory of their dying did not even learn of its existence until far too late. So why don't more people know of it? And why don't they know of it sooner?

The first inclination for several of us was to blame the doctors. Doctors have primary control over most of the basic decisions regarding both whether hospice services should be recommended at all and, if so, when. Doctors, we argued, are committed too strongly to curative therapies. Some are reluctant to inform patients and families even of the possibility of hospice type care, let alone its advantages. They have a professional commitment to the victories of medicine and therefore to the defeat of disease and death. In the case of specialists in particular, often their professional commitment is to defeat the disease itself; too often they are not mindful that the battlefield on which they are fighting is the life of a dying person. And beyond these powerful professional commitments, some, either directly or indirectly, have a financial

interest in the continuation of the curative therapies that would, as things now stand, have to be suspended upon hospice referral.

I think it fair to say that all of us felt that this anti-hospice attitude, or at least a strong reluctance to inform about hospice and palliative care, on the part of some sectors of mainstream medicine is a significant barrier to a more appropriate use of hospice type care at the end of life. Efforts to improve doctors' understanding should continue, and use of social marketing to influence the attitudes of those in mainstream medicine should be encouraged. (The use of social marketing might be similar to what is suggested below for consumers.) But several of us felt that medical practice was not the only barrier. For one thing, the attitude of mainstream medicine toward hospice type care is improving. Articles in the professional literature and increasing numbers of statements by medical leaders in public forums indicate a growing favorable attitude to hospice-type care by the traditional dispensers of curative therapy. And yet earlier and more appropriate utilization of the care has generally not improved. Surely there must be other barriers.

Denial of Death: Individual and Cultural

Potential consumers—both dying patients and their families—could, of course, learn of the possibility of hospice-type care from some source other than doctors. Hospitals and clinics could provide information and sponsor educational and consciousness-raising programs. Consumers could do some research on their own and initiate conversations with their doctors about advance care planning, including consideration of when hospice would be appropriate for them. Why don't they? Why don't consumers demand hospice care as at least one of the alternatives when they consider what is appropriate for care during the trajectory of their particular illness? Why is there not what one of our group referred to as "a massive outraged demand" for access to hospice type care?

One reason is that patients and families often don't want to hear the "hospice message." It is difficult to consistently attract an audience to programs that inform people of hospice or palliative care services. There is a profound reluctance to even think about anything other than restorative therapies. When doctors or friends or nurses or chaplains mention hospice as a possibility, pa-

John M. Stanley, "What the People Would Want If They Knew More About It: A Case for the Social Marketing of Hospice Care," *Hastings Center Report Special Supplement* 33, no. 2 (2003), pp. S22-S23.

tients and families may very well avoid hearing. This reluctance on the part of potential consumers to learn about hospice conspires with doctors' reluctance to inform and is re-enforced by a general cultural denial of death, resulting in avoidance or at least delay in consideration of hospice care.

What we felt was most needed was to provide the public with more information and education to create that outraged demand. We need an upstream, culture-wide, mass educational effort aimed at unveiling the many advantages of hospice type care. But the general avoidance and denial of death in our culture makes it very difficult for any programs designed to inform health care consumers of the advantages of hospice-type care at the end of life to succeed. Up to this point, organizations trying to inform consumers about hospice have focused on telling potential consumers what they ought to be thinking about death and dying, what they ought to be doing, and how they ought to be planning for death. And these efforts have, on the whole, had disappointing results—largely because the people in the target audience really don't want to think about death at all.

One possibility that we felt has not been adequately explored is the employment of a social marketing approach. We suggest launching a mass advertising campaign that would address people's hopes and fears about the ways they might die, demonstrating the advantages of "asking your doctor" if an earlier election of hospice type care "would be right for you." Further, we recommend employing more sophisticated techniques, such as those suggested by experts in consumer-based health communications.¹ Quantitative and qualitative consumer data would target first those consumer segments most likely to be responsive. Attention would be paid to the specific communications openings and media vehicles that would be most effective for the designed mes-

sages. Perhaps most important of all, we recommend attempting to reconstruct the public's understanding of the meaning of hospice, dissociating it from imminent death, and reassociating it with trust and support and reduction of burden to loved ones during one of life's difficult transitions.

What if in our educational messages we focused less on hospice philosophy and of "interdisciplinary teams coming into your homes" and more on what a dying person's hopes and desires might be for personal comfort during the dying process? For making "a good finish"? For appropriate reconciliations of estrangement? For dying in the best way possible for that individual person, and, especially, for planning for the benefit of those who will be left behind? What if we focused on the two messages we already know are deeply felt concerns of dying patients and their families: that they don't want to be a burden to their loved ones and that it is not death that concerns them, but the dying process?² What if we dared to *advertise* hospice as a package of care that addressed those two fears directly and effectively? And what if, as the punch line to the advertisement, we urged the target audience to "tell your doctor that you think that hospice-type care is right for you and for your loved ones"? Would such efforts make significant inroads against the cultural denial of death? Would they lead to a public demand, informed, if not outraged, for more and earlier access to hospice type care? Many of us feel this approach has promise, and we hope for success.

1. See S.M. Sutton, G.I. Balch, and R.C. Lefebvre, "Strategic Questions for Consumer-Based Health Communications," *Public Health Reports* 110, 725-33.

2. See American Health Decisions and Georgia Health Decisions, *The Quest to Die with Dignity: An Analysis of Americans' Values, Opinions, and Attitudes concerning End-of-Life Care* (Atlanta, Ga.: American Health Decisions, 1997).

tions and the economic structure in which health care organizations must function. Competitive pressures in the market make it difficult for both non-profit and for-profit organizations to fulfill moral obligations with respect to access and quality of care and remain financially viable. The fact is that hospitals, nursing homes, managed care organizations, and hospices themselves will all have to make changes in the way they function if access to hospice care is to be increased and if the quality of care for persons with a soon-to-be fatal illness is to be improved.

Some of these changes are possible within the existing framework and simply require the attention and commitment of management to bring them about. Others will be difficult for individual institutions to make in the absence of broader structural change.

Health care organizations—including hospices—have a moral responsibility to do what is feasible within the existing structure and to cooperate with others in advocating for the structural changes needed to make it possible to meet their moral obligations. Given the hospice move-

ment's historical experience in making care more responsive to the values and preferences of dying persons, the hospice community has a special responsibility to take the lead in a national effort to improve access to timely, compassionate, and appropriate palliative care.

Government. Government has two important roles in health care. It is a major third-party payer, and it regulates the behavior of others in the health care sector. The federally funded Medicare program is the major third-party payer for people who are nearing the end of life and who are in

Hospice and Alzheimer Disease: A Study in Access and Simple Justice

BY BRUCE JENNINGS

Hospice care for terminally ill patients with cancer has grown markedly during the past two decades and has become a significant part of the American health care system. Since its origins in the early 1970s, hospice has been relatively slow in broadening its mission and expertise beyond cancer, but today about 40 percent of hospice patients die of something other than cancer; a significant and growing number are in the end stages of congestive heart failure, chronic obstructive pulmonary disease, AIDs, amyotrophic lateral sclerosis, or some other chronic debilitating illness.

Among those conditions for which hospice care would be a blessing for many patients and families, however, Alzheimer disease (AD) stands out as a vast domain of unmet palliative care need. It is true that hospice care is largely home based, but it can also be provided in nursing homes and other long-term care facilities, and that is where the vast majority of AD patients reside during the end stage of their disease. Hospice care is an approach that forgoes life-extending treatment, which is often futile and inhumane in cases of end-stage AD. Hospice is a holistic, family-centered approach to care, which is exactly what is called for when the dying patient has already lost much of himself or herself (memory, cognitive ability, communication, a sense of self) and families have typically already undergone a lengthy ordeal of grief and loss. Seemingly tailor-made for AD, why then is hospice care so rare for those dying with dementia?

For the fact is that hospice is not widely recognized and not very often used by Alzheimer families. AD was listed on the death certificates of only 23,000 of the 2.5 million people who died last year. But in fact many more than that, maybe as many as 100,000, actually died with Alzheimer's. No one knows for sure how many AD patients are enrolled in hospice programs each year, but a good estimate is that about 7 percent of the nation's hospice patients are individuals with dementia. (It is not known how many of those have a primary diagnosis of AD and how many are patients whose dementia is secondary to some other terminal condition such as cancer.) The sad fact is that otherwise medically robust and "healthy" AD patients fall between the cracks of our health care system near the end of their lives.

Truth to tell, this happens to AD patients and families throughout the course of the disease. In early stages, as-

sistance at home is nearly impossible to afford, no provision for respite care to give family caregivers a break is available in insurance policies, and rehabilitation services are denied. Until 2002 Medicare simply refused to pay for such services if a patient had an AD diagnosis. Later, the kinds of supports that would allow patients to remain at home are lacking or unaffordable. AD patients are placed in nursing homes not because they need or want to be there, and not because their families want them there, but because it is the only place they can afford to go to get a modicum of safety, nursing care, and dignity. Finally, as they are dying, uninterested in eating and unable to swallow, largely unresponsive to their surroundings and barely conscious, AD patients are once more the hot potato that no one in the health care system really wants to touch. Nursing homes do what they can, but they are not always attuned to the palliative care needs of the dying, and they have virtually nothing to offer families who are deeply in need of healing.

Is this really a problem? Perhaps the lack of AD patients going into hospice programs reflects the informed choices and decisions of Alzheimer's families. I don't believe that. This state of affairs reflects a lack of information more than an informed choice. And it reflects financial, systemic, and attitudinal barriers precisely of the kind detailed in "Access to Hospice Care: Expanding Boundaries, Overcoming Barriers."

What are the reasons for the low rate of hospice care for dementia patients? What ethical and value issues does an Alzheimer family face when considering hospice, if they hear about it at all? What special challenges do Alzheimer patients and families pose to hospice programs and care givers? How can hospices be better enabled to provide care for Alzheimer patients and families?

These are the questions that must be explored in a more concerted dialogue between the hospice community and the Alzheimer's community in the future. Hospice programs are finally ready to rise to meet the challenge of Alzheimer care; and Alzheimer families are ready to learn about and to embrace the hospice approach to end of life care. If the policymakers, physicians, and other "experts" cannot facilitate this rapprochement, then they should get out of the way and at least stop creating barriers to it.

What barriers? In the first place, of course, there is the Medicare Hospice Benefit and its six-month life expectancy rule. Utilization review and fraud and abuse investigators have tended to single out Alzheimer patients (who tend to have the longest lengths of stay) in the charts they review, and hospices are gun shy when it

Bruce Jennings, "Hospice and Alzheimer Disease: A Study in Access and Simple Justice," *Hastings Center Report Special Supplement* 33, no. 2 (2003), pp. S24-S26.

comes to admitting or retaining AD patients who might “live too long.” This is discrimination against patients with dementia, pure and simple, and it has got to stop. Investigators should be directed by their superiors to use a different approach, and hospice programs should stand up and fight the discrimination through administrative appeals and in court, as many have successfully. The fact is that AD does not lend itself very well to prognostication.¹ One of the best things that could happen to AD patients and their families (short of the new medicines now on the horizon that may prevent or treat AD) would be for hospice physicians and those experienced with AD to come up with reasonable guidelines for the admission and recertification of AD patients and for policy makers to accept them. The current Local Medical Review Policy on Alzheimer Disease is overly restrictive and do not reflect a state-of-the-art understanding of late-stage AD.

Moreover, there is inadequate physician awareness and referral of AD patients to hospice in the community. This is such a familiar story. What more can be said about it? Actually, there is something important to be said about the attitude of doctors that parallels that of AD families.

Some Alzheimer families may have ethical or theological concerns about forgoing life-prolonging treatment and opting for palliative and comfort measures only. These concerns can and should be allayed. If there is one thing that the law, ethics, and the theology of virtually all faiths agree on, it is that hospice care for end-stage Alzheimer’s patients is ethically appropriate in almost all cases. Having an advance directive is best, but even without one it is both ethically and legally acceptable (states’ rules vary) for family members to make decisions to forgo life-sustaining treatment (including CPR, artificial nutrition and hydration, and antibiotic therapy) and to opt for comfort measures only when these decisions are in the best interest of the patient and in accord with his or her prior wishes and values.

Still, families (and physicians reluctant to refer) may have emotional reasons rather than principled ethical or religious reasons for feeling wary of hospice. Those feelings should not be dismissed or ignored; but they do need to be counteracted. Because hospice has been understood as a “last resort,” and as a place where people go to die, enrolling a loved one in hospice— particularly if it is someone whom you have cared for with great difficulty, anguish, and self-sacrifice for a very long time— may feel like a betrayal, both of the loved one and of yourself. Many families have already faced similar feelings at the time of nursing home placement and may see hospice as going through all that yet again. The remedy is real information about hospice, what it stands for and what it provides. The remedy is time to get to know the people of hospice, what it has done for other patients and families. Good hospice care is so far from being abandonment and betrayal that these feelings among many Alzheimer families—authentic and genuine as they undoubtedly are—are an exquisite irony.

Looking at the problem from the other side of the bed, so to speak, many hospice programs frankly have been reluctant to take on AD patients due to their concerns about the special care needs of these patients and families. Hospice programs and professionals sometimes harbor misconceptions and stereotypes about dementia that make them hesitant to reach out to Alzheimer patients. Better information and experience can overcome these misconceptions. Moreover, there are significant differences between the needs and expectations of Alzheimer families and families that have been coping with various forms of cancer. AD families may not take kindly to the tendency of hospice professionals and volunteers to come into the home, with a burst of energy and perk, and take charge of someone the family (usually one or two family members, mainly women relatives) has cared for, with precious little outside help, for years. Hospices need to appreciate these differences and respect them, just as Alzheimer families will have to understand

the health states in which hospice care are likely to be appropriate. The federal-state Medicaid program is a second important source of payment for health care for the elderly since it “fills in the holes” in Medicare for very poor Medicaid recipients. Medicaid also pays for health care for certain categories of the non-elderly poor. The program plays a particularly important role in long-term care; it pays some or all of the cost of custodial care in a nursing home for the majority of people receiving such

care. Many such patients have some form of dementia, and nearly all of them will remain nursing home residents and Medicaid beneficiaries until they die.

Federal and state governments have a moral responsibility to evaluate these programs in the light of the societal moral obligation to achieve equitable access, and to make the changes needed to ensure that there is adequate access to hospice care. It has been argued that if change has not occurred, it is simply a reflection of

the failure of the public to demand it forcefully enough. We would argue that just as doctors have a moral obligation to exercise active agency on behalf of their patients and help them determine what is in their best interest, so do legislators and bureaucrats have a moral obligation to be active agents for citizens. It is their duty to investigate the values and preferences of the public and shape public programs to respond to them, rather than simply passively respond to lobbying by interest groups. In the

and accommodate themselves to the hospice approach to care.

I have heard it said that AD patients are inappropriate for hospice because they cannot benefit from the kinds of care hospice has to offer. Hospice is all about meaningful life closure, and the patient who cannot remember, cannot speak or otherwise communicate, who does not recognize family, friends, or caregivers and cannot therefore come to closure with any of them, is a patient for whom hospice has little or nothing to offer.

Whatever force these observations may have, they miss the forest. Let's be clear: AD patients need the services hospices provide. They need it just as much, albeit perhaps in different ways, than cognitively intact patients do.² They have pain that often goes untreated because unnoticed and improperly assessed. Communication becomes different as cognitive and speech pathologies proliferate, but it does not disappear until very late, almost at the very end. AD patients need human concern, presence, touch, and witness no less than other dying persons.³

Families too need the services hospices can provide—resistant though they may be, and different though their grieving may be. It is one thing to learn that someone you love will be gone in about three months, as I did when my mother was diagnosed with advanced cancer of the esophagus. It is another to see someone you love fade and disappear over several years, and then face loss anew when a final decision about a feeding tube, or antibiotic treatments for pneumonia has to be made, as I discovered with my father's long dying with Alzheimer's. Hospice was present and very helpful in my mother's final illness. There was hardly a question about it (esophageal cancer is aggressive and no treatment really works), and she died well, by her lights and by mine. With my father a few years before, however, we never heard the term. Not from

doctors, nursing home people, or the local Alzheimer's support groups.

Too bad. Shortly before his death, my father had a broken hip for several months that no one in the nursing home noticed. By that time, he was no longer speaking. Maybe the better trained eye of a hospice nurse would have seen tell-tale signs of what the doctor said must have been constant pain. And at the time of his death, from pneumonia treated palliatively, my family could have used some support of our own. I am an only child, and my mother and I really had no one to talk to about his death but each other. And we really did not talk about that. For me, his death was a relief. She had given him so much care in the preceding decade it should have been an even bigger relief to her. Still, I'm not sure. Without him to care for. . . well. Alzheimer families have a great deal to talk about—a great deal of healing to do—and hospice might help.

The barriers to expanded hospice access for AD patients and families are real, and overcoming them should not be taken lightly. But when looked at from a certain point of view, they are just so *unnecessary*. I suggest we look at this not as accountants with sharp pencils or administrators with rough seas of regulation to navigate. For once, let's look at access to hospice with eyes of simple justice fixed on the reality of human suffering. People who know about Alzheimer's and people who know about hospice really must get their heads together and fix this soon.

1. N.A. Christakis, *Death Foretold: Prophecy and Prognosis in Medical Care* (Chicago: University of Chicago Press, 1999).

2. L. Volicer and A. Hurley, eds., *Hospice Care for Patients with Advanced Progressive Dementia* (New York: Springer, 1998).

3. T. Kitwood, *Dementia Reconsidered* (Buckingham, United Kingdom: Open University Press, 1997), and J. Killick and K. Allan, *Communication and the Care of People with Dementia* (Buckingham, United Kingdom: Open University Press, 2001).

case of Medicare, reform is already on the policy agenda; removing obstacles to access to hospice care should be included in the goals of reform.

Federal and state governments already have extensive regulatory responsibilities in health care. They have a moral responsibility to evalu-

ate the regulatory roles they currently play in the light of the societal moral obligation to achieve equitable access and to make the changes needed to ensure that regulation supports the goal of achieving equitable access to hospice care.

Finally, the federal government has a moral responsibility to take the lead in trying to find a way to break the political stalemate and restructure the American health care system so that access to the entire adequate level of care, including hospice care, is guaranteed to all.

III. Barriers Impeding Access

Numerous factors influence access to hospice care. Such factors include public policy, health insurance coverage, financing, the attitudes and practices of health care providers, and the attitudes and preferences of health care consumers. Of course, these factors can be positive as well as negative; they can facilitate access and utilization of hospice care as well as impede them. As we seek to facilitate greater access and utilization, we need to identify the impediments and “barriers” to access. Here we focus on three specific areas where the most powerful barriers exist: (1) laws, policies, and regulations affecting the organization, financing, and delivery of care, (2) attitudes and practices of health care providers, including referring physicians and hospice professionals themselves, who are the gatekeepers of the system, and (3) consumer misunderstanding, misinformation, and stigma against hospice.

To speak of “barriers” may give the misleading impression that access is being deliberately blocked, as in the case of racial discrimination, for example. But deliberate barriers are not the principal problem. For the most part, the impediments to hospice access are not deliberate or invidious; they are subtle, indirect, and often inadvertent. Even in the case of the public policy known as the Medicare Hospice Benefit (MHB), first enacted in 1983, the issue of constraining access to hospice is complex. Of course, there are conditions of eligibility that patients must meet in order to qualify for federal and state insurance funding. But simply because an individual is not eligible under the law and regulations for Medicare funding does not mean that he or she is not “appropriate for”—does not need and would not benefit from—hospice care.

Many people receive hospice care without recourse to Medicare funding. (In the absence of other sources

of funding, access to insurance becomes the functional equivalent of access to care.) Moreover, those conditions of eligibility, which will be discussed more fully below, are themselves viewed by many as increasingly outmoded, scientifically and ethically. We concur. In particular, hospice is now based on a medical prognosis of remaining length of life as a portal to an isolated package of services offered in an essentially all-or-nothing fashion. This approach must give way to a more flexible assessment of the patient and family’s condition within a continuum of services coordinated to meet changing needs over time.

The metaphor of barriers also implies that a person actively wants a particular good or benefit but is prevented from obtaining it by other people or by forces outside of his or her control. In the case of hospice, we believe that sometimes a person’s own failure to desire or actively seek hospice care can reasonably be considered a barrier. There is no access problem if a person would not benefit from hospice services according to his or her own values and interests. But if the person would benefit, and the lack of desire for hospice is based on misinformation and misperception rather than on an authentically informed choice to forgo hospice, then the perceptions should be counted as a barrier to access. We believe that this barrier is quite significant, and that overcoming it will be especially difficult. Doing so will require as many changes within the structure and functioning of hospice as it in the outside regulatory and cultural environment. Thus understanding the barriers to hospice access can help prepare for our recommendations for restructuring and reforming hospice.

Medicare Hospice Policy

Patients are eligible for the Medicare Hospice Benefit if a

physician certifies that they are likely to die within six months if their underlying terminal disease follows its usual course. The patient (or the patient’s representative if the patient lacks decisionmaking capacity) in turn agrees to waive all other Medicare coverage related to their terminal illness under Part A—Medicare’s hospital benefits. A hospice patient’s primary physician can still bill under Part B (Medicare). Hospice patients may be hospitalized for brief periods. They will be covered for palliative medical procedures as well as for various nursing and counseling services and assistance with activities of daily living. Spiritual counseling must also be provided, if it is requested. Family members can receive bereavement counseling and follow-up for one year after the patient’s death and longer, if necessary. The purpose and underlying orientation of hospice is neither to prolong life (or, perhaps more accurately, the dying process) nor to hasten death.

Medicare payment for hospice requires that the patient be reassessed periodically (initially after each of the first two ninety-day periods, and then every sixty days after that) to determine whether hospice care is still appropriate. There is no upper limit to the number of sixty-day recertifications a patient may receive. Even though only patients expected to live less than six months are eligible for the Medicare hospice benefit at the outset, they should not be declared ineligible simply because they live longer than that (although it took a recent ruling from the Centers for Medicare and Medicaid Services (CMS) to establish this point). In terms of its early philosophy and in terms of Medicare health policy, hospice was not intended to be a program of chronic or long-term care; it was designed to be of relatively short duration. This dilemma and central tension within hospice is particularly significant to the issue of access to

hospice care, since the prognostication of life expectancy is much more difficult with many of the terminal diseases that afflict large numbers of Americans—including heart disease, chronic obstructive pulmonary disease, and Alzheimer’s disease—than it is with some types of end-stage cancer.

At any time during this period the patient or family can decide to return to standard Medicare coverage for medical or hospital services that hospice does not provide (that is, for treatment that is curative rather than palliative in intent). The patient may later return from regular Medicare to the MHB, but must be certified once more as terminally ill. These provisions of the hospice benefit may be of particular significance to those patients and families because they may be hesitant to be “locked in” to a strict palliative care plan in the face of uncertainty or disagreement among family members and in the face of a desire to treat aggressively some life-threatening condition.

Hospice programs vary in the extent and type of services they offer, although the Medicare program sets basic standards and services (known as “conditions of participation”) that all certified hospices must fulfill. Some hospices offer palliative surgery, the administration of blood products, and artificial nutrition and hydration to their patients; all provide prescription drugs and other health care equipment that are related to the patient’s palliative care plan. Treatments for pre-existing medical conditions and conditions not related to the patient’s terminal illness, such as renal dialysis or treatment for traumatic injury, are still covered under ordinary Medicare, Medicaid, or private insurance. In general, hospice care is flexible and tailored to the dying patient’s needs, and to the needs of the family, within limits set by the professional expertise and judgment of the care team, the financial resources of the hospice, and public policy regulations.

Finally, the MHB can be applied in many different care settings, although the vast majority of hospice patients are cared for in private homes. Nonetheless, patients eligible for and receiving hospice care may reside in nursing homes or other long-term care facilities. The challenges of providing hospice care in nursing homes arise less from the perspective of the patient or family than from the differing perspectives of the hospice and the nursing home; they have different managements, different professional staffs, different caregiving orientations, different regulatory pressures, and different financial interests. These challenges appear to be effectively resolved when nursing home patients are frequently referred and periodic interchanges between the organizations’ management and clinical staff occur.

In the last few years, amid a growing effort by the federal government to crack down on cases of fraud in the Medicare program, hospice programs throughout the country have been audited, and patients with long length of stays have been targeted for review and investigation. This may have had a chilling effect on hospice programs, making them reluctant to take on patients likely to have a longer than average length of stay in the program.

Policy and Regulatory Barriers to Access

The problem is not the hospice philosophy or the planned, palliative, holistic approach to care, but rather the artifacts of Medicare policy (and similar restrictions in the private insurance sector) that inappropriately restrict utilization of hospice care. In creating the MHB and through subsequent modifications of it, Congress unquestionably increased access to hospice for millions of dying Americans and their families. Today, 75 percent of hospice patients nationwide are covered by the MHB.¹⁹ Nonetheless, certain provisions of the MHB present serious barriers to ac-

cess. Regulations developed to administer the MHB, methods employed in monitoring regulatory compliance, and penalties imposed for non-compliance have created additional obstacles in recent years.

The six-month rule. One major barrier to access is the MHB eligibility requirement that a physician certify that a patient has less than six months to live if his or her underlying disease follows its expected course. This provision of the law was designed to restrict access for two reasons: to control the overall costs to the Medicare program, and because the attitude in the early 1980s was that hospice should be restricted primarily to those in the terminal stage of an otherwise incurable and lethal form of cancer. Hospice was for those who could not be cured, or those whose life could not be substantially prolonged. Moreover, hospice was not to become another branch of the chronic and long-term care system. Rather than being integrated into existing nursing homes, for example, new and separate organizations certified as hospice programs were to be set up and would primarily provide in-home care to the dying.

These early characteristics, reasonable as they may have been at the time, are inadequate to meet the evolving needs of patients and families today. Hospice does and should serve persons dying of many different lethal, incurable diseases besides cancer. However, only solid tumor cancers lend themselves at all well to the prognostication of six-months life expectancy. Life expectancy for patients with congestive heart failure, chronic pulmonary lung disease, diabetes, renal failure, and other life-threatening diseases cannot be predicted with the specificity the MHB regulations seem to require.²⁰ Many physicians are thus unable or unwilling to sign hospice certification, and many hospice programs are worried that they will be accused of misconduct if they accept patients who may defy the initial prediction and remain on MHB coverage for more than six months.



Sadness and Consolation

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They may be concerned if the patient simply lives longer than the average hospice patient nationwide, which is about forty days. Hospice programs may also be open to retroactive denial of reimbursement for care already provided; if so, service to a number of such patients could be financially crippling to the hospice program.²¹

In sum, hospice admission based on rigid prognostication criteria is scientifically unsound on a patient-by-patient basis; therefore, patients are not referred to hospice as intended in the initial legislation. The intent of the 1982-3 hospice legislation was to enable additional services to patients and families during the last six months of a patient's life.²²

Fearing denial of reimbursement and ensuing financial difficulties, some hospice programs are denying access to those whose condition is not worsening or who might stay for so long that they would bring regulatory scrutiny upon the hospice agency. At the present time, the predominant posture of the hospice regulatory community seems to be to limit rather than to promote access and

length of stay. Whether this is the intended effect of the regulator's actions and interpretations, or whether such an outcome is an unintended consequence arising from an atmosphere of misunderstanding, caution, and mistrust, is difficult to say. What is clear is that hospices should not be penalized if the patient lives "too long." More to the point, the patient and family should not be penalized. Hospice should have the flexibility to adjust the care plan and the services delivered to fit changing patient conditions over time. Hospice should not be required to discontinue care and to sever established relationships with patient and family.

Thus the MHB patient eligibility criteria, coupled with fiscally punitive regulatory oversight by the federal government and by the private fiscal intermediaries that contract with the government to oversee hospice payments, pose ethical dilemmas for hospices. To survive the Medicare risk arrangement, the average hospice must have a patient mix that includes long lengths of stay; these patients offset the financial losses associated

with a high volume of low length of stay patients. If they admit too many patients who might live too long, they risk penalties that could prevent them from providing care to other patients closer to death. If they discriminate against patients who might live too long, on the other hand, they will seriously undermine the kind of access to needed and beneficial services that justice also requires.

The discrepancy and ethical dilemma come about because we know that persons who may actually live longer than six months nonetheless can significantly benefit from hospice services. A patient may not need every service that a hospice can provide all at once, but over time and across a continuum of care and a variety of care settings, special aspects of hospice care are very important to a given individual. The MHB, however, allows access only to intensive interdisciplinary services once the patient has crossed the six-month Rubicon. This one-size-fits-all perspective is mirrored in the flat per diem reimbursement rate that hospices receive for Medicare patients. It is not risk adjusted and is not keyed into the patient's dynamic plan of care.

Little wonder, then, that in 1998, the National Hospice and Palliative Care Organization identified the requirement of a six-months prognosis as the single most important barrier to extending hospice care to more terminally ill Medicare patients.²³

The stigma of the hospice option. A second aspect of public policy that constitutes an important barrier to access and utilization of hospice services is the MHB requirement that patients forgo life-prolonging treatments and waive Medicare coverage that would otherwise pay for such treatments. Hospice programs will normally include in a patient's care plan only those treatments that are palliative in nature and intent, and

The Relevance of Public Health in Improving Access to End of Life Care

BY CAROL D'ONOFRIO AND TRUE RYNDES

Addressing the ethical basis for improving access to hospice requires considering not only the needs of dying individuals, but also the needs and resources of the family, community, and society. Thus a population-based public health model is clearly relevant to the question of access. But while a public health model could make many critical contributions to improving end of life care, it is also limited. Extending the model to encompass concern for the dying may be prerequisite to engaging the public health community. There are three possible ways to expand the model.

Health Promotion and Disease Prevention

The goals and scope of public health in the United States reflect the World Health Organization's classic definition of health as "not merely the absence of disease, but optimal physical, mental, and social well-being." Applied to the dying, our consumer stakeholders viewed this definition as including attention to the relief of pain and suffering, maintenance of an individual's functional abilities and social relationships to the extent possible, reflections on the meaning of life, peaceful life closure, and support for grieving family members. Hospice embodies these values, and therefore increasing access to hospice can be viewed as promoting the health of people near the end of life.

Hospice cares for dying patients at home or in a homelike environment, where they generally feel safest and most comfortable and have the greatest degree of

control. Interdisciplinary hospice teams prevent patient isolation and abandonment, fragmentation of services, unnecessary hospitalizations, and avoidable stress to patients and families. Hospice standards promote patient choice, resolution of intra- and interpersonal problems, and growth at the end of life through coaching and therapeutic guidance. Hospice also goes beyond the traditional medical model by including the family in both the unit of care and the caregiving team, by working to relieve unbearable caregiver burden, and by maintaining supportive contact with grieving family members after their loved one's death.

The notion of health promotion for the dying is consistent with public health efforts to enhance quality of life, but it appears incompatible with the emphasis in the United States on increasing longevity. Consequently, the public health model does not provide a compelling rationale for including quality of dying in the nation's health promotion mission. Even if this obstacle can be overcome, public health weighs competing demands for scarce health promotion resources by assessing probable intervention outcomes in terms of Quality-Adjusted Life Years (QALYs) and other metrics that cannot capture the benefits of hospice care to patients and therefore doom it to low priority. For both of these reasons, focusing on the potential of hospice to reduce morbidity and prevent premature mortality among patients, their family members, and other caregivers may be more productive in engaging public health's intellectual and organizational resources.

Hospice professionals have long observed that the care they provide appears to reverse the decline of some dying patients. Hospice care also may prevent suicide and suicide ideation among terminally ill persons suffering from despair, severe pain, and acute depression. Hospice may

the hospice is normally expected to pay for the cost of such treatments even if it involves palliative radiation or palliative surgery. If patients do not agree to such a plan of care, they are normally not enrolled in a hospice program and must continue to receive normal Medicare coverage and normal medical care (including non-hospice palliative treatments, if available) in the mainstream health care system. Hospice patients who change their minds can of course leave the

MHB and re-enter the ordinary Medicare system at any time.

This arrangement reinforces the dichotomous thinking so prevalent in American culture that the dying or terminally ill occupy a separate zone outside of normal society and previous life experience. While hospice proponents are quick to say "hospice is about life and living," patients and families understandably are reluctant to accept hospice admission because it is an admission of impending death and because, to some, it is seen as

"giving up" and failing to "fight the good fight until the end," rather than as an active, sometimes even aggressive, mode of medical, nursing, psycho-social and spiritual care that provides many tangible benefits to the patient and family. Thomas Hoyer of CMS describes the stark separation envisioned at the time that regulations to administer the MHB were developed: "We saw the choice between hospice and Medicare as a momentous one; as a choice which would place beyond the everyday

have an even greater impact in preventing excess morbidity and mortality in family members who care for the dying and mourn their loss.¹ Elevated mortality following bereavement has been documented in Europe and the United States, while an extensive literature links bereavement to poor mental health, including post-traumatic stress disorder.² Although studies are needed to assess the extent to which hospice care can reduce these negative sequelae of dying, the significance of these problems will increase with the growth of the elderly population in the United States and the related caregiving burdens of family members. Public health therefore may be attracted to the preventive potential of hospice.

Vulnerable Populations

Public health seeks to protect those most at risk of injury, disease, and negative health consequences throughout the life course. Protecting children and youth has long been a priority, with special emphasis on perinatal health because the vulnerability of both mothers and infants is heightened during pregnancy, birth, and the months following. Public health has largely ignored the heightened needs, dependency, and increased vulnerability of people at the other end of life. Nevertheless, enormous numbers of Americans die an anticipated rather than sudden death, and many credible studies indicate that dying outside of hospice does not go well. Patients receive care from multiple providers in a variety of separately governed and poorly communicating settings. Many are forced to endure futile therapies and procedures they do not want in an environment that takes away their sense of control and neither acknowledges nor meets their individual needs. Distress from pain and other symptoms often goes unrelieved, and spiritual anguish is neither diagnosed nor treated. Fear of being a physical and financial burden to families is common.

These characteristics complete a full portrait of what Dame Cicely Saunders referred to as “total pain.” Others

equate these conditions with torture. Although it has been said that “nothing is worse than death,” the continuation of such very bad circumstances may be a worse option from the viewpoint both of patients and families and of a society concerned about the effective use of its resources. Nonetheless, reflecting medical culture and American culture generally, public health has denied death or regarded it as defeat. Consequently, public health advocacy and services for victims of war, political torture, and other violence have not been paralleled by concern for the silent victims of bad dying. No protest has been mounted against futile treatments or unwanted resuscitation. Fear that administering pain medication will result in addiction has been recognized as an unintended side effect of the War on Drugs, but few steps have been taken to ameliorate this problem. Perhaps refocusing on the plight of those living the last stages of life will awaken public health concern for the vulnerability of the dying. Public health’s strong moral commitment to social justice and the reduction of health disparities demands no less.

Core Functions

A 1988 report found the U.S. public health system to be in disarray, but with its fundamental problem-solving capacity intact.³ Subsequently, some progress has been made in strengthening the public health infrastructure, most recently to protect the nation against bioterrorism; however, the system still is ill prepared to handle the unprecedented challenges arising from rapid growth of the elderly population.⁴ Public health therefore needs to confront these issues through its core functions of assessment, policy development, and service assurance.⁵ Acknowledging as part of this initiative that dying is the inevitable outcome of chronic disease and aging would enable public health leaders to contribute significantly to improving end of life care.

It would be helpful to have a Surgeon General’s report

grasp of the patient the offer of curative care and substitute for it, every day, the reality of palliative care.”²⁴

In its early days, hospice was attractive to many patients and families because the alternative was dying in pain, or becoming dependent on providers who saw them as failures. Today, as life-extending treatments are increasingly available, patients and families are understandably leery of being compelled to choose between receiving care to extend life, on the one hand, and care directed to-

ward their comfort, on the other. Difficulty in making this decision delays access to hospice for many dying patients—often until they have only days or hours to live, as the statistics on hospice length of stay demonstrate.

This provision of the MHB is likely to become a much more formidable barrier to hospice access in coming years. Advances in molecular biology and technological innovations in bioengineering are fueling the development of new medical

therapies at an unprecedented pace. Concurrently, intensified efforts are being made to enroll patients in clinical trials testing new drugs and medical devices.²⁵ Even when patients recognize that participation in a clinical trial may not benefit them personally, many regard this as a meaningful legacy to the advancement of science that will help others.

Requiring that MHB enrollees forgo restorative therapies also has become a barrier to quality hospice care. It also excludes hospice from

on the health implications of dying from chronic disease to complement a 2002 report which indicates that chronic diseases are responsible for seven of every ten deaths in America and 75 percent of the one trillion dollars spent annually on health care in the United States.⁶ Consolidating available data on care of the dying within a public health framework would focus attention on this vulnerable population and their family members, provide strategic guidance to organizations working to improve end of life care, identify ways in which public health can contribute to this effort, and create a path-breaking resource for public education and community involvement. Most important, such a report would lay the foundation for additional public health assessment, policy development, and service assurance to improve care of the dying.

Public health also could help analyze the problem by studying the “epidemiology of bad dying,” developing new metrics to measure the extent to which currently recognized outcomes of “a good death” are being achieved, and assessing unmet population needs. In this regard, questions about the dying might be added to surveys monitoring progress toward the Healthy People 2010 objectives, particularly those concerned with functional status and access to needed health services.⁷ The World Health Organization’s 1990 Cancer Pain Initiative provides a valuable prototype for examining available interventions and resource requirements as the basis for public health policy development and service assurance.⁸ The Turning Point initiative offers opportunities to involve states and communities in transforming the public health system to assure compassionate care for the dying and their families.⁹ This goal should be part of the vision and moral commitment of public health in the twenty-first century.

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9. V. Lafronza, “Applications of Public Health Approaches for End of Life Care,” presentation at Increasing Access to Hospice Care Meeting II, Alexandria, Va., 13-14 July 2000.

contemporary efforts to integrate different kinds of care. During the last two decades, hospice pioneers, palliative care specialists, and some consumer advocates have come to view curative and palliative care as complementary approaches that should be provided in a changing mix over the course of an illness to meet patient needs. This concept has been most clearly articulated in guidelines for pain control issued by the World Health Organization and more recently in the United States by the Agency for Healthcare Research and Quality.²⁶

One way of increasing access to timely hospice care, tailored to the current condition and needs of the patient within a continuum of care, would be to allow hospice programs to offer different types of services to patients at earlier stages of their illness.

Constraints on the mission of hospice. A third aspect of public policy that creates a barrier to access and to broadening the range of patients who could be served by hospice are provisions in the MHB and hospice licensure requirements that place (or have been interpreted as placing) nar-

row restrictions on the services hospice programs are allowed to provide to non-MHB patients. Barriers previously discussed are exacerbated by the requirement that hospices serving patients enrolled in the MHB primarily be in the business of providing hospice care. Because of this poorly defined restriction, hospices that care for MHB enrollees tend to avoid serving Medicare beneficiaries before they enroll in the benefit. Patients and families who need counseling at the time of a terminal diagnosis therefore are denied access to the help that hospice professionals can pro-

vide. Efforts to integrate curative and palliative care in hospitals, nursing homes, and other non-hospice settings are often frustrated.²⁷ The Medicare Conditions of Participation (COP 418.50) and provider regulations in some states serve as barriers to upstream palliative care provided by a hospice. These barriers are not insurmountable, but they prevent hospice from addressing patient problems easily, economically, and systematically.

Despite this deterrent, some hospice organizations have been creative in developing special programs under other licenses to meet the needs of patients not enrolled in the MHB, their family members, and others in the community. Palliative care consultation by hospice professionals is one approach to improving end of life care in hospital settings. The consultants are available based on requests from the patient's attending physician. However, hospices that provide such programs must ensure that revenue streams are kept separate and that they comply with distinct sets of program regulations. The additional administrative costs discourage such efforts, but this may be one area where much can be done with nothing more than creative new regulations (or new interpretations of existing regulations) and intelligent hospice management and leadership.

Adversarial regulatory enforcement. Another important barrier to access that is related to public policy involves the variety of ways in which policy is interpreted and oversight functions are carried out by various public and private agencies. For example, the practices of CMS fiscal intermediaries (FIs) impose additional financial problems on MHB providers. If a payment claim is denied by the FI, it may be appealed to an administrative law judge, and, tellingly, most rulings are in favor of the hospice. But pending resolution of the appeal, the intermediary can withhold all MHB payments for that patient from a hospice provider.

In addition, MHB regulations have become increasingly inflexible over the years. For example, medical indicators that began as flexible, voluntary guidelines to assist private physicians in planning the care of their hospice patients have been taken over by CMS and the fiscal intermediaries and transformed into binding Local Medical Review Policies (LMRPs) that substantially affect the process by which a patient is allowed to continue on as a hospice patient under the MHB. Despite their psychological and social needs for service, if the patient's medical condition is not deteriorating, the hospice program may be required to deny the patient recertification as eligible for the MHB for the upcoming benefit period. In fact, it is often the mark of good hospice care that some aspects of the patient's medical condition (to say nothing of his or her psychological condition) may improve shortly after enrollment in a hospice program. In any case, hospice is not supposed to be about dying on a timetable or a fixed schedule. But a narrow interpretation of the LMRPs can substantially threaten access to hospice in perhaps the cruelest and most unjust way of all, by taking the care and the caregivers away from a patient and family once a therapeutic and trusting relationship has already been established. While CMS chief Thomas Scully sent a written communication to NHPCO in May 2002 acknowledging the difficulty of accurate prognostication, the effects of the FI's low tolerance of error regarding prognostic accuracy are expected to linger on.²⁸

Other examples of regulatory oversight that have a chilling effect on access and utilization of hospice arise in the context of fraud and abuse investigations. In the early 1990s, after a serious case of hospice fraud was uncovered in Puerto Rico, a pilot program of audits and investigations was launched in selected states around the country. This program has since been expanded into a nationwide effort. Continuing concern

about mounting health care costs, which are believed to be linked to widespread Medicare and Medicaid fraud, has spurred the Office of the Inspector General (OIG) in the Department of Health and Human Services to intensify its search for fraud and abuse.²⁹ Certified MHB providers have been subjected to intense scrutiny for the past several years.

These actions have impeded access to hospice in at least two critical ways. First, hospice leaders report that OIG activities had a chilling effect on the referral of non-cancer patients and contributed to the declining median length of hospice patient stay, which has dropped to as low as seven days in some parts of the country. Second, the OIG's actions have threatened the financial viability of some MHB providers. Even those eventually found to be in exemplary compliance had to absorb high costs associated with prolonged OIG investigations at the same time that the investigations were reducing patient census, staff productivity, and organizational income.

Special barriers in nursing home settings. The problems that hospices encounter when they attempt to care for dying persons who reside in nursing homes also force us to face difficult regulatory dilemmas. It seems likely that the next generation of hospice patients will be older, frailer, more cognitively impaired, and less able to be cared for at home than previous patients have been. The number of Americans needing long-term care and support will rise from 100 million today to 160 million by 2040. Many of them will die while residents of nursing homes.

Hospice must find a way to integrate its caregiving into the environment and culture of long-term care facilities if adequate hospice access is to be achieved. Diagnoses of patients who initiate hospice after nursing home admission are similar to those that characterize the typical long-stay nursing home residents. Thirty-seven percent of hospice nursing home pa-

tients have a principal diagnosis of cancer, compared to 63 percent of all 1996 Medicare hospice beneficiaries.³⁰ As in the home care setting, the MHB requirement for a definitive six-month terminal prognosis is a major impediment to access among nursing home residents. The imprecision of survival prognoses for persons with chronic illness, such as dementia, congestive heart failure, and chronic lung disease, may limit accessibility to the Medicare hospice benefit for the majority of nursing facility residents.³¹

Other regulatory problems abound in the nursing home. The MHB is available to nursing home residents who are eligible for both Medicare and Medicaid and to private pay residents, but not to those on the Nursing Home Medicare Benefit. When hospice care is provided in the nursing home, hospice is paid the Medicare hospice payment and 95 percent of the Nursing Home Medicaid per diem, which the hospice passes along to the nursing home to pay for the non-hospice care its staff provides. But there are financial incentives for nursing facility administrators to prefer Medicare SNF reimbursement over Hospice reimbursement. Reimbursement rates are higher relative to the rates the facility would receive were the dual-eligible beneficiary to elect Medicare hospice (and thus have Medicaid-reimbursed room and board). Therefore, nursing home administrators reportedly promote admission to Medicare skilled nursing care, and, by doing so, “discourage” Medicare hospice enrollment of nursing home residents. Furthermore, when a nursing home resident enrolled in hospice is admitted to Medicare-reimbursed skilled nursing home care after a hospitalization, the resident may be discharged from hospice if he or she cannot or will not privately pay for hospice care or for SNF room and board.

The divergent goals and perceptions of nursing homes and hospices contribute to access problems. Nurs-

ing home regulations reinforce restorative or rehabilitative goals. Survey procedures and policies contained in the state operations manual for both hospices and nursing homes are often contradictory. The survey procedures for each service are not coordinated. The effect is that a hospice patient in a skilled facility is surveyed by two different surveyors with different rules and potential deficiencies stemming from legitimately different approaches to care.

Through a series of reports beginning in 1997, the OIG questioned the length of hospice stay and possible duplication of services for nursing home residents receiving hospice, lower volumes of hospice services provided in nursing homes, and possible hospice kick-backs to nursing homes. Although the OIG found that the average length of hospice stay for nursing home residents was 181 days, subsequent studies questioned OIG methodology and disputed these findings. New analyses showed that the length of hospice stay for patients in nursing homes is largely similar to that of their counterparts in the community. Their average time in hospice is brief, with over 50 percent under hospice care for less than 30 days, 25 percent for a week or less, and 7 percent for two days or less.

Despite these regulatory roadblocks, change is still worth attempting because there are clear benefits to be gained by increasing hospice care in long term care settings.³² A comparison of Medicare beneficiaries who died in nursing homes with or without hospice revealed that hospice enrollment is associated with a statistically significant reduction in acute care hospitalization and increased likelihood of daily analgesic pain management.³³ Hospice patients in nursing facilities receive fewer intramuscular or intravenous analgesics, fewer physical restraints, fewer feeding tubes, and fewer hospitalizations. Non-hospice patients benefit as well, compared to non-hospice patients in nursing facilities that have no contractual relationship with a

hospice. Given the extremely large number of vulnerable patients experiencing dramatic staff shortages and limited access to quality palliative care in nursing homes, hospice providers should be *encouraged* by policymakers and regulators to participate in joint care delivery.

Barriers to Access Related to Health Care Providers

Closely related to the policy, regulatory, and financial factors that affect access to hospice are structural, organizational, managerial, and attitudinal factors. These come from health care professionals as individuals and from organizational policies and corporate cultures within health care institutions, not limited to but including hospice professionals and hospice programs themselves.

For the most part, our analysis indicates that the significant barriers to access come from sources outside the hospice community itself—from government, from non-hospice health care professionals, and from personal and social attitudes of consumers themselves. But it would be incomplete and untrue to say that all barriers to access are imposed on hospice programs from the outside. The hospice community needs to look within and critically assess its own prevailing traditions, attitudes, expectations, and practices. If the federal government were to say tomorrow that Medicare would pay for hospice for every person who could demonstrate a need for palliative care, the hospice access problem would still not be solved entirely. Organizational and social-cultural change would still be required, within hospice and outside.

Hospice professionals and organizations. Hospice organizations themselves—their policies and procedures, staff attitudes, and corporate culture—can inadvertently create barriers to access and earlier utilization. Organizational change is no easier in the hospice world than it is in other sectors of health care, govern-



How Old Women Die...

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ment, or business. Hospices are a heterogeneous array of organizations at differing stages of development. This diversity itself can be a barrier, for it slows the process of making organizational change. Bringing about change is often difficult because it involves asking individuals who have become highly successful and accomplished at doing one thing to risk doing something else. But those who have gone into hospice professions and management in the past are not timid. The creativity and ability to change in the face of changing social needs are available if hospice can muster the leadership to tap into them.

Geographical location can be a barrier to access. The distribution of hospice programs in the United States is a legacy of the non-profit, community-based origins of hospice, but there has been little systemic health planning in relation to hospice across the country.

In 2000, 13 percent of U.S. hospices were urban, 49 percent were

many hospice programs have discontinued rural services due to the low volume of patients and the considerable time and personnel costs of reaching them. Technology may be helpful here. It is estimated that 20 to 30 percent of hospice patients are appropriate recipients of telemedicine services (interdisciplinary assessment, emergency response, symptom management, inclusion of patient and family in team meetings, and so on). The use of telehomecare could reduce home care visits by 30 percent and cut hospital stays in half. RNs can do 15 to 25 "televisits" per day, which cost substantially less than a regular visit. Obstacles to implementation include the absence of federal and state reimbursement, questions regarding quality, interstate licensure and practice conflicts, patient confidentiality, absence of standards, cost, concerns regarding malpractice, and lack of technological infrastructure.

While the passage of the MHB greatly stimulated the growth in hos-

pice programs and in hospice utilization during the 1980s and 90s, overreliance on the MHB as a revenue source can itself be a barrier to access. Such hospices may be prone to deny admission to certain high risk-high cost patients. Moreover, many hospices are still unable or unwilling to serve diverse populations. Hospice began as a white, middle-class movement, and some still view it that way today.³⁴ For this reason, and because hospice organizations are often located in the "better" parts of town,³⁵ their ability to serve people of color and the poor has been questioned. Nevertheless, in 2000, 18 percent of hospice patients were members of racial and ethnic minority groups. Hospice thus has progressed significantly since its early days, but meeting the needs of dying patients from diverse cultures remains a challenge.

Some hospices are still ill prepared to deliver care to patients dying of diseases other than cancer. Although the number of such patients has steadily increased, 57 percent of hospice patients in 2000 were diagnosed with cancer upon admission. Increasing access for patients with end stage congestive heart failure, diabetes, and other chronic illnesses requires meeting their specialized needs. Some hospice programs may view themselves as ill prepared and unequipped to serve those with dementia, Alzheimer's, mental illness, and developmental disabilities. Similarly, some hospices may shy away from patients living alone or with dysfunctional families. Many hospices are reluctant to take on the even more difficult clinical and financial challenges of serving the homeless and those with a history of alcohol and drug abuse.

Although some hospices have strong community connections and have developed services customized to community needs, other hospice

programs lag behind in this area. Understanding community perspectives, mores, and values and a good working relationship of mutual trust and respect are essential ingredients of overcoming several barriers to access. They are necessary if hospices are to educate their communities about hospice care, and if they are to develop services that respond to the expectations of patients, families, physicians, and other community members. Without such accurate information sharing and trust, referrals and admissions may be reduced, care may be judged unsatisfactory, and community support may be scant.

Increasing access and serving more patients for a longer period of time requires program growth and the availability of competent staff. Some hospices have been unable to recruit the highly skilled clinicians needed to deliver technologically advanced forms of palliative care. Many hospices also have had difficulty recruiting bilingual and culturally competent staff. Others are plagued by general staff turnover. These problems, while of course not unique to hospice, limit the services a hospice can provide and also may negatively affect the quality of services delivered. The point here is not to single out hospices, for most of them are no more affected by these problems than are other health care institutions, but to note that the lack of adequate financing and other factors in the regulatory environment can unduly disadvantage hospice programs, as compared to other providers. This is an aspect of the equation leading to barriers to hospice access.

Physicians. Although professionals from many disciplines participate in delivering health care, the identification of provider barriers to hospice access has concentrated on physicians. Physicians have primary responsibility and accountability for patient care and therefore a unique relationship both with patients and their families and with other care providers. Unfortunately, little is known about ways in which the be-

havior and characteristics of other professional groups affect access to hospice care. As we review the ways in which physicians and other health professionals can create barriers to access, we should not forget that they also serve to facilitate access.

Failure to refer patients to hospice, delay of referrals until shortly before death, and ineffective referral procedures appear to be the most important provider barriers impeding hospice access. In a recent NHPCO survey of hospice providers, physician reluctance to refer, mentioned by 35 percent of respondents, was the number one reason identified for the decline in hospice length of stay. A number of qualitative studies, many of which were synthesized in a 1997 review, indicate that multiple factors may hinder referrals.³⁶

Physicians and other health professionals are trained to prolong life. Both the acute care focus of the U.S. health care system and the continual development of new medical technology reinforce the pursuit of this purpose and mission. Referral to hospice thus may be viewed as a medical failure, or as depriving patients of hope. Physicians also may deny the seriousness of a patient's condition and persist in the expectation that restorative treatments may rescue those who are dying. Willingness to forgo life-sustaining treatments for patients varies widely among medical specialties and for patients with similar prognoses but different diagnoses.³⁷ However, compared to other Western countries, physicians in the United States are more likely to intervene regardless of expected outcome.³⁸

Commitment to prolonging life may be based, in part, on denial and fear of death. Physicians and nurses often enter professional training with unresolved fears about death,³⁹ and because denial of death is engrained in the culture of the medical community,⁴⁰ these fears may never be addressed. In addition, physicians and nurses, like other people, are actively involved in denying their own mortality. It is not surprising, then, that

many physicians feel uncomfortable discussing end of life care and that most physicians have not talked with patients about their preferences for end of life care.⁴¹ When such communication does occur, it may focus only on the signing of advance directives. Physicians are committed to respecting patient autonomy and their right to choose. As one observer has said, "They'll present the odds of responding to a Phase I clinical trial and if the patient says he wants the 1 percent chance, the discussion ends."⁴² Nevertheless, many in the medical and bioethics community are now challenging the notion that physicians must always acquiesce to patient and family desires for futile treatments.⁴³

If a hospice referral is made, the physician may not provide enough information for the patient and family to respond to it. Counseling is frequently limited to brief, one-time discussions even though more interaction is needed to help patients understand the information provided, the choices available, and the probabilities involved.⁴⁴ Few physicians know how to proceed when patients or families indicate directly or through subtle signals that they do not want to discuss a terminal prognosis and care options. The educational and counseling methods used also may be ineffective. Attempts to change attitudes about dying through direct education may increase rather than alleviate anxiety.

According to members of the National Hospice Work Group, the most common question raised by consumers in family satisfaction surveys is "Why didn't we know about [the hospice] sooner?" While physicians have stated that patients should ideally receive conventional hospice care for three months before death, when asked why they have delayed informing patients of the hospice option, they often say they do not wish to withdraw hope from their patients. For their part, patients often assign a threatening developmental significance to hospice: "If I enter hospice, I

must face my death; if I don't, I won't have to think of myself as dying.”

One significant aspect of the problem of consumer misperception is that hospice is associated with imminent death rather than with the palliative skills and competencies that increase people's comfort and help them respond to the personal and social consequences of their disease and impending death. Once imminent death is clearly evident to a person, referral and admission to hospice are usually requested.

The MHB requirement that patients have six months or less to live presents a significant obstacle to hospice referrals. Because the life expectancy of patients is very difficult to predict unless they have solid tumor cancers, many physicians have difficulties in determining prognosis and are unwilling to make a prognostic judgment.⁴⁵ These barriers may be responsible for a high proportion of delays in hospice referral until patients are very close to death. Physician-patient discussion may not increase agreement about prognosis in severely ill patients.⁴⁶

Lack of physician knowledge about the availability of hospice, especially for non-cancer patients, is another barrier to referral. Lack of personal experience with hospice also may deter referrals. Conversely, physicians who have had a negative experience with hospice may decline to refer additional patients. Among physicians who know about hospice, some may lack information about referral procedures. And if patients are not eligible for the MHB, physicians may lack information about insurance benefits and billing procedures. Patient policies may not cover hospice services, or physicians may believe that hospice care for uninsured patients is not available. Some patients may be enrolled in managed health care plans that complicate the ability of physicians to make timely referrals or referrals to preferred community providers.

Physicians may not make referrals to hospice because they fear losing

contact with patients and control of their care. Many physicians value their relationships with patients and fear that referral to hospice will end their involvement with them, although this is not the usual reality. Some physicians also may be reluctant to refer patients to hospice because they fear that they will be asked to prescribe large doses of narcotics or engage in other behaviors that could jeopardize their medical license. In addition, physicians working in managed care organizations or minority communities may not refer patients to hospice out of fear that the referral will be perceived by the patient as economically motivated.

Indeed, fear of financial loss is another deterrent. Hospice providers responding to a NHPCO survey indicated that both increased competition throughout the health care industry and the addition of the Medicare Skilled Nursing Facility Benefit have contributed to decreases in the mean and median length of hospice stay. In addition, some physicians may erroneously fear that they will not be reimbursed for care of patients referred to hospice. For example, one doctor told a woman that early referral of her mother to hospice would have cost him \$3,600 in personal income. This barrier may be particularly salient to physicians whose practice is on the financial brink; however, it reflects misunderstanding about the MHB. Although physicians can reap the same economic benefits from patients referred to hospice that they would receive if the patient remained under their care in a non-hospice capacity, many physicians do not know this, and hospices have not informed them.

Consumer Barriers to Hospice

Consumer barriers to access arise from many sources. Attitudes, for example, are shaped over time through complex interactions between culture, personality, life circumstances, and experience. Although some barriers have been asso-

ciated with demographic variables, vast differences in knowledge, attitudes, and behavior exist within demographic subgroups and ultimately within families and individuals. Attributing consumer barriers to a particular characteristic such as race or ethnicity therefore can be inaccurate and misleading. Generalizations about any ethnic or cultural group are starting points for dialogue and investigation only; they are never sufficient as a basis for clinical decisionmaking or policy.

Many Americans simply do not know about hospice. They are not told about it, are told about it too late, are not told about it well, or may not want to hear it. Those who have heard about hospice and want more information may not know where to get it. A survey conducted by the National Hospice Foundation revealed that 75 percent of Americans do not know that hospice care can be provided in the home and 90 percent do not realize that hospice care can be fully covered through Medicare.⁴⁷ In addition, those who have heard about hospice care may not know what standard of care to expect. These barriers reflect deficiencies in public education about hospice and in provider communication with dying patients and their family members, yet they affect access by limiting the options patients and families can identify for care at the end of life.⁴⁸

The association of hospice with death is a major impediment to hospice enrollment. Some consumers may harbor misconceptions that delay or obstruct their willingness to consider hospice care. For example, patients and family members may fear that admission to hospice will result in abandonment by their doctor and the medical establishment. Some may fear managing death at home. Others may fear that the administration of morphine will lead to addiction, the loss of awareness in life's last days, or euthanasia through overdosing. Conversely, the requirement that hospice patients abstain from life-prolonging treatments may lead to the

mistaken impression that hospice withholds all types of care, including medications for relief of pain and other symptoms.

As already discussed, the MHB imposes a significant obstacle to hospice access by requiring that enrollees waive their rights to Part A Medicare coverage for curative treatments. Although the desire for such treatments is associated with the anticipated outcome, patients and families may overestimate the probability of survival. Clinicians observe that the stage of illness affects patients' optimism about prognosis, their desire to know the prognosis, and expectations about treatment, as well as fear that talking about end of life care with physicians might cause them to discontinue aggressive care.⁴⁹

Patients and families vary widely in their willingness to discuss impending death and preferences for end of life care with each other and with physicians and other professionals.⁵⁰ Over one-quarter of the American adults interviewed in one survey said that they would not discuss with their parents issues related to the parent's death, even if the parent were terminally ill and had less than six months to live. Adults also may have difficulty discussing their own approaching death with others, and those who are not dying may be reluctant to talk about the impending death of a terminally ill family member.

As illness advances, the patient, other family members, and the physician are likely to acknowledge the approach of death at different times. In their classic study, Glaser and Strauss documented the complex interactions that occur as various parties try to determine who is and is not aware that a person is dying.⁵¹ The desire to protect others from painful information, to spare them the agony of difficult choices, or to avoid conflict when perceptions and values differ are just some of the factors that may deter

disclosure. These dynamics, and continued denial of impending death by one or more key actors, can block communication over a prolonged period. Such problems interfere with the timely provision of information about hospice.⁴⁶ They also can delay and complicate advance planning for end of life care, with the result that decisions are not made until death is too close for patients to obtain optimum benefit from the guidance and counsel of the hospice interdisciplinary team.

In deference to patient autonomy, decisionmaking about end of life care has been left to the patient; however, family members also are often involved. The decisionmaking process is not easy, even at its best, for it begins with acknowledgement that life will end and requires communication with at least one other responsible party. If death does not appear imminent, other matters may be accorded higher priority.

Once begun, the decisionmaking process may be complicated by myriad other factors. Differences in knowledge about and attitudes toward options for care can lead to differences of opinion about the best choice, especially when no alternative seems optimal and selecting one requires deciding whether or not to continue life-prolonging treatment. If the patient suffers from diminishing cognitive capacity, other family members may argue about his or her presumed preferences. Guilt, resentments, and other residuals from longstanding relationships may affect the nature and course of discussion, as may religious beliefs, financial considerations, and the actual and expected roles of different family members in caregiving. Strong feelings about these issues may charge discussions with emotion, escalate tensions, and preclude the development of consensus.

Resulting delays in decisionmaking can completely impede access to

hospice or defer it until shortly before death. Although this barrier is attributed to consumers, other factors include health policy, health systems, and providers, which contribute to it by failing to provide support for patients and families facing difficult choices.

A number of efforts have been made to educate American communities about death and dying; however, attendance at public education programs about end of life issues generally has been disappointing. Compassion Sabbath, organized by hospices in some cities, has been successful in reaching community members who attend religious services on a designated weekend. The Partnership for Caring and state coalitions also successfully organized groups in many communities to view and discuss the Bill Moyers' television series on death and dying. In addition, community members have participated in discussions and other gatherings organized in response to tragedies. Still, most of the aforementioned events involve only some segments of the community on specific occasions. Unlike concerned citizen groups involved with Sacramento Health Decisions, few communities have ongoing public engagement programs to help people explore the profound questions raised by death and dying or to consider appropriate community response. Most American communities treat death and dying as a highly personal matter. When the need arises, friends, neighbors, and community organizations often spontaneously provide important help and support to dying individuals and their families. However, most communities have not engaged in advocacy or other efforts to shape public policies that affect the care of the dying. The dying and the bereaved are a silent and unorganized constituency, and yet policymakers tend to disregard reforms proposed by hospice and other organizations unless accompanied by public demand.

IV. Race, Ethnicity, and Culture

Hospice historically has served relatively few people of color, although some progress has been made. In 2000, 82 percent of all hospice patients in the United States were white; 8 percent were African American, 2 percent were Hispanic, 2 percent were “other,” and 6 percent were not classified by race or ethnicity.⁵² These data, together with reports that African Americans and Hispanics receive less pain medication than whites and a growing body of cultural research on death and dying, indicate that race and ethnicity are associated with barriers to hospice care.⁵³ Identifying and overcoming these barriers is important in improving access to end of life care now and will become even more critical in coming years. Between 1999 and 2030, the proportion of people of color age 65 and older in the United States is projected to rise from 16 percent to 25 percent.⁵⁴

Efforts to improve care of dying members of racial and ethnic minority groups must be understood within the larger historical and social context of their experience. Yet despite the importance of identifying and addressing issues that limit hospice access for people of color, such research is fraught with conceptual and methodological difficulties. Definitions are a fundamental issue, for the biologically based concept of race has been undermined by research showing more genetic variation within than across supposed racial groups. Ethnicity refers to country or region of genealogical origin; however, values and beliefs differ greatly among ethnic subgroups, many Americans have multi-ethnic backgrounds, and some come from families that have lived in the United States for many generations. Defining race and ethnicity therefore is not easy and is subject to various practices.

To add to the confusion, race and ethnicity are often erroneously equated with culture. Culture is defined as

a shared world view and way of living developed by a society and transmitted from one generation to another. Culture evolves over time, influenced by a people’s history, environment, social status, religion, and experience. Migration and immigration are associated with acculturation and assimilation, but these processes occur at a variable pace. Variations in traditions, customs, attitudes, and beliefs therefore develop within racial and ethnic subgroups, and ultimately within families and individuals. Variables such as year of immigration, the number of years lived in this country, preferred language, and degree of English language fluency have been used to classify Hispanic and Asian subgroups. But the number of categories quickly multiplies, substantial differences are still apparent within them, and the categories do not readily apply to many African and Native Americans.

Care must be taken not to avoid overgeneralizing findings. Mindful of these pitfalls, we attempt to provide an overview of barriers that may limit access to or utilization of hospice by people of color.

Experiences with health care. African Americans are aware of the discrimination they encounter in the broader health care system, and this awareness affects their attitude toward hospice. As one researcher has observed, “For African Americans, good palliative care needs to be part of a larger continuum of equitable care that includes prevention practices and risk assessment, diagnosis, and appropriate evidence-based curative treatment. Efforts to increase utilization of hospice and other palliative care services will fail if they do not address the larger societal issues faced by minorities. Community-based interventions—ones that have their origins within the community and therefore reflect these larger concerns—are more likely to be successful.”⁵⁵

In general, people of color are more likely than whites to distrust health care providers and the U.S. health care system. A 1994 survey of a representative sample of adults in the 48 contiguous states found that 19 percent of African Americans, 14 percent of Hispanics, and 8 percent of Asian Americans, compared to just 3 percent of whites, felt that they received inferior health care. Overall, 15 percent of minorities believed that they would receive better health care if they were of another race.⁵⁶

While not all members of racial and ethnic minorities distrust physicians and the health care system, health care providers should recognize the possibility that dying patients and their families will question the motives underlying referral to hospice and other physician decisionmaking at the end of life. Patients and their families also may be concerned that hospice care will be of lower quality than hospital care and will be detached from personal needs and concerns. If they perceive that hospice providers are bureaucratic, they may also be uncomfortable dealing with them or their agency.

Religion. Moreover, religion is central in the lives and deaths of many people of color, and yet may be neglected in health care settings focused primarily on the physical care of patients.⁵⁷ As a result, religious beliefs and values that affect the care of the dying may not be considered in making a hospice referral or describing hospice services. Other barriers may arise when hospice providers fail to recognize or respect religious traditions, or when the utilization of hospice services impedes the provision of help and comfort by the patient’s religious community.

Religion and spirituality are centrally important to African Americans. Religion provides hope, a place for belonging and feeling esteemed, and a place for releasing pent-up emotions. Church is the place of car-

Rediscovering Community at the Core of the Human Condition and Social Covenant

BY IRA BYOCK

Community is a core value for end of life care. It could not be otherwise. Dying confronts us with questions that go to the heart of what it means to be alive and human. Looking at these questions, we find that, fundamentally, human beings are social animals. Indeed, humanness may have little meaning without a context of relationships with others. Vanderpool asserted, “Being part of a community is essential for the development of consciousness and individuality and is characterized by communication, mutuality, and the ethical ideals of fidelity, gratitude, reciprocity, justice, and love.”¹

At its most rudimentary level, society is about people choosing an alternative to isolation and competition. The primal social compact is about offering cooperation and accepting responsibility; self-interest rooted in mutual obligation. This fundamental contract—or is it a covenant?—was the initial impetus for society and remains a sustaining force today. Writing in that tradition, philosopher Norman Daniels has identified “equality of opportunity” as the foundation stone of justice and has outlined principles to guide policy decisions and enable a moral assessment of proposed health care systems. Several years ago Daniels and fellow philosopher Dan Brook wrote this about the Clinton administration health plan:

“We are members not only of a national community but also of many other communities that flourish within our society: religious, racial and ethnic, as well as the neighborhoods, towns and cities in which people share a sense of common life. Fundamental to all these different communities is a shared concern and responsibility for one’s fellow members, especially those suffering misfortune and in need of help.”²

Applied to situations of illness-related suffering, disability and dying, these core values suggest basic components of care that we are obligated to extend:

Providing shelter from the elements. Metaphorically, we say to the other person, “We will keep you warm and dry.”

Maintaining hygiene. “We will keep you clean.”

Assisting with elimination. “We will help you with your bowel and bladder function.”

Offering food and drink. “We will always offer you something to eat and drink—and help you to do it.”

Keeping company, non-abandonment. “We will be with you. You will not have to go through this time in your life entirely alone.”

Alleviating suffering. “We will do whatever we can, with as much skill and expertise as available, to lessen your discomfort.”

Obligations and expectations of care find little place within the prevailing contractual framework of patient-provider relations that emphasizes individuals, rights and liberties. If, however, the fundamental social compact is a covenant, by extension, we must incorporate covenantal values and principles within our caring and our ethical analyses. One reason for doing so is that many people prefer for their proxies to make decisions about their care in ways that are, as Joseph Fins has argued, more covenantal than contractual.³

Inherent limitations of a contractual model carry profound clinical and social implications. Fins notes that the contractual decisionmaking is founded on underlying distrust and requires external strategies such as advance directives, which assign responsibilities, rules and restrictions on surrogates. Protection of autonomous individuals from unwanted intrusion is the highest value. This insight sheds light on the “right to die” as a logical extension of the contractual model as applied to illness, suffering, and dying. It is the right to avoid being protected from oneself. In this context, “assisted suicide” seems a misnomer, a contradiction in terms. Suicide is by nature a solitary act. The act of suicide by an ill person (successful or not) represents not only a rejection of care but an attempt to unilaterally sever the social contract.

Traditionally, hospice has operated from an alternative covenantal and community-based approach. Not surprisingly, hospice is often positioned as a counterpoint to physician-assisted suicide in ethics discussions and texts. A social covenant is based in trust and is durable; the connection with community cannot be severed. Within a covenantal approach to illness, caregiving, dying, and grief, people respond to others out of a lived sense of mutuality and because they are motivated by a desire to care. In acting covenantally, I make decisions affecting the well-being of another, conscious that her well-being affects my own.

The hospice model of care seeks to integrate medical excellence within a community approach to end-of-life experience and care. In addition to clinical professionals, the interdisciplinary team typically includes one or more clergy serving as chaplains. Additionally, a variety of trained and supervised community volunteers from

Ira Byock, “Rediscovering Community at the Core of the Human Condition and Social Covenant,” *Hastings Center Report Special Supplement* 33, no. 2, (2003), pp. S40-S41.

many walks of life serve patients first and foremost by being present, spending time together and demonstrating that the person who is ill matters to them. Some may help with household chores, or assist with life review, or offer other services, such as a massage or manicure simply to brighten the ill person's day. Volunteers also serve the clinical team, most visibly by contributing observations and insights to the care planning process. More importantly, however, by their time, effort, and presence, volunteers remind busy hospice clinicians of the basic social and community values that professions were created to advance.

Our ability to respond to one another in community is not confined to obligation and recognized problems. We also have "response-abilities" to enhance a person's quality of life and the life of the community: We can bear witness; we can promote opportunity.

Bearing witness. Metaphorically, we can say to the person who may be dying, "We will bear witness to your pain and your sorrows, your disappointments and your triumphs. We will listen to the stories of your life and will remember the story of your passing." Volunteers within hospice or from a variety of both faith-based and secular community organizations amplify and extend clinical capacities in this realm.

Promoting opportunity. The old saw, "People die as they have lived," is only half true. Some people change in ways that are valuable and important to them and their families during the time they are dying. Empiric evidence amply supports the concept of human development at the end of life.⁴ In the developmental work of reviewing their lives, sharing bad news, reconciling (when needed) and completing relationships with others, and exploring existential and spiritual aspects of life, some people value assistance. Contributing to others and achieving a satisfactory sense of completion and life closure are important to patients and families facing life-limiting illness. Beyond the basics of caring, within a responsive community and social covenant, we can encourage others to tell their story as a contribution to the community's collective history.

Extending help with these inherently difficult and nearly universal personal issues fits within a social

covenant that exists before one's birth and extends through one's death. People need not accept this help; they need only know it is being freely offered. So, too, within this covenantal framework of community, I believe that even as we die we retain rudimentary responsibilities to our caregivers, families, and communities. We are obligated to make our needs known and to accept care that meets our needs without violating our values. To the extent we are able, we have a responsibility to complete our affairs and significant relationships. We have, if not a responsibility, at least a socially constructive opportunity to tell our stories.

Assertions of basic elements of care and social responsibilities might seem naïve and sentimental in the contemporary world of health care and public policy, especially in the prevailing climate of soaring health care costs and hard budget choices. However, as revealed by the Access to Hospice Care: Expanding Boundaries, Overcoming Barriers project, they are fundamental to the very moral structure, not only of health care, but also of society as a whole. One of the responsibilities of each profession is to provide leadership to the social corpus on matters within the profession's purview. It is essential that the professions especially, in collaboration with the larger community, balance respect for people's rights and liberties, with a robust sense of responsibility—and response-ability. Hospice epitomizes that response.

1. H.Y. Vanderpool, "The Ethics of Terminal Care," *JAMA* 238 (1978), 850-52.

2. D.W. Brock and N. Daniels, "Ethical Foundations of the Clinton Administration's Proposed Health Care System," *JAMA* 271 (1994), 1189-96.

3. J.J. Fins, "Commentary: From Contract to Covenant in Advance Care Planning," *Journal of Law, Medicine, and Ethics* 27, no. 1 (1999), 46-51.

4. B.M. Mount and J. Scott, "Wither Hospice Evaluation," *Journal of Chronic Disease* 36, no. 11 (1983), 731-36; M. Kearney, "Palliative Medicine: Just Another Specialty?" *Palliative Medicine* 6 (1992), 39-46; I.R. Byock and M.P. Merriman, "Measuring Quality of Life for Patients with Terminal Illness: The Missoula-VITAS Quality of Life Index," *Palliative Medicine* 12, no. 4 (1998), 231-44; I.R. Byock, "The Nature of Suffering and the Nature of Opportunity at the End of Life," *Clinical Geriatric Medicine* 12, no. 2 (1996), 237-52.

ing and acceptance, regardless of class or circumstances. The African American clergy are important sources of strength for sick and hospitalized patients and their families. Belief in immortality is an essential part of the outlook of many African Americans. For them, death is not their final state. These beliefs may conflict with

the concept of "end of life care," which has been defined as the domain of hospice, and regardless of qualifiers such as "compassionate" and "quality," much language about hospice reflects the notion that death is final. In discussing death with African American patients and families, hospice providers therefore inadvertently may

identify themselves with a viewpoint that is antithetical to the beliefs of African Americans.

Still other religious beliefs or practices about the end of life are common among other racial and ethnic groups. For many Hispanics, death is determined by God's will, and suffering is an integral part of the process.

Family members and friends offer prayers at the bedside, at a home altar, and in church. Candles may be kept burning twenty-four hours a day as means of continuous worship. Clergy and lay visitors are common in the hospital and at home. Most Asians regard death as part of the normal life cycle, and within the family system, the ideal response is one of serenity, even to the point of denial. A sense of "closed awareness" has been described, in which the medical staff and patient are aware of impending death but avoid discussing it.⁵⁸ Values and beliefs vary greatly among the approximately 350 Native American tribes or nations in the United States. While most believe in an afterlife, some, like the Navajo, do not.⁵⁹

The role of the individual. Many people of color do not share the value of individualism that is central in mainstream American culture. The individual therefore may not be considered autonomous and separate from the family, and the family may be regarded as more important than the individual. Cultural definitions of family also may differ from the traditional American concept of the nuclear family; they may encompass a large extended network.

African American culture places a strong value on the collective, values "community" as a good in itself, and believes in honoring members of their immediate community, especially the family. The family bonds that dominate the African American culture often are used as a protective measure against outside forces.⁶⁰ Caring for the sick and dying at home is a long-standing tradition among African Americans. Relatives come from other locales to help. Friends, neighbors, and the religious community also participate in providing care and support to dying patients and families. Terms such as home care, hospice, respite care, and volunteerism are never used to describe these services. African American families feel a strong sense of obligation to gather at the time of death.

Among Hispanics, the concept of *personalismo* connotes "a deep sense of being part of a network that comprises one's family as well as a sense of family as an extension of the person."⁶¹ The valuing of family considerations over individual or community needs is nearly universal.⁶² Relatives of Hispanics also participate in the physical and spiritual care of the dying, and many travel considerable distances to do this. Hispanic family members are nearly always willing to provide personal care, but they may be unwilling to provide technical care unless extensive teaching is provided. In some Hispanic families, pregnant women do not provide personal care or attend the funeral. Children sometimes are shielded from involvement in care of the dying, but they also may have great responsibility.

In many Asian cultures, the concept of self also tends to be familial. Boundaries between self and others are less rigidly drawn than in Western cultures; an individual's life is interconnected with others, and there is a distinct sense of mutual obligation.⁶³ These values profoundly influence care of the dying and related patient and family roles. The Asian family, too, is intimately involved in care of the dying, and family members are often present in medical settings to serve as interpreters if necessary and also to shelter the patient from a bad prognosis or diagnosis and the burden of decisionmaking.

The role of the family. Family traditions and values exert a strong influence on decisionmaking about care of the dying patient. African American families gather, make their views known, and discuss their opinions about what should be done until a comfortable consensus is reached. When the patient's condition does not provide sufficient time for such discussion, those who must make decisions without consulting other family members bear the emotional burden of offending them.⁶⁴ Health care providers who do not understand or appreciate this tradition may appear to be pressuring decisions.

Many Mexican-Americans and other Hispanics also adhere to a family-centered model of medical decisionmaking. One survey found that 45 percent of elderly Mexican Americans believed that the family, not the patient, should be the primary decisionmaker in terminal care. Mexican American men are often expected to provide for and be in charge of their families.

The high value placed on the family by many racial and ethnic groups is attached to expectations about family and community roles in the care of the dying. Perceptions about the extent to which hospice permits members of the family and community to fulfill their traditional roles is likely to influence acceptance of referrals to hospice.

Informing the patient. Although informing dying patients about their condition is a dominant value in U.S. medicine and mainstream American culture, people from a number of ethnic groups believe that patients should be protected from this information. A 1995 survey of 800 elderly Los Angeles residents from four ethnic groups found that while nearly 90 percent of Blacks and Whites said that they would prefer a straight prognosis, 45 percent of Korean Americans and 65 percent of Mexican Americans said that they would not want to be told if they had a fatal illness. Belief that patients should be told the truth about their diagnosis was correlated with degree of acculturation.⁶⁵ In discussions with diverse ethnic groups, the Sacramento Health Decisions Project similarly found that first-generation immigrants regarded talking about advance planning as taboo because this would be a bad omen, but that second- and third-generation residents were much more open about the topic.

To engage a Chinese patient in a discussion of prognosis or code status may be perceived as casting a death curse, making the person despair and possibly die sooner.⁶⁶ When a patient's illness is life-threatening, it is assumed that practitioners will talk

with the family rather than with the patient, who is to be protected. The insistence of American physicians on truth-telling is perceived as dangerous and rude. Continued efforts to consult the patient and family about treatment choices and the continuance of life support may be perceived as a lack of commitment to the patient. Similar attitudes have been reported among Armenians and Korean Americans, among whom physical symptoms have been induced when a poor prognosis is given. Some hospice workers serving culturally diverse populations thus have learned to finesse informed consent and to trust relatives to communicate to the patient what hospice means. Even when talking with families, some hospice workers “never say the C-word (cancer), the D-word (death) or even the H-word (hospice).”⁶⁷

Cultural differences in the perception and expression of pain and other symptoms may compromise the ability of hospice providers to assess the distress of dying patients. Beliefs about suffering also may lead to conflicts about the appropriateness of palliative treatments. Many African Americans believe that suffering is to be endured as part of a spiritual commitment and as a test of faith. These beliefs may be rooted in religious views. In addition, however, the ap-

proach of death evokes an ethic of struggle that is central to African American identity. Mexican Americans usually place a very high value on stoicism about pain and other symptoms regardless of whether the source is a physical problem or interpersonal issues.⁶⁸

When dying patients and their family members feel that health care providers do not respect their preferences for end of life care and do not understand the values, beliefs, and traditions that underlie them, communications may break down and conflicts develop. In particular, communication and negotiation about limiting or discontinuing therapies—a condition for enrollment in the MHB—may become more difficult, increasing the likelihood of overt conflict and serious moral disputes.

How one communicates is as important as what is said. Addressing African Americans formally rather than by their first name is important in signifying respect. Verbal and non-verbal communications among Mexican Americans and other Hispanics also are usually characterized by respect and an element of formality, especially early in relationships and when older people are involved. Physical touch by strangers and casual use of first names may be viewed as overly familiar.⁶⁹ However, personal

empathy (*personalismo*) and warmth (*simpatía*) are appreciated, and closeness and physical touch are appropriate as the relationship develops. The Asian communication style favors an indirect approach that is sensitive to family structure. Native Americans frequently value silence and may not be very outspoken about their needs. Direct eye contact is considered disrespectful.

Because language embodies culture, simple translations do not assure effective communication between health care providers and patients or family members who do not speak English. Family and friends therefore should not be used to provide interpretation services unless requested by the patient.⁷⁰ Also, using children as translators in health interactions should be avoided as much as possible; the role places too much responsibility on them.

Lack of cultural sensitivity in letters, brochures, fact sheets, and other written materials also may be a barrier to hospice access. Information, including pictures and presentation, may be geared for whites.⁷¹ Reading level also may be inappropriate, for literacy in English, as well as other languages, varies among people of color and especially those of low socioeconomic status.

V. Toward New Models for Hospice

Values serve as compass settings for public policy and social change. We have argued that the status quo in the realized access and utilization of hospice care is not ethically acceptable. Justice and equity call for reform and change. Moreover, there is the compelling nature of the vulnerability and need that dying itself brings about, regardless of personal or idiosyncratic differences in response. Mortality and chronic, eventually terminal illness are the great equalizers; they do not respect differences of wealth, power, education, cultural background, or ethnicity. If dying includes everyone within its ambit, our society's caregiving response to dying should be no less inclusive. If dying tests the dignity and sense of meaning of all who experience it, then our caregiving systems should be designed to assist and support the dignity and meaningful continuation of a life through the dying process. This system is hospice, and it should also be accessible to everyone.

There is a consensus on the need for fundamental change in American end of life care. The main stakeholder groups in this arena—consumers, providers, the hospice community,

public and private policymakers and community leaders, and the bioethics community—largely agree on what is wrong with the present system: there is too much emphasis on expensive, burdensome, and futile life-prolonging care and too little emphasis on palliative care that relieves suffering and sustains quality of living. There is also widespread agreement that hospice care must be made equitably available to a broader population of patients near death. Hospice is valuable as a component of end of life care planning and case management, and also as a component of palliative care in earlier stages of chronic illness. Where there remains less agreement is on precisely what services should be offered, and at what stage in the course of the disease.

A commitment to just access to hospice care is not sufficient if it is merely an ideal to be sought in the distant future, once other needs are met and health care costs are under control. A commitment to what justice requires in caring for the needs of the dying must be translated into tangible institutional structures and policy mandates. It must come to inform those things that motivate behavior in the health care system, from social

marketing to professional education; from the provision of funding for services to the cultivation of a professional calling. Making it tangible requires a new vision of hospice, one that holds firm to many of the traditions and values of the hospice movement but finds new and more flexible organizational forms through which to express those values.

Value-Based Hospice

The vision of best hospice practice that we offer is based on three characteristics of hospice: (1) Hospice provides expert assistance with the management of the “condition” of the dying person and her family. (2) Hospice is flexible and dynamic in developing new expertise and services to meet changing community needs. (3) In managing a patient's condition, hospice provides continuity of caregiving and care planning, across a broad continuum of settings and services, as the person moves along a trajectory of chronic, debilitating, and life-limiting illness. These characteristics reflect goals that hospice has sought to adhere to; they also provide elements for structuring the new vision of hospice.

Condition management. Hospice has been successful because it has therapeutically responded to the consequences of the patient's illness, her total condition, or situation, not just her disease. Hospice is often referred to as a “holistic” form of care, and is often said to follow a “bio-psycho-social model” of treatment in contrast to mainstream allopathic medicine, in which the focus is on the biomedical aspects of a pathological process, without much regard for the psychological and social aspects of the patient's lived experience of the disease or the implications of the disease state for family members or others (Table 1). The notion of “managing” a total human situation or condition implies

Table 1.
Aspects of a patient's and family's condition

<i>Pathologies: Medically defined disease</i>	<i>Consequences: The experience of illness</i>
<i>Lung cancer</i>	<i>“I can't catch my breath.”</i>
<i>Congestive heart failure</i>	<i>“I'm losing weight.”</i>
<i>Severed spinal cord</i>	<i>“What if the treatments don't work?”</i>
<i>Emphysema</i>	<i>“What will this mean to my family?”</i>
<i>Dementia</i>	<i>“My wife can't turn me.”</i>
	<i>“How can we compensate for a lost function?”</i>
	<i>“How will this change my life?”</i>
	<i>“What do I need to resolve?”</i>

Is Discontinuity in Palliative Care a Culpable Act of Omission?

BY TRUE RYNDES AND LINDA EMANUEL

The fragmentation and discontinuity of care in the present system should become major concerns in palliative care. People facing serious illness and their families express concern about such inadequacies of care because they fear these problems reflect a broken relationship with their care providers.¹ Breaks in continuity appear as losses of information or momentum regarding care of one's *bios*, or physicality, as well as interruptions in the understanding of a patient's and family's *humanum*, or context.² Losses of information—as might happen when clinical data are lost or not transferred across sites of care—may result in diagnostic shortcomings. It may result in a lack of clarity about which physician, nurse, or other professional is in charge of the patient who is seen by multiple people. The other kind of break—an interruption in contextual understanding—undermines the patient's and family's emotional comfort, which is secured by a sense of trustworthiness among professionals. The disjunctions in relationships among the patient's family members and trusted providers, which occur as the location of care and the care team changes, may undermine the terminally ill patient's quality of remaining life at a time when many seek exceptional authenticity in relationships.

In medicine generally, coordination and continuity of care are lauded; their absence is understood as a problem.³ We agree, but suggest that this is to understate the issue. We characterize insufficient striving for continuity of care as a failure in ethical standards and claim that its absence in palliative care is of special significance.

In all major frameworks of medical ethics, continuity of care is readily justified. In the framework set out by Beauchamp and Childress, continuity is justified by at least three of the four cardinal principles.⁴ Because continuity provides for needed aspects of care, it is justified by the principle of beneficence. Because it avoids needless suffering, it is justified by non-maleficence. And because it tends to allow the patient to remain in better control of his or her illness care choices, it is justified by autonomy.

In more traditional codes of professional conduct, professionals receive injunctions to care, to cure, to be trustworthy, and to contribute to the well-being of society.⁵ Since discontinuity causes deficits in medical therapy, much as many other lapses in standards of practice, continuity is part of the injunctions to care and to cure.⁶

The effects of discontinuity resemble the effects of abandonment, thus continuity is part of the injunction to be trustworthy. Because continuity in palliative care contributes to desirable outcomes in the final phase of life, it better allows for the desired last stages of living relationship, and this lives with survivors in important ways, it is also part of the injunction to contribute to the well-being of society.

No matter which ethical framework is used, then, the moral obligation is clear. Further, because the dying are characterized as having special status due to their vulnerability, and because there is little opportunity to redress adverse events the way one might correct a surgical complication, continuity in care of the dying has a special importance.

Lack of continuity of care is often the result of shortfalls in management of patient care. Insofar as it may be an individual or medical systems feature, both are avoidable; individual professionals' responsibilities can be set up and systems can be designed to provide full continuity. That is, care roles, teamwork, and systems can be designed to achieve continuity. Lack of continuity in care is therefore an avoidable moral shortfall for professionals and those who are responsible for the design and management of the care system.

Continuity of Care in Hospice

As a philosophy of care that values the family context and home care, hospice tries to provide care in which institutionalization is minimized. Familiarity of environment is particularly important to the mentally or physically frail since social contexts are generally not easily transportable. Yet as an illness progresses, patients sometimes must move from one care setting to another. Hospice patients sign up to obtain palliative care, regardless of the care setting in which they reside. Part of honoring this obligation requires hospice to attend to the needs of continuity when the site of care does change.

While most non-hospice health care providers, such as hospital nurses, do not follow their terminally ill patients to other care sites, hospice staff are charged by the Medicare Conditions of Participation, as well as by industry and accreditation standards, with the specific and unique responsibilities to both provide *and* oversee palliative care as the patient moves across care sites with which they have contractual relationships. Continuity of care is optimized by this form of care management, not just for their medical needs but for the growth opportu-

True Ryndes and Linda Emanuel, "Is Discontinuity in Palliative Care a Culpable Act of Omission?" *Hastings Center Report Special Supplement* 33, no. 2 (2003), pp. S45-S47.

nities that rise out of therapeutic support in life closure tasks.

When hospice care management is conducted in a sensitive and intentionally therapeutic manner, human issues emerge that define the context of care for the patient/family unit. A patient's needs, concerns, values, relationships, and fears create the context within which hospice care management is provided. For example, clinicians caring for those made vulnerable by illness must address patients' concerns for their loved ones, fears of dying, fears of being a burden, needs for forgiveness, needs to forgive, and need for reconciliation. Similarly, they are likely to address the caregiver's physical and emotional burden, their social isolation, unspoken wishes, role reversals, and grief. These issues influence a patient's adherence to medical treatments but also and more importantly affect his summation of what it has meant to be human. Effective coaching of dying patients through their illness and death or bereavement depends on a shared vision of the full psychosocial and spiritual context, as the patients reflect on the meaning of their role in society, the value of their legacy, their life lessons. Care can be optimized by all providers when the coordinating interdisciplinary team, such as can be found in hospice, simultaneously addresses medical problems and contextual issues. Although many studies remain to be done, providers in the field feel that hospices' adherence to continuity of care standards has been helpful in facilitating the passage of essential information regarding patients' preferences, values, relationships, clinical profiles, and goals of care to the various teams and team members from whom a patient receives care.

Continuity in Palliative Care Beyond Hospice

People facing life-threatening illness should be able to receive excellent palliative care whether in hospice or in another care setting. Hospices need continuous self-assessment and improvement as well, but non-hospice systems have faced the bulk of public dissatisfaction and should take a hard look at the types of outcomes that are jeopardized by discontinuity in care. Using the "end results outcome model" created by the National Hospice and Palliative Care Organization (NHPCO), a few examples can illustrate the ways in which discontinuity negatively affects a patient's quality of life closure.⁷

Safe dying. "Patients will die . . . in an environment that does not aggravate or hasten dying." Practice gaps in various care settings (home, nursing home, hospital) are clearly linked to threats to patient safety, particularly when it is not clear during times of emergency who is medically in charge of unconscious patients, patients without caregivers, patients with multiple diagnoses, or patients with dementia. Similarly, lost laboratory test results may have clarified that (for example) a patient's

growing confusion and subsequent fall at home resulted from an easily correctible situation such as digitalis toxicity and was not an irreversible aspect of dying.

Comfortable dying. "Patients will die free of distressing symptoms." It is not uncommon for there to be misperceptions about the meaning of a patient's distress, based on incomplete messaging among team members. A devoutly religious cancer patient, wracked with guilt for a past "sin," may express his suffering as "pressure in my head," "living in pain," and "heaviness in my chest." The busy hospital nurse, unaware that the patient is receiving assistance from his priest in wrestling with issues of forgiveness, may inadvertently respond to his complaints with additional analgesia. Or, a distressed family member's perception that a loved one's physical pain is not adequately managed may persuade an on-call home health agency nurse to provide unwarranted analgesia to a patient who had achieved a personally acceptable balance between levels of discomfort and consciousness.

Self-determined life closure. "Anticipating death, mentally competent patients have full autonomy to make decisions about how the remainder of their life is spent within the allowances of law." New care providers, failing to appreciate the complex developmental ground which the patient and family have covered in embracing the patient's actual health status, may too quickly confront and erode their adaptive denial, leaving them emotionally denuded rather than supported. In other circumstances, a patient's unrelated significant other, who has provided long-term care at home, may have no legitimized standing in some institutional care settings, leaving the patient bereft of the most meaningful support in life closure activities.

Effective grieving. "Grief is a natural, expected reaction to loss that is experienced psychologically, socially, behaviorally, and physically." The characteristics of the mourner, the nature and meaning of the specific loss, characteristics of the death, and social and physiologic factors will all influence the grieving process. For family members, grieving is effective when it eventually supports the individual's ability to adjust to their environment without the deceased and regain the ability to invest in other activities and relationships. Health care professionals are in a position to support the very different grief profiles and tasks of patients and families. Unaware of the hospice team's counseling goals, nursing home staff may fail to distinguish grief-related situational depression from a more profound clinical depression requiring medical intervention, thereby suppressing the patient's ability to effectively work through the grieving process by overmedicating her. Or, a family member's displaced anger toward hospital staff may not be understood as an aspect of his grieving by "temp" nurses staffing the hospital. Such anger warrants professional evaluation but may instead result in fewer episodes of

care to the patient.

In an ideal world, we should feel confident that all care providers share pertinent information in a coordinated system that serves the patient throughout the course of his or her illness. Toward that end, members of the Healthcare Providers Stakeholder group of the Increasing Access to Hospice Care Project Task Force conclude that a functional palliative care system must have these characteristics:

- 1) Preservation of information: A patient's full medical record moves from one care setting to the next.
- 2) Maximized continuity in the individuals who provide care: Wherever possible, care providers move with the patient. A case manager who works across institutional lines is of great value.
- 3) Minimized numbers of caregivers for minimized complexity in coordination.
- 4) Preservation of context: The patient's and family's primary contextual issues are communicated as patients change care settings.
- 5) Communicated patient-centered vision and goals of care: The goals of care need not remain the same, but should evolve with the goals of patient and family.
- 6) Reimbursement mechanisms that support a seamless transition between components of the system so that families do not have to learn new systems at times of crisis.
- 7) Uniformity in standards of palliative care across settings.

We believe these intentionally crafted elements of continuity have an unrecognized moral value because they ameliorate suffering and potentiate human growth. Conversely, their absence contributes to needless suffering.

1. B. Tyler et al., "The Quest to Die with Dignity: An Analysis of Americans' Values, Opinions and Attitudes concerning End of Life Care," Atlanta, Ga.: American Health Decisions, 1997; 12-14.
2. M. Lamm, "The Jewish Way in Dying: The Jewish Component in Hospice Care," presentation at the 52nd General Assembly of the Council of Jewish Federations.
3. In the literature, "fragmentation" usually refers to the absence of coordinated care delivery when specialists attend specific aspects of a person's condition. "Discontinuity" commonly refers to what happens when significant information is lost as patients transfer between sites of care. In the context of this article, however, we use the terms interchangeably, for their effects and remedies are comparable. Their presence indicates a failing on the part of professionals and systems of care.
4. T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics*, third edition (New York, N.Y.: Oxford University Press; 1989).
5. L. Emanuel, M. Iris, and J. Webster, "Ethical Aspects of Geriatric Palliative Care," in *Geriatric Palliative Care*, ed. S. Morrison and D. Meier (Oxford University Press).
6. R.I. Cook, M. Render, D.D. Woods, "Gaps in the Continuity of Care and Patient Safety," *British Medical Journal* 320 (2000), 791-94.
7. National Hospice and Palliative Care Organization, *A Pathway for Patients and Families Facing Terminal Illness* (Alexandria, Va.: National Hospice and Palliative Care Organization, 1997).

a respect for the integrity and participation of both patient and family members and betokens an active process of controlling symptoms and handling aspects of everyday life so that they do not undermine the kinds of relationships, reminiscences, communication, feelings, and activities that the patient finds meaningful and that give remaining life its positive quality.

The emotional and social meaning of "condition"—the consequences of disease on the lives of patients and those around them—may be at least as important to patients as the physical impairment itself.⁷² However, while "Americans think it is important to plan for death and dying, they are uncomfortable with the topic and resist taking action."⁷³ This underscores the importance of a social marketing approach to public engagement. While future policy action may eventually arise as a result of

the baby boom generation's emerging caregiving crisis, expanding hospice policy in the near term will require a compelling national prevention strategy directed toward the elimination of avoidable distress among seriously ill patients in all settings.

Historically, a keystone of hospice philosophy has been the dictum that "the patient and family are the unit of care." This view is supported by the Medicare Conditions of Participation, JCAHO and CHAP accreditation standards, and the professional standards promoted by the National Hospice and Palliative Care Organization. Attention to the needs of caregiving family members has been found to improve consumer satisfaction levels and result in lower health care utilization among hospice caregivers. According to a survey by the National Alliance of Caregivers and the Association for the Advancement of Retired Persons, 73 percent of

family caregivers are women. They devote an average of four and one-half years to providing care, but often ten years or more. Fifteen percent of all caregivers and 31 percent of those providing the highest level of care report that they subsequently suffer from significant physical illness or emotional stress.

Furthermore, in a large population-based cohort study of 819 caregiving and non-caregiving participants, ranging from sixty-six to ninety-six years of age, it was found that those who reported mental or emotional strain associated with the chronic stress of caregiving had a mortality risk 63 percent higher than non-caregiving controls. Specifically, the at-risk group was found to have fewer preventive behaviors, decreased immunity, greater cardiovascular reactivity, and slower wound healing.⁷⁴

Thus failure to address or control the distressing elements of a patients'

Table 2.
A History of Responding to Changing Community Need

1973	First U.S. hospice founded in New Haven. Predominant model was inpatient care. Palliative approach narrowed to cloaking the symptoms, not eradicating their cause.
1981	Hospice Demonstration Project conducted. The project included twenty-one sites. The populations studied were largely white, middle-class people with cancer.
1983	Medicare Hospice Benefit (MHB) established. This created a major push to provide care at home.
1984-89	<ul style="list-style-type: none"> • Earlier conceptions regarding hospice/palliative care are challenged: Palliative care is redefined as appropriate care, not just cloaking of symptoms. Some innovative hospices begin to offer blood, perenteral fluids, chemotherapies, radiation therapies, and surgical procedures, as well as treatments of opportunistic diseases, pushing the Medicare Hospice Benefit boundaries and philosophies of some (smaller) hospices. • Programs proliferate in urban areas and inner cities. • Hospice programs begin providing care to persons in Skilled Nursing Facilities. • Hospices respond to patients dying from non-cancer chronic diseases, dementias, and general debility. • Response to people with AIDS begins in San Francisco and New York, and then spreads across the country. • Pediatric hospice care is offered. • Hospices support compassionate detachment from respirators. • Hospices serve patients wishing to terminate dialysis.
1990s	<ul style="list-style-type: none"> • Hospices extend care to: <ul style="list-style-type: none"> • children born dying and their families • dying prisoners • faith-based populations (Muslim, Jewish, Fundamentalist Christian) • Hospice models emerge that provide consultative care for patients who are not medically or emotionally ready for the MHB. • Many hospices reach out to bereaved community members not previously served by hospice, such as those affected by terrorism, natural disasters, suicide, and accidental death: <ul style="list-style-type: none"> • children and teens experiencing loss of parents and siblings • parents losing children • survivors of HIV/AIDS-related losses • individuals experiencing loss from catastrophic circumstances such as sudden traumatic death • survivors of suicide in the family, school, or close community • communities experiencing catastrophic events such as airplane crashes, mass shootings
2000s	<ul style="list-style-type: none"> • Both outside and within the hospice community there is increased emphasis on construction of an evidence base to promote quality improvement and best practices in palliative care. • Medical visits at home by palliative care physicians and nurse practitioners. • Hospices develop senior care management services. • Hospice/PACE relationships develop. Hospices partner with PACE program and consider designation as sites of “all-inclusive care of frail elderly” under Medicare/Medicaid PMPM payment structure. • Hospices undertake collaborative palliative care partnerships with hospitals, consult services and units, joint education

care (such as unrelieved symptoms, emotional and spiritual anguish, conflicting or vague communications) puts considerable strain on the caregivers. In fact, it has morbid consequences for them. As the nursing and nurse aide labor pool shrinks and the volume of need for chronic and terminally ill services at home rises, all caregivers—but notably aging female caregivers—confront a predictably bleak future. The cost of domestic caregiving is largely invisible, while the “cost to business” or “cost to taxpayer” tend to be at the center of policymakers’ attention. Many former caregivers, mainly wives and mothers, with no family left to care for them, will themselves die in nursing homes.⁷⁵ This is a tragic social contract in return for the money they saved society with their unpaid labors of love.

Changing service in response to changing community need. Through its sources of financing and its organizational forms, hospice should be flexible enough to adapt and change in response to changing community needs. The historical development of hospice, both as a concept and as a form of health care practice, demonstrates the dynamic and fluid character of a responsive and holistically oriented form of end of life care. (Table 2 expands on hospice’s historical development.)

Amid the wide variety of programs and services that make up the hospice world today, there are signs of an expansive movement toward earlier intervention in the disease trajectory, more continuity of care across a greater number of settings, and more responsiveness to community needs and functions beyond those associated with end of life care for individual patients and families. Some hospices are not only clinical care delivery agencies, but are also becoming public health agencies and institutions of health education and health promotion. Our research indicates that existing hospice programs are already so diverse that they can be classified into three basic types—Medicare hospices,

community hospices, and comprehensive hospice centers.

Medicare Hospices primarily serve patients eligible for the Medicare Hospice Benefit and receive a very high proportion of their income from Medicare. Most of these programs are small, and many of them are independent. They have limited ability to tolerate financial risk or to innovate in their services outside the standard Medicare Conditions of Participation. This type of hospice is believed to still be the single largest group of hospices in the nation today.

Community hospices also rely on Medicare reimbursement but go beyond the Medicare population to offer services to patients who are not medically or emotionally ready for traditional hospice care, as well as to the community at large. These services are based on the core competency of condition management.

Comprehensive hospice centers are community hospices with a dedicated academic mission. They are committed to improving care through professional education and research, and they are often of exceptional size, community position, and philanthropic fund-raising capacity. Some are attached to medical and nursing education programs and serve as teaching hospices. In addition to serving individual patients and community organizations, they are also active in the health policy arena at the local, state, and even the national level.

Continuity of care across a continuum of services. Hospice is a form of care, not a physical location. Some hospices do have in-patient facilities, but those remain the exception rather than the rule. Hospice providers are peripatetic: they travel from setting to setting and patients rarely come to them. Consequently, hospice professionals often find themselves in a dual-provider role with home care agencies, nursing homes, and hospitals. This experience has taught hospice how to negotiate the fissures and crevices of the American health care system. Even when hospice is called

in very shortly before the patient's death, patients and families often establish relationships with hospice providers and rely on them to orchestrate dealings with pharmacies, community physicians, other health care providers, sometimes clergy, and even neighbors and friends. Historically, hospice has been both a managed care service and a philosophy of care that patients access through a process of informed consent. In accreditation and certification standards, hospices have always been required to ensure that the special philosophy of care is provided across settings. Hospice must build on its experience base and provide enhanced continuity across institutional settings for patients and families unfamiliar with the complexities of health system partners, as well as those wrestling with complex clinical and personal decisions. The varieties of familial and institutional caregiving systems and the number of aging and very aged individuals will contribute to this need.

Serving as a broker or "case manager" is often as important to patients and families as providing pain medication and other symptom control measures. And for those who qualify, the Medicare Hospice Benefit is literally the only program in the entire American health care system that allows patients and families to forget about financial worries and to concentrate instead on the hard work of grieving and living in the face of dying. To complement this blessing, families need to be assured that the right type of services, medicine, and equipment will be available to the patient as he or she moves through the trajectory and changing needs of illness. Hospice at its best is "condition management for continuity of care across a continuum of services." The formulation is a mouthful, but every term is important in it. It is one of the principal contributions that hospice is in the best position to provide, structurally and historically, for end of life care.

The Promise of Hospice in an Aging Society

These three components of best practice and high-quality end of life care are both significant accomplishments of hospice's past and necessary steps toward its future. Hospice must develop new organizational forms if it is to provide these three components to its patients and families and to the communities it serves. The development of such new forms of hospice financing and delivery will tax the creativity and management skills of hospice leaders. It will also require that policymakers leave behind their former emphasis on an individual's categorical eligibility (required six-month prognosis or narrowly medical symptomatic indices, such as the current Local Medical Review Policies) and focus instead on hospice's ability to assume the responsibility and liability for the care of a diverse population. In particular, hospices should be encouraged to implement their continuity of care expertise within a continuum of palliative services, facilitating case management and care planning based on the appropriateness of services given the changes in the patient's and the family's needs over time.

This point is graphically represented by the stylized diagrams shown the accompanying figures. One often-proposed reform would be to modify the current Medical Hospice Benefit (illustrated in Figure 1) by expanding the eligibility period from six months to one year. This would represent a step forward from the point of view of just access, to be sure. But it would only address the policy and regulatory barriers associated with the six-month life expectancy rule. It would do little to address the other structural and attitudinal barriers we have identified. In order to address and to overcome the barriers to hospice access in a more comprehensive way, hospice must be reinvented and re-envisioned along the lines shown in figures 2 and 3. Figure 2 represents the transformation of the traditional hospice as a

Figure 1.
The Medicare Hospice Benefit

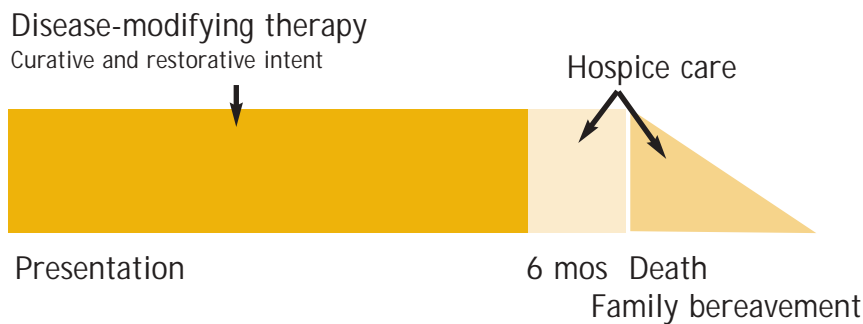
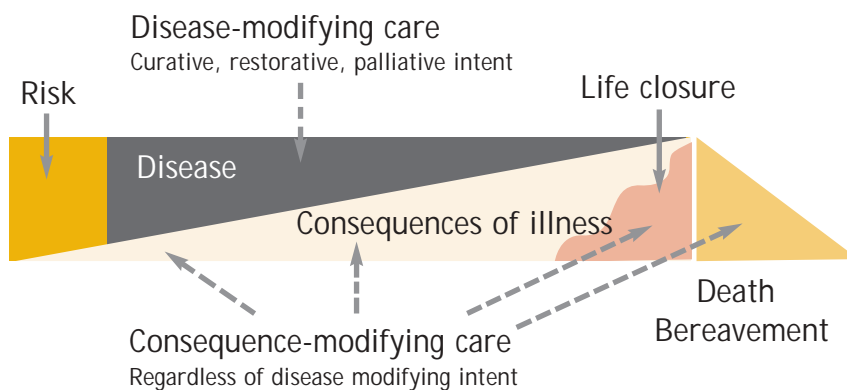


Figure 2.
Hospice as a Continuum of Care



niche provider at the tail end of a disease into a provider whose purview ranges across the trajectory of a life-limiting disease. Moreover, the model of traditional hospice as a specialized service and an independent agency with a limited mission will gradually be transformed into a more comprehensive model of hospice care in which hospice becomes the coordinating center for a range of palliative services that can be accessed by patients in various ways as the patient's underlying condition evolves from diagnosis to death. Figure 3 emphasizes that the hospice treats both the patient and the patient's family.

Many current and narrowly defined hospice policies and regulations, including otherwise laudable efforts

to prevent Medicare fraud, are out of step with what is most innovative and creative in the hospice community today. An audit of the services provided by hospices within the National Hospice Work Group found that many are already well beyond the confines of the Medicare hospice type. In addition to focusing on the care of those facing a terminal illness, many of these hospices are active in the delivery or development of philanthropically supported programs for individuals who want symptom management and adaptive counseling even as they pursue active treatment directed toward prolongation of life. These hospices also serve those facing the debilitating effects of aging or the consequences of sudden and cata-

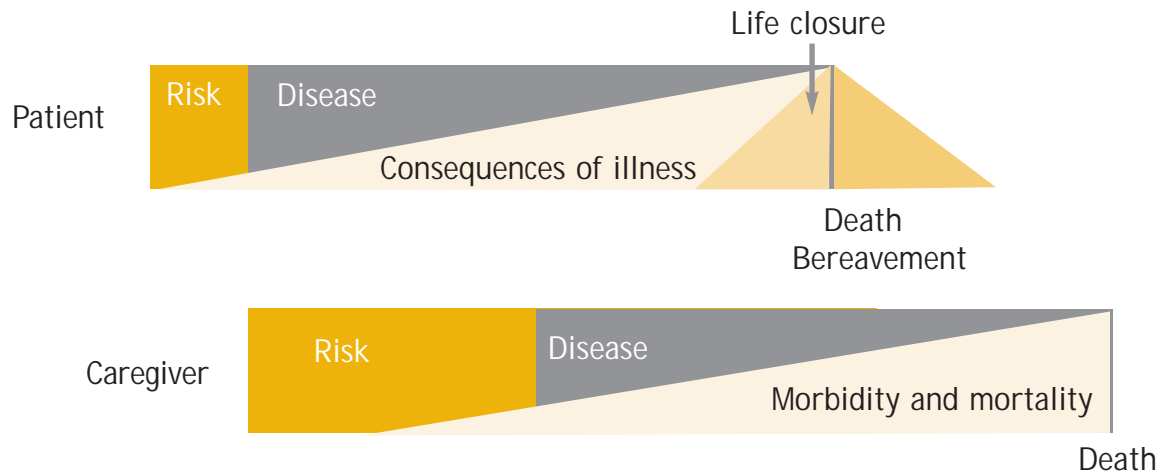
strophic death. In short, it is clear that these programs have expanded the expression of core interdisciplinary competencies to individuals other than those imminently dying. While the first expression of hospice competencies has been care of the dying; this is not the core hospice competency. The core hospice competency is the interdisciplinary response to the human consequences of chronic disease, disability, and aging.

With this in mind, we should begin to think of hospice as offering something of value to many different groups of patients, or to a given patient and family at many points along a spectrum of symptoms and services and across stages of chronic illness. To provide the impetus for policy and practice changes that will increase access to hospice care, we need first to re-envision hospice as a concept of health care—a new way of thinking about the nature and goals of health care itself—rather than an end stage form of care.

Foreseeable demographic factors will shape the delivery of all health care in the future. They highlight the importance of condition-based hospice care delivery systems, for the human consequences of chronic, debilitating disease will increase as larger numbers of people live longer. Eighty million Americans are currently living with chronic disease. That number is expected to nearly double by the year 2030. Moreover, between 2010 and 2030, the population over age 65 will rise more than 70 percent, while under current law the population paying payroll taxes will rise less than 4 percent. By 2020 the absolute size of the RN workforce will be approximately the same size it is today, nearly 20 percent below requirements.⁷⁶ Finally, by 2025, those with low incomes and multiple chronic health problems, particularly women, will be forced to spend nearly 72 percent of their income for health care.⁷⁷

These facts and trends paint a disturbing picture of the future of end of life care. The shortage of caregiving personnel will jeopardize the avail-

Figure 3.
A Vision of Comprehensive Hospice Care



ability of physical support and the availability of medications. It may require a return to widespread institutionalization near the end of life. It may lead to intergenerational conflicts between the aging baby boom generation and younger cohorts.

Indeed, as we have studied and reflected on the problem of increasing access to hospice care, we have come to the conclusion that an adequate understanding and ethical perspective require us to envision hospice as a potentially new paradigm of social health care for an aging society. If we can learn how to define, organize, finance, and deliver hospice care properly, then we may have found the key to coping with the major problem of caring for staggering numbers of persons with chronic, degenerative disease, who must make difficult adjustments and transitions in their lives as they pass through various stages and phases of their disease, both in terms of its biological manifestations and in terms of the cultural meaning and social implications of the chronic disease experience. The experience of chronic disease segues into the experience of dying with no bright lines, no radical symptomatic changes, and no scientific medical prognostications. The flow and rhythms, as well as the

goals and care plans, of hospice must be allowed to match the rhythms of chronic illness as it becomes an increasingly widespread social condition. Of all the existing structures and specialties in health care today, it is hospice that has the best chance of successfully transforming itself into this chronic care social medicine of the future.

The adjustment and transformation will not be easy. In the future, hospice will need to address the conditions that these demographic trends will generate. The future hospice must be technically proficient in clinical practice and in telecommunications. It must also use staff time efficiently, tailoring interdisciplinary teams and palliative treatment regimens to the specific needs of patients throughout the continuum of care. Hospice volunteers will be needed in greater numbers, and they must be well trained and well treated. Offering an opportunity for volunteerism is one way in which the hospice benefits the community as well as individual patients. Specialists in fields such as real estate and housing, transportation, insurance, financial planning, and elder law will have a (virtual) role to play on hospice teams and in consultation with hospice plan-

ning boards. New care provider roles must be encouraged to emerge, and nursing leadership must examine how strong traditional gender identification with the role inhibits the recruitment of men into the nursing workforce.

The promise for a larger mission in the future, perhaps as much as the ethically compelling nature of the end of life care needs that it can meet for those without access today, is the principal reason for being urgently and deeply concerned about policy reforms in the finance and delivery of hospice.

This vision goes far beyond the issue of equitably distributing a service to heretofore unserved or underserved individuals and groups. At least in the case of hospice care, justice goes beyond the issue of distributing something whose nature and characteristics are firmly established and well understood. With hospice, the nature of the service to be justly accessible or distributed is itself open to question and in flux. The myriad problems of access that we face in hospice today are not only due to overly restrictive rules of eligibility, financing, and delivery; they are a legacy of a more fundamental mistake, namely, conceptualizing hospice as a

fixed entity whose mission was to provide a specialized niche service to one population with one (vastly compelling) need—the care of persons dying of incurable cancer who, in effect, had been abandoned by mainstream medicine. Almost immediately, as far back as the mid-1980s, hospice began to chafe at that specialized bridle and harness. It is high time to give it a much freer rein.

This report began with the claim that the care dying people receive in the United States can and should be improved. We end with the hope and

the belief that it will be, and soon. This will require a strong ethical conviction about the injustice of denying access to hospice and palliative care to those who would benefit from it and a renewed sense of determination to set the system right. We have attempted to provide a foundation for that ethical conviction, an unblinking assessment of the barriers and difficulties that need to be overcome, and a number of suggestions that contain fresh ideas and will at least set us moving in the right direction, if

not provide complete solutions to the problems we face.

We welcome further analysis and debate concerning the ethical foundations of just access to hospice and palliative care. We look forward to working with leaders in end of life care to bring about policy reform and institutional change. And we hope that our recommendations will be taken at least as a useful contribution to ongoing efforts at expanding hospice access and fairness in the health care system more generally.

VI. Approaching Just Access: Recommendations

The following recommendations are the result of five Hospice Access and Values Project Task Force meetings (involving segregated and mixed stakeholder discussions as well as solicited papers), and responses to thirteen foundational queries on the Access and Values website from September 1999 through August 2001. The recommendations identify a realistic but challenging course for the future of hospice in America. They will require patience, political leadership, broad debate, a willingness to compromise, and an openness to new ideas. They also require further research and increased understanding of why the health care system behaves as it does and of how various new practices may affect the needs and well-being of dying patients and their families.

Some recommendations have been shared in whole or in part with various stakeholders and constituencies: Congress, hospice providers, invested consumers, and other stakeholder representatives. Other recommendations, such as Hospice/PACE programming, have already resulted in preliminary discussions among Access and Values participants and national association leaders, for they outline reasonable demonstration projects worthy of federal funding support.

A. Recommendations Concerning Policy and Regulatory Barriers to Access

Recommendation 1: *Healthcare 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.*

1) As was done by the Kellogg Foundation with the emerging hospice movement in the early '80s, we recommend that a national field sur-

vey of services calling themselves "palliative care" be conducted. The survey will:

- determine what elements these services have in common and how they qualitatively differ;
- use the exhaustive NHPCO Standards of Hospice Care/Robert Wood Johnson Foundation Precepts of Palliative Care Crosswalk as a foundation for the survey;
- document the scope of palliative care services in U.S. hospitals in order to assess the integration of this service within the practice activity of the hospital and determine the relationship, if any, of palliative care consultation to hospice admissions; and
- identify specific savings realized from improved end of life care practices, such as patient cost avoidances and lower health care utilization by family caregivers who are relieved of the intensity of their caregiving burden.

2) We recommend that a national forum be convened to bring together key constituencies, including provider and consumer groups, to establish a definition for palliative care to provide the framework for service delivery models, standards of care delivery, and reimbursement models.

3) We recommend that a position paper be developed in conjunction with the national study and forum that will elucidate current and proposed distinctions between palliative medicine, palliative care, and the care available through hospices of various types.

4) We recommend that this position paper and a record of the deliberations and conclusions of the study and forum be presented to members of Congress, executive branch officials, and other policymakers at the federal and state level. These materi-

als should inform the discussions and recommendations proposed for Medicare beneficiaries in acute hospitals, rehabilitation programs, and long-term care centers as well as ambulatory, home care, and hospice programs.

Recommendation 2: *Public policy should expand the scope of hospice services.*

We recommend that Congress approve a series of demonstration projects to Advance Hospice Access (AHA). The goals of the AHA Projects would be twofold. One goal would be to advance hospice access for persons who do not yet qualify for traditional hospice due to extended or uncertain prognosis and/or their preference for therapies directed toward cure or prolongation of life. Second, the projects would foster and promote access to hospice's condition management competencies through innovative community relationships, as with PACE or Parish Nursing.

The AHA projects would identify ways to make hospice's palliative services available to those receiving institutional and outpatient care prior to the conventional hospice access point. Patient preference, caregiver need, and functional status, not just diagnostic criteria, would be considered in determining eligibility. The demonstrations would study the time and tasks of the palliative care encounter to define and adjust the relative value unit for this component of care, then define and measure the palliative care component of the care provided to patients in hospitals, nursing homes, home health agencies, and outpatient settings. Determination of the efficacy of early interventions on the reduction of health, economic, and social burdens of caregivers would also be a key function of the demonstrations, as they are likely significant.

Hospices eligible for these projects would have to demonstrate the use of

innovative community service connectors, such as continuity of care volunteers, by multiple organizations including hospices, resulting in enhanced access to palliative care and improved continuity of care across care settings.

The expected outcomes of these two types of demonstration projects would be:

- to determine the effects of palliative care on patient's responses to curative treatments;
- to improve pain and symptom management;
- to respond to the consequences of the patient's serious illness by addressing family dynamics of patients with new "bad diagnoses," frequent admissions, or failing treatments;
- to decrease procedures not aligned with the patient's goals; and
- to create a model of compassionate "third act" care for patients with dementia and their families.

Included in these demonstrations should be a mixture of programs with the capacity to operationalize delivery of services via telemedicine applications. (See Telemedicine recommendation 6 below.)

Recommendation 3: *Policy-makers should act immediately to bring about policy reform regarding the absolute application of an individual's prognosis as a primary criterion for reimbursement of services.*

CMS officials have recently noted slight increases in the average length of stay in hospice in 2000 and 2001. These increases coincide with a letter from former HCFA administrator Nancy-Ann Min De Parle clarifying that hospices and beneficiaries should not be penalized "if a patient lives longer than six months." This has been followed by even more explicit communications to hospices and

physicians by CMS Administrator Thomas Scully recognizing "that terminal illnesses do not have entirely predictable courses." These are very positive signs, yet we recommend CMS and its fiscal intermediaries protect hospices, referring physicians and patients from regulatory misinterpretation in the future by establishing a statistically accurate definition of prognosis that recognizes its relevance as a *population* measure, not an individual one. This is consistent with a wide literature addressing the fallibility of medical prognostication on individual patients. For any population of patients with serious life-threatening illness there is a probability of death with a mean, standard deviations from the mean, median, and mode. A population-based statistic is also consistent with Congress's original intent in developing a risk arrangement with a maximum cap.

Recommendation 4: *Expand access and delivery of hospice to dying persons residing in long-term care facilities.*

1) We recommend that Congress modify Medicare Part A and Medicare RUG reimbursement system to support hospice care of the resident without financial penalty to the nursing home and the resident/family unit.

2) CMS and state departments of health must adopt a common survey process for hospice patients in nursing homes so that patients' self-determination in allowing death to take its normal course is not subordinate to clinically and personally harmful regulatory requirements, such as the enforcement of feedings among dying patients.

3) CMS should require that any state licensed facility may not prohibit the delivery of hospice care as provided under the Medicare or Medicaid hospice programs. (A comparative analysis of hospice services to patients in Skilled Nursing Facilities (SNFs) is currently being conducted by the National Hospice and Palliative Care Organization. This mono-

graph will highlight the ways in which states variably provide access to hospice services.)

B. Recommendations Concerning Service Delivery Barriers to Access

Recommendation 5: *Leaders in the hospice community and in mainstream medicine must promote hospice-hospital partnerships in order to meet the current and projected needs of the rapidly expanding volume of chronically and terminally ill patients.*

Activities to promote this relationship have begun in earnest over the course of this project, led primarily by the Center to Advance Palliative Care and the National Hospice and Palliative Care Organization. Examples of collaborative relationships, if not models, have been identified. These efforts should be continued and supported.

1) The quality of end of life care for the unprecedented volume of patients in the next 30 years will be dependent on professionals operating outside of their traditional service silos. Consequently, we recommend that leadership groups in hospice and palliative care (such as NHPCO, CAPC, the Academy of Hospice and Palliative Medicine, the Hospice and Palliative Nurses Association, and Partnership for Caring) work with palliative care physicians, hospice leaders, and hospital administrators to construct a regulatory reform agenda that would enable improved outcomes for hospitalized patients in need of hospice and palliative care.

2) We recommend the development of ongoing studies of *maturing* hospital/hospice models in which hospitals have successfully integrated comprehensive palliative care programs into their organizations longer than five years. These models would be surveyed to identify replicable variables critical to the long-term success of these ventures. Included in such studies would be a review of the effectiveness of grant-supported hos-

pital palliative care initiatives. The objectives of this review would be to identify and monitor initiatives to institutionalize palliative care services once grant support is discontinued, to identify the quality and financial arguments for continuation of services, and to publicize successful outcomes and assess failures to be avoided.

3) A few years ago, an important study undertaken by the Institute of Medicine galvanized discussion and expert opinion around the goal of improving palliative care services. Accordingly, we recommend that the Surgeon General undertake a report on the quality of dying in America, and that it confront the topic not only as a challenge for medical culture and science but in the broadest terms as an ethical, cultural, and societal question of the first order, one that requires a rethinking of assumptions and established practices throughout the health care institutions where most people die. A new Surgeon General's report would not only command attention, as only Surgeon General's reports in the past have been able to do, it would provide the proper venue for seeing the care of the dying as a public health issue, for little is known about the incidence of death and quality of dying, by diagnosis, in hospitals before or immediately after discharge. We recommend that a Surgeon General's report on the quality of dying in American hospitals would reasonably include the results of a retrospective review of the medical records of patients in a large stratified sampling of community and academic hospital settings. The objectives of this review would be to determine at least the following actionable items:

- the cause of deaths of all patients who died, the correlation between discharge diagnosis and cause of death on the death certificate, and the types of patients who died in any part of the hospital whose charts reflected need states immediately prior to death that would

have been responsive to palliative care but did not receive it (for example, the patient's symptoms were unmanaged);

- the frequency of symptoms encountered and adequately managed, the level of continuity of care among providers and between providers and family members, and levels at which key patient preferences are met; and

- any hospital-based practice patterns, including discharge planning, that may constitute barriers to hospice consultation and/or referral within those systems.

A second part of this study would include a systematic review of a population of patients who died shortly after discharge (with seven days, for example) from community and academic hospitals. This part would identify at least the following:

- cause of death and term of illness, including patients with newly diagnosed catastrophic disease;
- residential status of patient (private residence, SNF, ALF, and so on);
- caregiver status;
- the types of health service at home, when applicable;
- the existence of formal and informal community resources and support to patient and family pre and post death; and
- the types of patients whose hospital medical charts were absent of any communication regarding a guarded prognosis and/or the nature of the patient's condition.

Finally, we need to know more about how to evaluate and assess the quality and outcomes of all forms of end of life care. We recommend that a metric be developed, perhaps

through Healthy People 2010, for patients in acute, skilled, hospice, and home care settings. The metric would continuously determine the presence and effectiveness of end of life practices on patients facing sudden and anticipated deaths.

Recommendation 6: *Develop telemedicine to expand access to palliative care.*

The imminent collision between the burgeoning senior population and the decreasing numbers of healthcare providers will dramatically alter how care is provided to the chronically and terminally ill, yet there seems to be no sense of urgency among federal and state officials regarding this coming crisis. We therefore recommend that CMS, HRSA, or some other appropriate government agency move quickly to fund multisite telehospice demonstration projects, in which centrally located palliative care specialists may interact at a moment's notice both with family caregivers in private residences in a stratified selection of geographic settings, to include, urban, suburban, inner city, rural and wilderness areas, and with staff in nonhospice inpatient settings such as hospitals, nursing homes and assisted living facilities.

Recommendations concerning Attitudinal Barriers to Access

Recommendation 7: *Engage the Business Community.*

We recommend that the major national hospice foundations, in concert with community hospices, assist the business community in providing forums where opinion leaders from all sectors can come together to discuss and debate the critical healthcare issues that we face in the next twenty years. Good care of dying Americans is clearly a workforce issue because it relates to productivity of employees as patients and as caregivers. Productivity issues affected by chronic terminal illness are likely going to increase as the working population

ages. Both the U.S. Chamber of Commerce and the Employer Task Force of the Robert Wood Johnson-funded Last Acts Campaign have taken important first steps in helping hospices take credible steps forward.

It is critical to establish a consistent message to business leaders. While many hospices are not for profit, they must convert their outcomes into economic terms. For example, hospice decreases total costs for the employer by:

- decreasing lost productivity at work by providing support in the tasks of caregiving, as well as a response to stress of conflicting priorities and unresolved grief;
- diminishing the cost of secondary illness of the employee caregiver that is the result of caregiver burden;
- serving as an alternative to less appropriate long-term care and home care; and
- providing consultation to management on issues they will inevitably and repeatedly face related to employee absenteeism as well as coping with the tasks and stress of caregiving and grief.

In the face of an aging workforce and a shrinking labor market, the health and productivity of workers is critical to business success. Regardless of the level of their own financial contribution, employers must find ways to ensure that the physical and psychological health needs of employees are addressed if they are to stay on the job. While the business community is not directly responsible for managed care, medical treatments, or the rising cost of prescription drugs, it has the position and opportunity to promote care for its workers that is sensitive, humane, coordinated, and cost-effective, while reducing absenteeism and turnover.

Recommendation 8: Develop educational programs to “reintroduce”

hospice and palliative care to the public in light of their new capabilities, flexibility, and accessibility.

1) In line with the service innovations of the community and comprehensive hospices, we recommend developing population-wide educational and outreach programs emphasizing that hospice is no longer just about death and dying. National hospice foundations whose goals are public engagement and public empowerment over care at the end of life are encouraged to work with and expand their campaigns and other educational efforts, refraining from associating the word “hospice” with its structural *attributes* (such as the interdisciplinary team) and its intimate and singular association with suffering and imminent death in favor of a more positive message about the *benefits* of hospice programs: comfort, safety, choice, and support in responding to the life consequences associated with illness and disability, particularly during life’s “third act.”

2) Within the hospice community new educational programs (both pre-service and in-service) should be developed to equip hospice providers to meet the challenges of expanded access to hospice, both in terms of expanding hospice care “upstream” to include meeting the complex clinical and psychosocial needs of patients at earlier stages of possibly fatal illness and in terms of expanding hospice outward to incorporate more patients with a variety of non-cancer diagnoses and personal living situations.

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The following individuals took part in various project meetings and assisted with the project: Pam Barrett (Hospice and Palliative Care of Greensboro, N.C.); Samira Beckwith (Hope Hospice); Paul Brenner (Children's Hospice International); Helen Burstin (AHRQ); Courtney S. Campbell (Oregon State University); John Carney (NHPCO); David Cassarett (University of Pennsylvania); David Clark (University of Sheffield, UK); Jan Cetti (San Diego Hospice); Chris Cody (NHPCO); Robert d'Antuono (Mt. Sinai Hospital, N.Y.); Deborah Dailey (Hospice of Dayton); Dorothy Deremo (Hospice of Michigan); Pam Doty (EAP); Susan Drongowski (Nathan Adelson Hospice); M. Garey Eakes (Partnership for Caring); David English (Hospice of Northern Virginia); Dave Fielding (Hospice of Palm Beach County); Richard Fife (VITAS); Thomas Hoyer (Centers for Medicare Services); Walter Hunter (Vistacare); David Kessler; Jonathan Keyserling (NHPCO); J. Thomas Koutsoumpas (VITAS); Vincent Lafronza (National Association of City and County Health Officials); Howard Lerner (HRSA); Mary Lerner (Hospice Foundation of Central New York); Joanne Lynn (RAND); Keith Meador (Duke University); Kathleen C. Milne (RAND); Marilyn Moon (Urban In-

stitute); Patti Moore (The Watershed Group); Mary McCarthy (Hospice and Palliative Care of Cape Cod); Pat Murphy (Hospice of Martin and St. Lucie); Naomi Naiemnan (American Hospice Foundation); Hilde L. Nelson (Michigan State University); Sally Okun (Center for Life Care); Joe O'Neill (White House Office of National AIDS Policy); Gregory Pappas (Office of the Surgeon General); Jeannee Parker Martin (The Corridor Group); Kate Payne (Clinical Ethics Center); Dottie Pitner (Palliative Care Center and Hospice of the North Shore); Christina M. Puchalski (George Washington University); David Rehm (Vistacare); David Simpson (Hospice of the Western Reserve); Bev Sloan (Hospice of Metro Denver); Brad Stuart (Sutter VNA and Hospice); Claire Tehan (Trinity Care Hospice); Joan Teno (Center for Gerontology and Health Care Research at Brown Medical School); Ann Morgan Vickery (Hogan and Hartson, LLP); Charles von Gunten (San Diego Hospice); Myrl Weinberg (National Health Council); Vicki Weisfeld (Robert Wood Johnson Foundation); Christy Whitney (Hospice and Palliative Care of Western Colorado); Ann M. Wilkinson (RAND); Analee Wulfskuhle (Home and Hospice Care of Rhode Island); and Matthew Wynia (AMA).

Task Force Members

Organizational affiliations for identification purposes only; affiliations current as of 2002.

Mary Ann Bailly
The Hastings Center
Garrison, N.Y.

Dan W. Brock
National Institutes of Health
Bethesda, Md.

Gretchen M. Brown
Hospice of the Bluegrass
Lexington, Ky.

Ira Byock
Palliative Care Services
Missoula, Mont.

Virginia Casey
The Picker Institute
Boston, Mass.

Carolyn J. Cassin
Beth Israel Medical Center
New York, N.Y.

Tammy Choate
Bondware, Inc.
Nashville, Tenn.

Marcia Comstock
Comstock Consulting Group
Wayne, Pa.

Stephen Connor
National Hospice & Palliative Care Organization
Alexandria, Va.

Karen Davie
National Hospice & Palliative Care Organization
Alexandria, Va.
(formerly President/CEO)

Carol D'Onofrio
University of California
Berkeley, Calif.

Linda L. Emanuel
Northwestern University Medical School
Chicago, Ill.

Betty R. Ferrell
City of Hope Medical Center
Duarte, Calif.

Frank D. Ferris
San Diego Hospice
San Diego, Calif.

Marilyn Field
Institute of Medicine
Washington, D.C.

Kathleen Foley
Memorial Sloan Kettering Cancer Center
New York, N.Y.

Francis H. Geer
St. Phillips Church in the Highlands
Garrison, N.Y.

Marge Ginsburg
Sacramento Healthcare Decisions
Sacramento, Calif.

Sandra Harmon-Weiss
Aetna-US Healthcare
Blue Bell, Pa.

Bernice Catherine Harper
The Center for Medicare and Medicaid Services
Baltimore, Md.

Bruce Jennings
The Hastings Center
Garrison, N.Y.

Sandra H. Johnson
Saint Louis University
St. Louis, Mo.

Amber Jones
Hertzberg Palliative Care Institute
Mt. Sinai School of Medicine
New York, N.Y.

Karen Kaplan
Partnership for Caring
Washington, D.C.

Mary J. Labyak
Hospice of the Florida Suncoast
Largo, Fl.

Bentley Lipscomb
AARP
St. Petersburg, Fl.

Helen B. McNeal
Maria Consulting
Chevy Chase, Md.

Diane Meier
Hertzberg Palliative Care Institute
Mt. Sinai School of Medicine
New York, N.Y.

Alan Meisel
University of Pittsburgh
Pittsburgh, Pa.

Susan Miller
Brown University Medical School
Providence, R.I.

True Ryndes
National Hospice Work Group
San Diego, Calif.

Charles Sabatino
American Bar Association
Washington, D.C.

J. Donald Schumacher
National Hospice and Palliative Care Organization
Alexandria, Va.
(current President/CEO)

Mildred Solomon
Center for Applied Ethics
Education Development Center, Inc.
Newton, Mass.

John M. Stanley
Lawrence University
Appleton, Wis.

Daniel P. Sulmasy
Saint Vincent's Hospital & Medical Center
New York, N.Y.

Donato J. Tramuto
Protocare Sciences
Santa Monica, Calif.

Laurie Zoloth
San Francisco State University
San Francisco, Calif.

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ABOUT
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A professional coalition of hospice pioneers, executives, consultants, and researchers, The National Hospice Work Group (NHWG) is committed to increasing access to the palliative competencies of hospice care. For more than 25 years many of its members have made significant local and national contributions to the care of patients facing life-threatening illnesses, regardless of diagnosis. Through issues analysis, advocacy, best practice exchange, research and education, they continue advancing a valued philosophy of care for people affected by the profound effects of aging, disability and disease.

The twenty-five NHWG members are located across the United States. Those members with hospice programs serve from 100 to over 2500 patients per day in rural and urban communities, suburbs and inner cities. Blending traditional and alternative (or complementary) therapies, their programs have developed a valuable track record in responding to the human and medical consequences of serious illness. In addition to developing expertise in pain and symptom management, they have pioneered an approach to care that responds to patients' and families' emotional and spiritual needs, whether the patient is at home, the hospital or nursing home.

In addition to traditional hospice services, many NHWG organizations offer palliative treatment services and provide consultation and education through affiliations with local hospitals, colleges and universities. Members believe that the lessons learned in traditional hospice care will help them deliver humane service earlier in the course of treatment, as persons wrestle with complex personal and clinical decisions associated with eventually fatal disease.

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