CHAPTER 7

Improving care at the end of life

RECOMMENDATIONS

The Secretary of Health and Human Services should—

7A make end-of-life care a national quality improvement priority for Medicare+Choice and traditional Medicare.

7B support research on care at the end of life, and work with nongovernmental organizations as they (1) educate the health care profession and the public about care at the end of life, and (2) develop measures to accredit health care organizations and provide public accountability for the quality of end-of-life care.

7C sponsor projects to develop and test measures of the quality of end-of-life care for Medicare beneficiaries, and enlist quality improvement organizations and Medicare+Choice plans to implement quality improvement programs for care at the end of life.

7D promote advance care planning by practitioners and patients well before terminal health crises occur.

CHAPTER 7

Improving care at the end of life

In this chapter

- Using measures of quality to improve care at the end of life
- Increasing the use of advance care planning
- End-of-life care and Medicare's hospice benefit

Nearly 2 million Medicare beneficiaries die each year. Too many of their physical, emotional, and other needs go unmet, although good care could minimize or eliminate this unnecessary suffering. Even hospices—which pioneered care for the dying—help only a small fraction of patients and are often used far later than they should be. The Medicare Payment Advisory Commission joins many others in finding the present situation unacceptable. Ensuring that beneficiaries receive humane, appropriate care at the end of their lives should be a priority for the Medicare program. This chapter describes ways in which Medicare can improve care for the dying.

The nature of dying has changed since the times when most deaths were sudden and unexpected. Today, the principal causes of death for Medicare beneficiaries are chronic heart failure, chronic lung disease, dementia, stroke, and cancer. As a result, the dying process is now typically long and protracted, and it is usually associated with chronic illness and disability. Intermittent, but increasing, social and health care support is needed during this final phase of life. Curative and palliative treatment must often be combined in various ways. In short, the "end of life" can stretch over a period of years, placing significant new demands on our social and health care systems.

The gap between ideal care and the care now given to beneficiaries is wider in end-of-life care than in probably any other area of medicine. The Medicare Payment Advisory Commission (MedPAC) believes closing this gap should be a priority for the Medicare program.

RECOMMENDATION 7A

The Secretary of Health and Human Services should make end-of-life care a national quality improvement priority for Medicare+Choice and traditional Medicare.

Numerous factors account for our deficiencies in caring for the dying, but perhaps the most important is the nearly exclusive cultural and technical orientation of American medicine toward curative rather than palliative treatment. Much knowledge of effective palliative care exists, but it has been infrequently taught to health care professionals and infrequently put into practice (Quill and Billings 1998). The public also could benefit from learning more about end-of-life care. In earlier times, choosing from among treatment options for the dying process was not necessary. It now often is. Dying patients and their loved ones need to play an active role in securing a "good death" that reflects their wishes and meets their needs.

To improve care at the end of life, progress is needed in at least three areas:

- learning how to provide better care at the end of life,
- educating the health care profession and the public, and
- delivering and paying for care at the end of life.

More research is clearly needed: basic research on the dying process and symptoms at the end of life, clinical research on care that meets the needs of the dying, and health services research on how best to fund and deliver care. The federal government issued a program announcement in 1997 for research on how to treat symptoms of dying patients, but it apparently did not result in the funding of any research studies. A new request for applications (NR-99-004) seeks to fund 10 to 12 studies to generate scientific knowledge that will lead to improved care at the end of life.

Fostering professional and public education about good end-of-life care is probably the single best way to improve that care quickly. Physicians, for example, should be trained in end-of-life care from the beginning preclinical years through residency and beyond (Barnard et al. 1999). The profession has begun to meet this challenge. The American Medical Association, for example, created the Education for Physicians on End-of-life Care (EPEC) program, which has trained some 250 physician educators to teach their peers about end-of-life care. Other professional organizations are educating physicians, nurses, and the public about care for the dying (ACP-ASIM Observer 1998, American Association of Colleges of Nursing 1998). The American Board of Internal Medicine, other specialty boards, and residency review committees have begun to require training in end-of-life care for professional certification. California is considering whether to require continuing medical education in pain management as a condition for relicensure (Gianelli 1999). Medicare should encourage these efforts and monitor their progress.

Accreditation and the publication of information about the performance of health care organizations—such as health plans, hospitals, hospices, and medical groups—can provide additional incentives to improve care at the end of life. Nongovernmental groups, including the Joint Commission on Accreditation of Healthcare Organizations, the National Committee for Quality Assurance, the Foundation for Accountability, and the National Hospice Organization, are developing measures of quality for end-of-life care. These measures can be used for accreditation and for public comparisons of quality. They need to be broadly applicable for use by payers and the public. As the principal payer for care at the end of life in the United States, Medicare should ensure that these measures meet its needs.

Some work has been done on how to best deliver good end-of-life care. For example, the Center to Improve Care for the Dying collaborated with the Institute for Healthcare Improvement to improve care for the dying, and many other organizations and institutions are making formal efforts to improve such care (IOM 1997). But much innovation and testing are still needed to develop better systems for delivering care at the end of life. Needed services should be provided seamlessly despite fragmented delivery systems, for example, and continuity both in caregivers and approaches to care must be assured.

Payment policies also should promote the provision of needed care. Risk adjustment or other methods may need to be developed, for example, to pay capitated delivery systems enough to provide effective palliative care. The Health Care Financing Administration (HCFA) created a palliative care diagnosis code in 1996 to determine whether a new diagnosis-related group (DRG) was needed to pay hospitals for palliative care (Cassel and Vladeck 1996). The agency found that spending and lengths of stay were not significantly different within

DRGs for hospital stays in which palliative care was given and those in which it was not given. HCFA concluded that the evidence to date did not demonstrate a need to create a new DRG for palliative care (HCFA 1998). However, the agency's research method does not seem appropriate for answering the principal question, which is whether a new DRG is needed when the primary purpose of an admission is palliative care.

RECOMMENDATION 7B

The Secretary should support research on care at the end of life, and work with nongovernmental organizations as they (1) educate the health care profession and the public about care at the end of life, and (2) develop measures to accredit health care organizations and provide public accountability for the quality of end-of-life care.

The rest of this chapter describes selected ways in which Medicare can improve care for beneficiaries at the end of life. The next section discusses the importance of quality measures for end-of-life care and how Medicare can use such measures in quality improvement programs. The challenge for Medicare is to push for the development and implementation of quality measures and quality improvement programs for care at the end of life as quickly as possible, while not moving beyond what the state of the art can reasonably support. The chapter also analyzes the limited effectiveness of advance directives and suggests that federal policy focus instead on advance care planning. The last section explains the limitations of the Medicare hospice benefit and the challenges involved in extending palliative care to all beneficiaries who need it.

Using measures of quality to improve end-of-life care

Quality measures for end-of-life care vary in their state of development, but some are good enough to enable traditional Medicare and Medicare+Choice plans to begin quality improvement programs for at least some aspects of end-of-life care. Rigorous measures are being developed for accreditation and public accountability for the quality of care at the end of life, but it will be longer before a comprehensive set of such measures is in place.

RECOMMENDATION 7C

The Secretary should sponsor projects to develop and test measures of the quality of end-of-life care for Medicare beneficiaries, and enlist quality improvement organizations and Medicare+Choice plans to implement quality improvement programs for care at the end of life.

Measuring quality is central to improving it

To improve quality, one must be able to define and measure it. Providers have to know what they are trying to change and whether they are successful. This fundamental insight underlies two models of quality improvement in health care. In the continuous quality improvement or total quality management approach, organizations create an internal climate of quality improvement. Throughout the organization, people identify and measure important processes and outcomes, change the delivery system, assess the effect of those changes, and continuously repeat cycles of improvement.

A second and complementary approach is competition on quality. Under this model, health care organizations produce information on their performance for purchasers and consumers to use. Public information on performance can be seen as both a right of consumers to vital information about their health care and a spur to providers to do better.

Although both of these approaches to quality improvement rely on measures of quality, they do not place the same level of stress on the measures. Far more is required of measures used for public comparisons and accountability. These measures must be highly defensible if they are to affect the credentialing, selection, and payment of providers. The data must be defined and collected consistently across organizations and sites of care. Data collection should be relatively complete, and the number of observations must be great enough to reveal statistically significant differences. Finally, risk adjustment of the measures is critical to account for differences in the populations being compared.

Internal quality improvement, by contrast, demands less of quality measures. Providers can often take into account imperfections in the data and the measures, and the measurement process can evolve quickly as learning progresses about what needs to be measured and how to measure it (Lasker et al. 1992).

Efforts to develop measures of quality of end-of-life care

Researchers have made substantial progress in conceptualizing the important domains that should be addressed by high-quality care at the end of life and hence by measures of quality (Stewart et al. 1999). Experts do not agree on a single best conception, but the various proposals overlap considerably (see Table 7-1).

In 1996, a group of experts began to assemble a tool kit of available instruments to assess the quality of care in many of these domains (IOM 1997; Toolkit 1999). Since then, numerous initiatives have adapted, developed, and tested new measures, although the state of the art is uneven. Many measures need to be refined, validated for dying Medicare patients, and tested for responsiveness to changes in the item being measured.

Pain has been the most studied physical symptom. Knowledge of how to treat pain effectively is substantial, and good process and outcome measures have been refined, validated, and made available for use (Toolkit 1999). For other physical symptoms, such as fatigue, shortness of

TABLE 7-1

Comparison of several conceptions of the domains of quality care at the end of life

	Singer et al. 1999	Emanuel and Emanuel 1998	Institute of Medicine 1997	American Geriatrics Society 1997
Overall			Overall quality of life	Global quality of life
Physical	Receiving adequate pain and symptom management	Physical symptoms	Physical well-being and functioning	Support of function and autonomy
Emotional		Psychological and cognitive symptoms	Psychosocial well-being and functioning	Physical and emotional symptoms
Social	Strengthening relationships	Social relationships and support	Psychosocial well-being and functioning	
Spiritual		Spiritual and existential needs	Spiritual well-being	
Control	Achieving a sense of control; avoiding inappropriate prolongation of dying			Advance care planning; aggressive care near death
Satisfaction			Patient perceptions of care; family perceptions and well-being	Patient and family satisfaction
Family	Relieving burden	Economic demands and caregiving needs	Family perceptions and well-being	Family burden; bereavement
Other		Hopes and expectations		Provider continuity and skill; survival time

breath, anorexia, and nausea, knowledge of effective treatment and the state of assessment instruments vary.

Validated assessment instruments exist for many types of emotional and psychological symptoms, such as depression and anxiety, but they often need to be adapted for patients at the end of life. The 1996 toolkit included nine measures of emotional symptoms. Similarly, social functioning is often considered an important end-of-life domain, but existing measures need to be adapted and validated for patients at the end of life (Emanuel and Emanuel 1998).

The 1996 tool kit contained 17 measures of spiritual and religious well-being, but little is known about how to use them and improve the spiritual condition of dying patients (Emanuel and Emanuel 1998). Hopes and expectations are similarly deemed important, but there is scant knowledge or consensus on what to do about them.

Control over care while dying is an important goal that patients value (Singer et al. 1999). Process measures involving advance directives and concordance of treatment with patients' wishes have been used in several studies.

The tool kit in 1996 contained 13 measures of satisfaction with care, a standard component of quality in general. In this area, a family's satisfaction with care is typically assessed some time after the patient's death. Economic and

caregiving burdens on the patients' families (broadly conceived) are important to both patients and families. Various measures of these burdens might be used.

Some difficult challenges complicate the assessment of the quality of care at the end of life (IOM 1997, Rudberg et al. 1997). These include:

- Subjectivity. Many measures are necessarily subjective. This does not mean they cannot be assessed accurately, but it requires that instruments be carefully developed, tested, and interpreted.
- Choice of respondent. Patients near the end of life may not be physically, mentally, or emotionally able to participate in quality assessment. Surrogates often need to be used, but the choice of surrogates may not be straightforward. In addition, their responses may differ from those that the patient would have given.
- Time of sampling. The dying process is one of ongoing change, and it differs among patients. Because patients' priorities and the care they require also change over time, quality of care would optimally be measured at multiple times. Different measures of quality of care may be needed at different times. The sole uniform benchmark in the process—the time of death—can only be known after the fact.
- Case finding. Identifying the patients whose care should be studied can be problematic. Some diseases, including many forms of cancer, have clearly identifiable times of diagnosis and fairly predictable downward courses. The majority of Medicare patients who die, however, succumb to chronic illnesses they have lived with for some time. Their periodic acute declines, recoveries, and ultimately fatal crisis are not readily predictable. Criteria need to be developed to select whose care should be studied among the many patients with chronic and ultimately fatal illnesses.
- Burden and cost. The preceding challenges can make assessing the quality of end-of-life care burdensome and costly. Measures and measurement processes need to be devised that consume acceptable amounts of resources.

Notwithstanding these challenges, many organizations are developing, testing, and using new measures of quality of end-of-life care. These initiatives are likely to produce additional usable quality measures in the near future.

Although the extent of activity in developing and testing quality measures is encouraging, much more is needed to assess and improve the end-of-life care received by Medicare beneficiaries. The current activities are relatively small in scale. The measures typically need to be validated and sometimes adapted for Medicare populations.

The scale of the federal effort in this area seems inadequate to the task. Of the 10 research studies currently funded by the Department of Health and Human Services that principally address aspects of care at the end of life, only one seeks to develop instruments that could help assess quality of care. An additional 10 to

Organizations developing, testing, and using measures of quality of end-of-life care

The Robert Wood Johnson Foundation is supporting continued work on the tool kit of quality measures for end-of-life care (Teno 1999).

The United Hospital Fund is sponsoring a demonstration project in five New York hospitals that includes assessment tools developed or adapted by each hospital (Hopper 1999).

The Department of Veterans Affairs is trying to improve palliative and end-of-life care using performance measures of outcomes and processes.

The Joint Commission on Accreditation of Healthcare Organizations is preparing new standards for pain assessment and management (Dahl 1999).

The National Hospice Organization is developing a set of performance measures, including outcomes measures, for hospice care (Connor 1999).

Shugoll Research is developing a core set of national quality indicators for end-of-life care (Jackman 1999).

The Center to Improve Care for the Dying is organizing a demonstration called "MediCaring" for chronically ill patients who do not yet qualify for hospice care (Skolnick 1998).

The Institute for Healthcare Improvement collaborated with the Center to Improve Care for the Dying on a project to improve end-of-life care (IOM 1997).

University of Washington researchers are preparing a set of peer evaluation measures for end-of-life care (Wennrich 1999).

The Project on Death in America has funded work to assess the quality of palliative care given to inpatients (Sulmasy 1999).

The Foundation for Accountability is developing a set of instruments for public comparisons and accountability for quality of care at the end of life (Bethell 1999). ■

12 projects will be funded late this year under Request for Application (RFA) NR-99-004 on "Research on Care at the End of Life," but measure development is only 1 of 27 suggested topic areas.

Relevant studies could qualify for funding this year under another RFA (HS-99-001), "Measures of Quality of Care for Vulnerable Populations." Terminal illness qualifies as 1 of 13 factors that can produce vulnerability. One-third of the available funds are set aside for six clinical areas that do not directly include care at the end of life, however, and the RFA expresses a preference for studies of non-Medicare populations.

How can Medicare use quality measures to improve care at the end of life?

Medicare currently has two direct means to enhance the quality of care its beneficiaries receive. The traditional Medicare fee-for-service program uses the quality improvement organizations (QIOs) to carry out local and national quality improvement projects.[1] The Medicare+Choice program is implementing the new Quality Improvement System for Managed Care (QISMC), which prescribes standards for the internal quality improvement activities of Medicare+Choice plans (MedPAC 1999). Both can use the quality measures being developed to stimulate providers to begin quality improvement cycles for end-of-life care.

The QIOs are now required to perform a mix of national and local quality improvement projects. For all the QIOs, six national targets for improvement were selected in clinical areas in which quality standards and measures are well developed.[2] Each QIO is also required to undertake local projects, with the subject of each project determined by the QIO based on its interests, capabilities, and perceptions of local needs.

Given the early stage of development of quality measures for care at the end of life, it would be premature for the QIO program to adopt a new national quality improvement program for end-of-life care. But, just as in the private sector, the opportunity is ripe for QIOs to initiate a variety of projects addressing different aspects of care at the end of life. In addition, these projects could validate and compare measures of quality of care for use in the Medicare program.

If QIO projects begin soon, in two to three years HCFA will be well on its way to understanding what works to improve care at the end of life in the fee-for-service Medicare program. The information from QIO projects and the many nongovernmental initiatives under way could then be used to evaluate care at the end of life to the level of a national quality improvement focus for the QIO program.

Improving care at the end of life should be a goal for Medicare+Choice plans as well. Medicare+Choice plans can allocate resources flexibly to meet beneficiaries' needs, which offers an exciting opportunity for innovation and improvement in end-of-life care. HCFA can use QISMC to stimulate health plan activities by:

- developing and promulgating quality measures for end-of-life care that can be used by health plans to meet QISMC standards.
- using its "deeming" authority to encourage compliance with private accrediting organizations' standards for care at the end of life as they are developed.
- encouraging health plans to choose end-of-life care as the subject of quality improvement projects, and supporting these projects.

Increasing the use of advance care planning

An important domain of quality care at the end of life is ensuring that patients control their own care. This goal has not been met. The barriers to success are formidable, yet giving patients meaningful control of their care is essential for respecting personal and cultural differences at the end of life.

This section analyzes the limited effectiveness of current federal policy on advance directives as embodied by the Patient Self-Determination Act. It suggests how policy could refocus more broadly on advance care planning rather than on advance directives.

RECOMMENDATION 7D

The Secretary should promote advance care planning by practitioners and patients well before terminal health crises occur.

The limits of the Patient Self-Determination Act and advance directives

The Patient Self-Determination Act (PSDA) represents a unique federal attempt to improve care at the end of life. The law requires hospitals and other health care institutions to inform patients about advance directives and to incorporate any advance directive into their medical records. Its intent is to promote the use of advance directives and ensure that patients' care is consistent with their preferences.

In practice, the PSDA has had limited effectiveness (IOM 1997). The number of patients with advance directives has increased somewhat, although this may be due partly to a secular trend. The PSDA has not prompted higher rates of discussions between patients and physicians about advance care planning

1 The organizations now prefer to be called quality improvement organizations because they believe this name reflects the scope and orientation of their current responsibilities better than peer review organizations, the term used in statute and by HCFA.

2 The six target areas are acute myocardial infarction, flu and pneumonia, heart failure, stroke, diabetes, and breast cancer.

(Emanuel et al. 1993). When an admitting clerk fulfills the requirements of the PSDA as part of the admission process—as is often the case—a meaningful conversation or decision about advance directives is unlikely. A minority of the population has completed advance directives, and only a minority of advance directives become known to the treating physicians. Advance directives are often unavailable to paramedics and physicians when a patient becomes acutely ill (Morrison et al. 1995). This is a system problem (see Chapter 3).

Studies also have failed to show an appreciable effect of advance directives on care (Miles et al. 1996). Even one study's determined effort to improve communication about advance directives and care preferences among inpatients, families, and their physicians was largely unsuccessful in improving care, perhaps in part because the discussions took place during hospitalizations for acute illness (Teno et al. 1997).

Cultural differences can pose a barrier to the increased use of advance directives. The values underlying advance directives may not be shared by non-European American cultures (Ersek et al. 1998). Korean and Mexican Americans, for example, are more likely to favor a family-oriented model of medical decisionmaking as compared to the patient autonomy model that underlies advance directives (Blackhall et al. 1995). Traditional Navajo culture avoids negative thoughts and concepts; one study concluded that advance care planning violates traditional Navajo values (Carrese and Rhodes 1995).

African Americans discuss and complete advance directives less often than whites. When asked, they also more often express preferences for aggressive treatment. It is not known whether these differences reflect cultural values, mistrust of the health care system, qualitative differences in interactions when patients and physicians are of different races, or other factors (Silverman et al. 1995, Shepardson et al. 1999).

Shifting the focus of policy to advance care planning

One response to the difficulties experienced with advance directives is to refocus attention more broadly on advance care planning, one product of which can be an advance directive. The most important aspect of this approach is the planning process and the interactions that occur because of it, not any particular document (Singer et al. 1998, Teno and Lynn 1996).

A key feature of advance care planning is that it should encompass more than planning for decisions that will be made when the patient is incompetent. One physician articulated this philosophy by describing advance care planning as having three parts (Gillick 1995). First, patients need to understand their overall medical condition and the likely course of their illness. Second, they should be able to appreciate what the experience of treatment would be like for them. Finally, they need to formulate broad goals for their care and delineate circumstances in which palliative or curative treatment would be indicated. This process is especially appropriate for patients with chronic illnesses that are not imminently fatal and that require a dynamic mix of curative and palliative treatment.

Medicare could promote advance care planning in several ways:

- by informing physicians how they can be paid for it,
- by supporting the refinement of measures of the quality of advance care planning, and
- by stimulating innovative programs to promote advance care planning.

Paying physicians for advance care planning

Medicare payment policy already supports advance care planning. If it constitutes the principal part (more than 50 percent) of a physician visit, physicians can bill for advance care planning using standard evaluation and management codes (for example, established patient office visit), with the level of service being determined by the length of the visit.

Medicare's payment policy should encourage physicians to schedule visits for advance care planning, but the policy is not widely known or understood, based on telephone conversations with a sample of experts on end-of-life care and with members of specialty societies' payment policy committees. MedPAC found that some experts did not think advance care planning could be billed as a separate service, while others made incorrect recommendations for billing for it (for example, by using the preventive medicine counseling codes, which are reserved for risk factor reduction counseling with healthy individuals). HCFA should clarify and publicize the availability of payment for advance care planning under the Medicare Fee Schedule.

Measuring the quality of advance care planning

The analysis in this chapter of quality measures for end-of-life care in general applies to advance care planning as a specific example. To improve the performance of this aspect of the health care system, measures are needed to identify good advance care planning. The federal government should support the development and testing of such measures as part of its broader support for developing quality measures for end-of-life care. First-generation measures exist; they need to be refined and tested in varied settings. For example, the Department of Veterans Affairs is using measures of advance care planning in an effort to improve palliative and end-of-life care. And the tool kit of quality measures for end-of-life care contains usable measures of the quality of advance care planning (Toolkit 1999).

Increasing the use and effectiveness of advance care planning

Many efforts have been made to improve the rate of advance care planning and to increase compliance with the resulting expressed preferences, but the gains have

been relatively modest (Miles et al. 1996). Innovation is needed to make substantial progress.

Successful models do exist. In one initiative to improve the use of advance care planning, competing health systems in La Crosse, Wisconsin, developed a joint program in 1991 (Hammes and Rooney 1998). This continuing program, called "Respecting Your Choices," has three key features: (Hammes 1999a).

- Education. The cooperative program developed and distributed a range of educational materials for people with different levels of knowledge about advance care planning and advance directives. The program also used a formal initial course and periodic refresher seminars to train more than 350 nonphysicians—including social workers, chaplains, and community volunteers—as advance care planning educators. These educators' sessions with patients focused on understanding, reflection, communication, and relationships, not primarily on completing an advance directive.
- Community outreach. The educational materials and advance care planning educators were available in community settings. Educational conferences and meetings were held for community lawyers, clergy, and other service groups that requested them.
- Institutional infrastructure. Participating health care institutions changed policies and procedures, such as the handling of medical records, to ensure that advance care planning documents were prominently included in each patient's active floor chart.

In 1995 and 1996, investigators formally evaluated the use of advance directives and compliance with them during care at the end of life. Researchers studied all deaths in one geographic area during an 11-month period. Of 540 decedents studied, there was written evidence of advance care planning (power of attorney for health care, instructive documents such as a living will, or physician notes documenting a discussion with the patient) for 85 percent of them. The median time between the documentation of advance care planning and death was more than one year.

Even more impressive was the extent to which care at the end of life followed the advance care planning. Of decedents with documented advance care planning, 95 percent had the document in their medical records at the time of death, and treatment decisions were consistent with the document 98 percent of the time. Even in the relatively few instances of apparent inconsistency, patients' preferences generally did not seem carelessly disregarded. Sixteen times, for example, patients were hospitalized contrary to their documented preference. Six of these patients were competent and decided to be admitted, and two were admitted for pain management. In the remaining eight cases, the family requested hospitalization. Overall, people with documented advance care planning were seven times more likely to die outside of the hospital than those without it (Hammes 1999b).

A five-year process to improve end-of-life care in Oregon nursing homes has also yielded impressive results (Teno 1998). In addition to the development and use of a new written advance directive, state policies and institutional processes were reformed to promote advance care planning and improve end-of-life care.

Medicare's QIOs and Medicare+Choice plans have a promising foundation on which to build, although the La Crosse and Oregon programs may not directly translate to all communities. Promoting advance directives and advance care planning may be more difficult with some populations, depending on their ethnic and cultural makeup, access to health care, and socioeconomic status. In trying different, innovative approaches, identifying and respecting cultural differences is particularly critical.

End-of life care and Medicare's hospice benefit

Hospice care typically addresses many aspects of quality end-of-life care (see Table 7-1). This approach to treatment recognizes that impending death may make palliative care more desirable than curative care. The goal of hospice care is to help terminally ill patients continue as normal a life as possible and remain uninstitutionalized. Using a multidisciplinary team of providers, hospices provide medical, social, psychological, and spiritual care to patients and respite care and counseling for patients' families. Hospices' coordination of care to provide comfort in the final stages of a terminal disease can be a welcome alternative for patients who do not want aggressive treatment in a hospital.

Hospices are the primary institutional providers of palliative care in the Medicare program. The growth of hospice care in Medicare and through other public and private payers indicates that the so-called hospice movement has tapped significant public demand. Since their entry in the Medicare program in 1983, hospices generally have "demonstrated excellent care" for the population that they serve (Lynn and Wilkinson 1997).

The number of hospices and total Medicare spending on hospice services have grown considerably in recent years, with Medicare spending on hospice care exceeding $2 billion in 1997 (see Table 7-2). Medicare finances about two-thirds of all hospice spending.

Through a combination of Medicare eligibility rules, hospice admission policies, and other factors, however, a number of patients who could benefit from the services of hospices are excluded from such treatment. Patients may have difficulty getting care because of the types of diseases they have, their home living arrangements, or cultural factors.

TABLE 7-2

Medicare hospices and spending, 1991–1997

Year	Total spending (millions)	Spending per beneficiary	Number of hospices
1991	$533	$4,365	1,011
1992	1,095	5,304	1,039
1993	1,243	5,779	1,288
1994	1,614	6,069	1,602
1995	1,873	6,056	1,857
1996	1,999	6,120	2,090
1997	2,211	NA	2,133

Source: HCFA Office of the Actuary and Federal Register, October 5, 1998.

Medicare payment rules for hospices

Beneficiary election of hospice care

Medicare covers hospice care for beneficiaries who elect the benefit and are certified by a hospice medical director and an attending physician as terminally ill, with less than six months to live if the disease follows its usual course. A patient who opts for hospice care waives all rights for curative care under the Medicare program for illness related to the terminal condition. Medicare will continue to cover illnesses and injuries unrelated to the terminal condition and outside the hospice plan of care.

The initial benefit period is 90 days, which may be followed by another 90 days of coverage. Subsequently, a beneficiary may elect an unlimited number of 60-day benefit periods. The hospice medical director must recertify that the patient is terminally ill at the beginning of each 60-day period.

At any time, a beneficiary may opt out of hospice care and seek curative treatment for the terminal illness. Beneficiaries also may change their designated hospice once in each election period.

Payment for hospice services

Medicare pays prospective, per diem rates for hospice care. There are four rates, depending on the location and type of service provided. Payment is made for only one type of service per day:

- Continuous home care. Patients receive nursing care and sometimes home health aide or homemaker services continually at home. Continuous home care is furnished only during periods of crisis and only as required to maintain patients at home.
- Routine home care. Patients stay at home but do not receive continuous care as defined above.
- General inpatient care. Patients receive care in an inpatient facility to control pain or manage acute symptoms that cannot be managed in another setting.
- Inpatient respite care. Patients receive short-term care at a facility to relieve family caregivers.

Medicare pays the routine home care rate unless patients require continuous or inpatient care. Inpatient care days (respite or general) may not exceed 20 percent of all patient care days. Further, reimbursement to any hospice is subject to an annual cap per beneficiary. Legislation instituted the cap at $6,500 per year in 1984, updated by the medical consumer price index each year. The cap is now above $14,000. Unique among providers participating in the Medicare program, hospices must employ unpaid volunteers for a minimum of 5 percent of total patient care hours.

The national rates for each category of care per diem will be updated by the hospital market basket index minus 1 percent for fiscal years 1998 through 2002. The labor portion of each of the four per diem rates is adjusted by a county-specific wage index based on hospital cost report data from 1993.

Beneficiaries' only out-of-pocket expenses for hospice care are a maximum $5 copayment for drugs or biologicals and 5 percent of the rate for a day of inpatient respite care, subject to an annual limit equal to the inpatient hospital deductible. Normal copayments and deductibles apply for services that are not considered hospice care.

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Medicare payment rules for hospices

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Types of hospice services

With some exceptions for nonurban areas, hospice employees must provide what regulations classify as the hospice core services. These are nursing services; medical social services; and bereavement, spiritual, and dietary counseling. In addition to the core services, the hospice must provide or contract to provide physicians' services, physical and occupational therapy, speech-language pathology, home health aide and homemaker services, medical supplies and appliances, and short-term inpatient care.

Hospice and Medicare+Choice

Beneficiaries enrolled in Medicare+Choice plans have access to hospices. When plan enrollees elect the hospice benefit, HCFA directly pays the hospice for their care, and the payment to the Medicare+Choice plan is reduced.

The principle of organized care on which most Medicare+Choice plans operate fits well with hospice care. Hospices provide an interdisciplinary team that coordinates care across providers and settings. One Medicare+Choice organization, which operates its own hospice, coordinates end-of-life care for congestive heart failure and chronic obstructive pulmonary disease patients. Patients are treated with a combination of palliative and life-extending treatment when appropriate. Until patients are eligible to elect hospice under the six-month prognosis rule, care is provided primarily under the auspices of home health care. Both before and after hospice election, the patients have access to a physician, nurse, and social worker for themselves and family members. The goal is to make care as seamless as possible through the transition from the pre- to post-election periods. ■

Access issues and hospice eligibility rules

Most Medicare hospice patients have cancer. Because Medicare eligibility for hospice hinges on patients' prognoses of six or fewer months to live, the Medicare rules generally accommodate the trajectory of cancer patients' decline, which for most types of cancers is predictable and rapid in the end stages.

People with terminal chronic conditions for which the decline is not as rapid or predictable, such as congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD), could benefit from the services of a hospice but often are not able to do so (Lynn and Wilkinson 1997, MedPAC 1998). For such patients, the trajectory of decline is usually longer than for cancer patients and is punctuated by difficult-to-predict acute events, thus estimates of a six-month survival time for a CHF or COPD patient, to enable hospice eligibility, can be difficult to predict. Moreover, because of recent investigations by the Office of Inspector General examining long hospice stays, physicians may be reluctant to make six-month diagnoses in all but the clearest cases to avoid any perception of fraud. In such instances, the patient may be admitted to the hospice either after hospice services may be of optimal value, or not at all.

Medicare rules allow only those who have elected the hospice benefit to receive services from hospice providers, and Medicare generally limits hospices to providing only palliative care. Thus a gap in care can arise for those suffering from chronic diseases who could benefit from life-extending treatment as well as palliative care. Because all patients who elect hospice care must have access to the full array of services, hospices cannot serve patients who have not formally elected the benefit but may desire certain targeted palliative services before they are eligible.

Settings beyond hospices for coordinated end-of-life care should be researched and tested. The duration and severity of different illnesses vary over their normal courses, resulting in varying patient needs. Further study of the course of chronic and terminal diseases such as COPD, CHF, and Alzheimer's disease could lead to a coordinated care system that provides appropriate care at the appropriate time.

Hospice patients and home care

The Medicare rules that limit inpatient care for beneficiaries electing hospice care result in patients spending most of their treatment time at home. Indeed, hospice treatment was originally designed for patients to spend their last days in a familiar and comfortable home setting with loved ones. But as patients' conditions deteriorate, they need more help from informal caregivers, usually family members.

Medicare rules do not require hospice patients to have designated informal caregivers, but managing illness is difficult without them. According to the

National Hospice Organization, 13 percent of hospices will not accept patients at all without designated primary caregivers, and 27 percent decide case-by-case whether to admit patients without them. Therefore, patients with weak, strained, or nonexistent family contacts may not be able to get hospice care.

Cultural factors and hospice care

Compounding eligibility and home care difficulties can be a range of cultural factors related to death and the process of dying. First, the scientific orientation of the mainstream culture of medicine and the desires of the public often result in providers, patients, and families continuing with curative therapies rather than "giving up" and "abandoning" a patient to hospice (Merritt et al. 1998). Medical education curricula pay little attention to end-of-life treatment. The parsimonious training of medical personnel in end-of-life issues often contributes to decisions to continue curative treatment that may be of dubious value to the dying patient.

Second, cultural and language barriers among providers, patients, and patients' families can inhibit frank discussion of hospice options. Such decisions are often the most difficult of a lifetime, and people can have different cultural constructions of the meaning of death and the need to make end-of-life decisions. In any context, however, clear and thoughtful discussion is necessary. Hospices, though, may not be in the best position to serve people from a wide range of cultures. One hospice executive maintains that hospices "are successful in addressing the needs of middle class, white, elderly persons with cancer who have family members to care for them at home. However, there is a need to provide better access to care within diverse settings and for diverse populations" (Brenner 1997). Further, the National Hospice Organization identified hospice staff deficiencies in fluency with non-English languages and familiarity with diverse cultures as important barriers to hospice care (National Hospice Organization 1994). Hospices are likely to find the means necessary to broaden their outreach to eligible patients of all backgrounds, however, as the industry grows and competition for patients increases.

The future of hospice care

The ability to address the challenges of eligibility, access, and communication, as well as a changing health care system, will determine the future of the Medicare hospice program. As noted in this chapter, changes in care at the end of life are likely in the near future. To find the best ways to care for all beneficiaries at the end of life, Medicare should draw on the experience it has gained in successfully running hospice programs. For their part, hospices should strive to serve those who are eligible for, and who want, their services and also should work with other providers, as appropriate, to research better coordinated end-of-life care. ■

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