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Paying for Terminal Illness

The experience of dying has moved from a private family matter to the public professional sphere. Medicare hospice coverage is intended to be comprehensive, but its eligibility rules and per diem limits deprive some patients of needed care. This article examines these limits and the alternative models for care of the dying.

By Journal Staff

The vocal public debate over the right to determine one's own way of dying must, first or last, depend upon society's willingness to pay for terminal care—whatever that is to include.

The experience of dying has changed over recent decades. The need for assistance from society results in part from the fact that death itself has moved from a private family matter to the public professional sphere.

As late as 1939, less than half of the population died in hospitals, nursing homes, or other institutions. By 1992, over 80 percent did so.¹ The dying

came to be separated from their home environments and people, and placed in the care of professionals with a commitment to institutional and professional values that might conflict sharply with the patient's preferences. At the least, institutional dying caused patients and family a regrettable loss of privacy and intimacy at a sensitive time.

In the early 1980s, perhaps a thousand hospices existed nationwide. Mostly small, they were funded with payments from patients, charities, and private and public grants. In 1983, Congress created the Medicare hospice benefit to provide broad medical and social services benefits, including home health services, outpatient drugs for pain control, physician services, counseling, and short-term residential care in a skilled nursing facility or a hospital. Core services are provided 24 hours a day. The emphasis is on palliative care, defined as diagnostic and therapeutic intervention intended to relieve pain and other symptoms but without the goal of prolonging life.²

The beneficiary who elects hospice care forgoes Medicare benefits intended to treat the terminal illness. The beneficiary must have a diagnosis projecting death within six months to qualify to make the election, and can opt to return to Medicare coverage under Parts A and B to receive curative treatment.

Medicare hospice care involves few copayments. The beneficiary is responsible for a copayment on each prescription filled of the lesser of \$15 or 5 percent of cost. There is also a copayment for inpatient respite care.

Prior to the Balanced Budget Act of 1997, the Medicare hospice benefit consisted of two 90-day periods and one additional period of 30 days, with

an extension of care for the rest of the patient's life.³ The Balanced Budget Act provided for two 90-day periods followed by an unlimited number of 60-day periods. At the beginning of each 60-day period, a hospice physician must certify that the patient has a terminal illness with death anticipated within six months.

The structure of hospice care has posed problems for patients and for the program's successful expansion. The 210-day stay is based on typical needs of cancer patients, hospice's traditional target group. Advocates have pointed out that the structure of benefits is unsuited to the needs of many, such as those with chronic obstructive pulmonary disease whose prognosis is unpredictable. Other chronic, and ultimately fatal, conditions have an acute phase during which hospice-type services might be needed and death might seem imminent, only to have severe symptoms go into remission. For these patients, the hospice eligibility period might be too short. Even the 60-day extensions imply predictability that is frequently lacking.

For other dying patients, hospice care might come too late, so the stay is too short to serve hospice goals of physical, psychological, and spiritual comfort for patients and their families. The patient and family members must become familiar with the professional visitors to the home in order to learn and benefit from their experiences and knowledge. Yet, the average length of certification for hospice care dropped throughout the past decade, from over two months to less than 20 days in one study. Although a three-month stay may be considered optimum for hospice goals, one study reported the median survival time for hospice patients to be 36 days.⁴ Further, only about 17 percent of dying persons use a hospice program.

Capped per diem payments to hospices also are suspect, although the full picture of their impact is unclear. Medicare pays hospices using four levels of per diem rates plus an overall cap. In 1997, the cap was \$13,974 times the number of enrolled patients. The per diem rate for routine home care was \$94.17. The Institute of Medicine noted that certain kinds of care, including the use of costly pain medications, late-night visits for medical or emotional crises, and use of high-tech equipment might be precluded by the rate.⁵

Extended low-tech services might also be impossible under the home care per diem. Family

members learn home care skills from visiting nurses and provide much of the round-the-clock care. While it is typical to provide a home health aide to be by the bedside when death is imminent, the per diem cap precludes extended periods of attendance needed by those without family caregivers.

Soon after creation of the Medicare hospice, and partly in reaction to the government's definition of hospice care, the Cleveland clinics established a Palliative Care Program, defining palliative care as the "total act of care of patients whose disease is not curable." The program incorporated inpatient and outpatient services with home health care, without time limits. In a program new in the 1990s, payer and patient preference for home care is emphasized at the Center to Improve Care of the Dying at George Washington University. The program emphasizes comprehensive community-based services, including family support. These are just two of the well-developed models that might provide direction for new hospice policy.

Hospice programs were scrutinized in recent years for services to patients who were not reasonably considered to be terminal. Those with clients reaching the end of life can envision how this happens: The assisted living or condominium dweller with chronic illness has a period of acute distress, perhaps is briefly hospitalized, and returns home with patient, doctors, and family considering "Maybe it would be better if . . ." Since extensive practical and counseling assistance is helpful, and needed prescriptions are less costly to the patient, he or she "elects" hospice care. And then the patient rallies, proving life is very strong even for those who are old and ill.

Hospice has been a managed-care "carve-out," that is, left out of the package of benefits covered by Medicare managed care. Perhaps the principal justification is the difficulty of incorporating payment for a hospice with payment for life-extending health care. The resolution of incompatible values and methods for health care and hospice care is not yet clear.

Yet, there are a number of observations that might improve the hospice benefit and experience:

Better pain management is critical. Conservative medical boards in many states have censured their doctors for liberal use of pain medication, erroneously identifying all generous use with

misuse and addiction. Such concerns are inappropriate for terminal patients. Yet, the artful use of pain medications for the chronically ill and dying has not been well studied. Nor is it taught in medical schools.

The conflict of values between acute medical care and palliative care of the dying must be resolved. The principal difficulty arises, it seems, from the relatively recent inability of physicians to discern when medical technology can assist the patient. The decision is complicated by the patient's personality and wishes, unmeasurable factors such as the perception of pain, and uncertainty about the outcome of medical procedures on patients who are already old and ill.

Endnotes

1. See Public Health Service, Department of Health and Human Services, National Center for Health Statistics, VITAL STATISTICS OF THE UNITED STATES, 1992, VOL. 2—MORTALITY, PART A (1996).
2. See 42 U.S.C. § 1395d(d).
3. See 42 U.S.C. § 1395(d)(1).
4. See Charlotte Snow, *IG: Many Hospice Patients Not Terminally Ill*, MODERN HEALTHCARE, Nov. 10 1997, at 52.
5. See Institute of Medicine, Committee on Care at the End of Life, APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE (1997).