



Marilyn Moon and Cristina Boccuti

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Marilyn Moon and Cristina Boccuti
The Urban Institute
2100 M Street, NW
Washington, DC 20037
(202) 261-5256
cboccuti@ui.urban.org

We gratefully acknowledge funding for this project from Last Acts®, a Robert Wood Johnson Foundation initiative. Theresa Varner and Andy Schneider, co-conveners of the Last Acts Financing Committee, provided helpful comments on earlier drafts of this paper, as did Joshua Weiner, Judy Feder, Stephen Connor, and Karen Orloff Kaplan. We are grateful to Krista Dowling for her research assistance.

The views expressed in this paper are those of the authors and should not be attributed to The Urban Institute.

Executive Summary

The Medicare program, which serves people age 65 and older and those with disabilities, is the most important source of health insurance for Americans at the end stages of their lives. Therefore, its rules regarding methods and levels of payment and covered benefits have a strong impact on end-of-life care. Medicare offers a hospice benefit that covers palliative care services for people with terminal illnesses. While 23 percent of Medicare beneficiaries who died in 2000 took advantage of the hospice benefit, the remainder relied on other parts of the Medicare program to obtain end-of-life care. This paper examines Medicare's role in facilitating access to end-of-life care for hospice and non-hospice beneficiaries. We describe and discuss the end-of-life benefits covered and the payment systems used for different provider types, as they relate to end-of-life care, and note potential areas of improvement.

Medicare's Role in Facilitating Access to End-of-Life Care

Medicare's hospice benefit provides access to palliative care for terminally ill beneficiaries who voluntarily agree to forgo curative treatment for their terminal illness. Covered hospice services include treatment to alleviate physical symptoms (such as pain) and the provision of bereavement services (emotional and spiritual) for patients and family members. The hospice benefit also covers up to five days of respite care. To elect the Medicare hospice benefit, beneficiaries must have a statement from their physician, certifying that they are terminally ill with a life expectancy of about six months or less, if the disease runs its normal course. People who live longer than originally expected may remain in the hospice program as long as their prognosis continues to fit the eligibility requirement.

While hospice use has tripled in the last decade, our research finds that some beneficiaries are less likely than others to enroll in hospice care. For example, males and minorities are less likely to elect hospice care than females and whites. Decedents who also have Medicaid assistance (dual eligibles) are less likely to enroll in the Medicare hospice benefit than those who do not. In contrast, Medicare decedents in managed care are more likely to elect hospice care than those in the traditional fee-for-service program. Cancer diagnoses are the most prevalent in hospice care, but non-cancer diagnoses (such as heart disease and Parkinson's disease) have become more frequent over the last decade.

Medicare covers many services outside of the hospice benefit that are also useful to people facing terminal illnesses. For example, Medicare covers skilled nursing services to home health patients, skilled nursing facility patients and hospital inpatients. Notably, however, bereavement and pastoral care services are not covered outside the hospice program. While Medicare covers prescription drugs for skilled nursing facility (SNF) and hospital inpatients, it does not cover most oral prescription drugs (including those for pain) for home health patients. However, many beneficiaries with supplemental insurance (particularly Medicaid assistance) have some access to outpatient drug coverage.

Medicare Payment Methods and Spending

Across health care settings, Medicare relies on different payment methods and payment rates to cover the cost of end-of-life care. Medicare pays hospice providers a fixed amount on a per diem basis. SNFs, home health agencies and hospitals are also paid on a prospective basis but, unlike



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hospice, their payment rates are adjusted by more detailed patient characteristics related to expected treatment costs. Hospice agencies have expressed concerns that Medicare's fixed daily hospice payments do not take into account the extra costs incurred during the initial days of a hospice patient's enrollment, which is a problem because an increasing number of hospice patients do not initiate hospice care until one week before their deaths.

Terminally ill Medicare beneficiaries in HMOs also may enroll in hospice care, in which case the HMO receives a lower monthly payment but is not financially responsible for the hospice care. Beneficiaries also have the choice to disenroll completely from their HMO, which may be preferable in cases where beneficiaries must pay high monthly premiums. Under the hospice benefit, Medicare beneficiaries have relatively few out-of-pocket expenses.

Spending for decedents accounts for more than one-quarter of Medicare's total annual spending, a share that has remained stable for two decades. The Medicare hospice program, which accounts for about 1 percent of Medicare's annual payments, was designed not as a Medicare cost-reducer, but as a program that provides appropriate care for dying patients. Accordingly, our research finds that average spending on decedents who used hospice care in the last calendar year of life (\$19,950) is not dramatically different from the amount spent on decedents who did not use hospice care (\$17,790). Though Medicare spending on hospice users is somewhat higher, these figures are quite close considering that some portion of those decedents who did not elect hospice died relatively suddenly and therefore used few medical services of any kind.

Best Practices and Potential Improvements for End-of-Life Care

While Medicare has made some inroads in improving care at the end of life, only a small

number of people now benefit. In addition to the hospice program, Medicare contributes to the Program for the All-inclusive Care of the Elderly (PACE)—a small but expanding coordinated care program for frail, elderly nursing-home-eligible adults who are usually in the last two or three years of their life. Since PACE admits patients based on their functional status and acuity level, their enrollees can enter a coordinated care program (with many palliative services available) earlier than patients who enroll in Medicare hospice.

A number of changes—many of them quite modest—could be made to the Medicare program to improve both access and quality of care provided to beneficiaries facing death. For example, Medicare could better publicize little-known policies to physicians, such as (1) their ability to bill for advance care planning sessions; (2) their ability to recertify hospice patients who survive longer than was expected; and (3) their new ability to register as a specialist in pain management with Medicare, if applicable. Better consumer information for patients and their families would also be useful.

The hospice benefit also faces several challenges that might be addressed with adjustments in payment and eligibility policy; these could be tested through demonstration projects supported by the Department of Health and Human Services. For instance, trial adjustments to hospice payments to account for patients with short stays or who need the provision of unusually expensive palliative treatments may provide useful solutions to current reimbursement problems. More flexible eligibility rules could allow hospice care to be available to a wider range of Medicare beneficiaries.

Conclusion

Much remains to be done to move the palliative care needs of people at the end of their

lives to a more mainstream position within Medicare. Most Americans who die are being served by the Medicare program, yet Medicare's attention to the end-of-life issue is largely confined to hospice, a relatively small though growing program. A careful look at end-of-life care ought to explore both hospice and traditional care settings to find areas for improve-

ment. The list of best practices remains limited; the small number of physicians and patients who are knowledgeable about these issues constitutes a major barrier. Even with attention to budget constraints, however, a number of improvements to end-of-life care could be made through either regulatory or legislative changes on a modest scale.

I. Introduction

Medicare is the primary health insurer for more than 80 percent of the people who die each year in the United States (Hogan, 2001). Therefore, its rules regarding payment and covered benefits have a strong impact on health care provision and spending during the dying process. Some beneficiaries who face terminal illnesses may prefer palliative care—focusing on alleviating physical symptoms and addressing psychological, social and spiritual issues—rather than curative treatment for their illness. Other beneficiaries in similar circumstances may desire more aggressive medical care. Some may want both. These decisions are highly personal and individual, and require knowledge of how Medicare provides access to various types of services in different settings. In this paper we explore the answers to three major questions in order to understand Medicare's role in end-of-life care, with special emphasis on Medicare's hospice program.

- How does Medicare facilitate the provision of end-of-life care services to meet the needs of dying beneficiaries?
- How does Medicare spend its resources on end-of-life care?
- How can Medicare improve end-of-life care?

Medicare's hospice benefit was established in 1983 as a specific palliative care benefit for those in their last six months of life. In 2000, 23 percent of the beneficiaries who died received hospice care (Hogan, 2002 cited in MedPAC, 2002). However, because hospice is only one of the several types of providers that administer care to Medicare beneficiaries who are dying, a larger share of beneficiaries receive end-of-life care in Medicare's fee-for-service program or in its

managed care program called Medicare+Choice. In this paper, therefore, we take a broad view of end-of-life care options. Specifically, we examine the services that Medicare does and does not cover and its systems of payment by type of care and setting, discussing advantages and disadvantages for both patients and providers. Payment adequacy and access to care are important considerations, for example.

Beneficiaries who qualify for Medicaid and those in managed care plans face special circumstances that we also discuss here. Spending on health care in the last year of life is high, as one might expect, given the illnesses that accompany death. We therefore present research findings (both ours and other researchers') on spending trends for care in the last year of life. We conclude this paper with some suggested changes to the Medicare program that could enhance the availability and quality of care provided to beneficiaries near the end of their lives.

What Is End-of-Life Care? What Is Palliative Care?

Definitions of what constitutes end-of-life care and palliative care and the relationship between the two vary considerably among experts, patients and providers. In this paper we regard end-of-life care as a broader term that refers to all health care provided to people with a terminal illness, whether the prognosis is a day or a decade. We refer to palliative care as a particular type of end-of-life care that terminally ill people may receive, usually by choice. Specifically, palliative care is noncurative care that focuses on controlling symptoms such as pain, maximizing personal functional activities, and addressing the emotional, spiritual and social concerns associated with death and dying.

Medicare's hospice benefit was designed specifically for those who want to receive only palliative care.

Palliative care is often contrasted with curative care and people tend to focus on palliative care only when they have exhausted the treatments available for curing a disease. In practice, the lines between cure and relief of suffering may be blurry; palliative care may be needed for many years and not just in the last few months of life, and some patients may seek active treatment throughout a terminal illness. These variations highlight the need to consider both philosophies of care when investigating Medicare's role in end-of-life care. Thus, in our look at the services people use at the end of their lives, we examine the effects of Medicare regulations on how patients may receive palliative and curative care in different settings.

The Precepts of Palliative Care—The *Last Acts* campaign has adopted a set of fundamental

principles for providing good palliative care to people who have an incurable, progressive illness. *Last Acts* defines palliative care as “care that achieves the best possible quality of life through relief of suffering, control of symptoms and restoration of functional capacity, while remaining sensitive to personal, cultural and religious values, beliefs and practices.” Five general goals relevant to the provision of palliative care are outlined:¹

1. Respecting patient preferences.
2. Providing comprehensive care.
3. Maximizing interdisciplinary resources.
4. Acknowledging caregiver concerns.
5. Creating health care systems flexible enough to support these goals.

II. Medicare's Role in Facilitating Access to End-of-Life Care

Medicare's Palliative Care Benefit: The Medicare Hospice Program

Medicare's hospice benefit provides access to palliative care for those beneficiaries who have terminal illnesses. To elect the Medicare hospice benefit, beneficiaries must be eligible for Medicare (Part A) and have a statement from their physician certifying that the patient is terminally ill with a life expectancy of about six months or less, if the disease runs its normal course. Beneficiaries are allowed two 90-day periods of hospice care and an unlimited number of 60-day periods. However, each hospice election must be accompanied by a physician's statement certifying that the patient can reasonably be expected to live for six months or less.

The hospice beneficiary voluntarily agrees to forgo curative treatment for the terminal illness.² By relinquishing such services, hospice beneficiaries are eligible to receive palliative care administered through a Medicare-approved hospice program. The restrictions on hospice reflect the fact that Congress was only willing to pass an added benefit in 1983 if it were structured so that it would not add substantially to Medicare's costs. As a consequence, not only were eligibility requirements restrictive, but enrollees also had to forgo certain Medicare benefits in exchange for the expanded services that hospice provides. These limitations have created some barriers for the hospice program.

Table 1: Medicare Benefit Eligibility and Coverage of End-of-Life Services, by Provider Type, 2002

	Hospice	Home Health	SNF	Hospital
Eligibility	Must have a life expectancy of 6 months or less and agree to forgo curative treatment	Must be generally homebound with a skilled health care service needed	Must have a prior hospitalization of 3 days or more and require daily inpatient skilled nursing or rehab services	Must be considered medically necessary
Health Care Services				
Skilled Nursing	Covered in full	Covered in full. Nursing must be intermittent or part-time. Maximum of 35 hrs/week of skilled nursing and home health aide services combined	Covered in full	Covered in full
Skilled Therapy (PT/OT/Speech)	Covered in full	Covered in full	Covered in full	Covered in full
Home Aide Services (e.g., dressing, feeding)	Covered in full	Covered in full	Not applicable	Not applicable
Homemaking Services/Custodial Care (e.g., cooking)	Covered in full	Not covered	Not applicable	Not applicable
Physician Services	Covered in full for hospice-affiliated services; 20% Part-B coinsurance applies for services not affiliated with the hospice (e.g., patient's personal physician)	Not part of the home health benefit, but covered under Part B with 20% coinsurance	Not part of the SNF benefit, but covered under Part B with 20% coinsurance	Covered in full for teaching physicians; 20% coinsurance applies for all other physician services
Nutritionist Services	Covered in full	Not part of the home health benefit, but covered under Part B for patients with end-stage renal disease or diabetes	Covered in full	Covered in full
Medical Social Services	Covered in full	Covered in full	Covered in full	Covered in full

Table 1 (continued)

	Hospice	Home Health	SNF	Hospital
Eligibility	Must have a life expectancy of 6 months or less and agree to forgo curative treatment	Must be generally homebound with a skilled health care service needed	Must have a prior hospitalization of 3 days or more and require daily inpatient skilled nursing or rehab services	Must be considered medically necessary
Health Care Services				
Bereavement and Pastoral Care	Covered in full for patient and family members	Not covered	Not covered	Not covered
Respite Care	Covered with 5% coinsurance; maximum 5 days per stay	Not covered	Not applicable	Not applicable
Continuous Nursing	Covered in full for a medical crisis	Not covered	Covered in full	Covered in full
Prescription Drugs	Covered if related to pain and symptom management of terminal illness; maximum co-payment of \$5/prescription	Not part of the home health benefit, but some specified oral, inhalation, and non-self administered drugs are covered under Part B with 20% coinsurance	Covered in full	Covered in full
DME and Medical Supplies	Covered in full	DME is covered with 20% coinsurance; Medical supplies are covered in full.	Covered in full	Covered in full
Curative Treatment	Not covered for terminal condition	Covered	Covered	Covered
Room and Board	Not covered	Not covered	Covered in full	Covered in full

Notes: Under the SNF benefit, beneficiary cost-sharing increases considerably after 20 days. Additional cost sharing for deductibles may apply. For 2002, the hospital deductible is \$812 per qualified admission; Part-B provided services have a \$100 deductible; Home Health and Hospice care have no deductibles. SNF is Skilled Nursing Facility. DME is Durable Medical Equipment.

Source: Medicare guidebooks for beneficiaries. Medicare Rights Center, and discussions with CMS staff.

Table 1 lists services that are covered by the Medicare hospice benefit. Most hospice care is based on routine home care and provides access to physical, psychological, social and spiritual care for dying persons, their families and other loved ones. Specifically, the Medicare hospice benefit covers skilled nursing care, hospice physician services, nutritionist services, medical appliances and supplies, prescription drugs, home health aide services, homemaker services, therapies (physical, occupational and speech), and bereavement counseling for the patient and/or family members. Also, Medicare covers up to five days of respite care designed to give informal caregivers some relief. The respite care can be provided to the patient in a freestanding hospice facility, a hospital or a nursing home. As noted, the Medicare hospice benefit does not cover curative treatments related to the terminal condition, nor general room and board.

Hospice care may be provided to Medicare beneficiaries in a number of settings: patients' homes, nursing homes, skilled nursing facilities, freestanding hospice facilities and hospital-based units. Hospice enrollees select a *program* rather than a facility and can potentially receive care in several types of facilities before dying. Thus it is not easy to determine where hospice care is being delivered. A large portion of Medicare's hospice users receive care in their homes; in 1993, almost 80 percent of elderly hospice users were able to die at home (Hogan, 2001).

Who Participates in Medicare's Hospice Benefit? Who Does Not?

The number of Medicare beneficiaries taking part in Medicare's hospice program tripled in the 1990s. A recently published report to Congress states that 464,000 beneficiaries received hospice care in 2000, up from 143,000 in 1992 (Hogan, 2002 as cited in MedPAC, 2002). This report also finds that 23 percent of the Medicare beneficiaries who died in 2000 used hospice

care, up from 9 percent in 1992. While cancer diagnoses are the most prevalent in hospice care, accounting for 51 percent of all hospice beneficiaries' diagnoses in 2000, non-cancer diagnoses (such as heart disease and Parkinson's disease) have grown considerably over the last decade—increasing 557 percent since 1992, according to this research.

Using the Medicare Current Beneficiary Survey (MCBS), we examined Medicare beneficiary data to analyze the characteristics of beneficiaries who used hospice care during the calendar year of their death, against those who did not. We pooled four years of data to increase sample size and thus the accuracy of our findings. Table 2 presents our results. The average age of hospice decedents was 78, one year less than the average age of Medicare decedents overall. Decedents under age 65, who were eligible for Medicare because of a disability or end-stage renal disease, were less likely to choose hospice care (11 percent), than their older counterparts (17 percent).

Other demographic characteristics were associated with some differences in hospice election. A slightly larger proportion of female decedents (17 percent) than male decedents (15 percent) chose hospice care; 17 percent of white Medicare decedents elected hospice, which was notably higher than the 11 percent rate for minority decedents.

With respect to insurance coverage, 26 percent of Medicare decedents enrolled in Medicare+Choice elected hospice care—a higher rate of hospice election than decedents in fee-for-service Medicare (15 percent).³ For Medicare decedents with full Medicaid coverage (dual eligibles), 13 percent participated in hospice care. Beneficiaries with more limited Medicaid assistance (e.g., to cover Medicare premiums) had slightly higher rates of hospice election (16 percent). In contrast, 17 percent of decedents without Medicaid assistance received hospice care.

Table 2: Demographic Characteristics of Decedents, by Hospice Status

	Decedents with Hospice Use	Decedents with No Hospice Use
Age		
average age	78	79
<65	11%	89%
65+	17%	83%
Gender		
Male	15%	85%
Female	17%	83%
Race		
White	17%	83%
Nonwhite	11%	89%
Education*		
Less than 8th grade	13%	87%
Some high school	20%	80%
High school diploma	17%	83%
Some college or more	19%	81%
Income**		
<100% FPL	14%	86%
100–199% FPL	16%	84%
200–299% FPL	16%	84%
300%+ FPL	20%	80%
Insurance		
<i>Medicaid</i>		
Medicaid Buy in	13%	87%
OMB/SLBM Buy in	16%	84%
No Medicaid assistance	17%	83%
<i>Medicare+Choice</i>		
Any HMO enrollment	26%	74%
No HMO enrollment	15%	85%
Residence		
Community	18%	82%
Facility	11%	89%
Both	19%	81%

* Education levels were not reported for 11% of these decedents.

** Federal Poverty Levels (FPL) were calculated using ASPE HHS Poverty Guidelines applicable to decedents' year of death.

Source: Urban Institute analysis of 1995-1998 Medicare Current Beneficiary Survey (MCBS) Cost and Use Files.

Because Medicaid eligibility is means-tested, trends in hospice use by income track closely with trends associated with Medicaid assistance. Low-income decedents had lower rates of hospice use than decedents with higher incomes. Specifically, 20 percent of decedents with incomes of 300 percent of the federal poverty level and above used hospice. In contrast, 14 percent of decedents with incomes below the federal poverty level used hospice.



To the extent that dying beneficiaries receive *some* form of health care prior to death, the majority receive end-of-life care in settings other than hospice.

Decedents who entered a nursing facility during the calendar year of their death were more likely to elect hospice care (19 percent) than decedents who resided in a nursing facility from the start of the calendar year of their death, among whom 11 percent elected hospice care. Of decedents who never resided in a nursing facility (i.e., resided in the community) throughout the calendar year of their death, almost 18 percent chose hospice. The lower rate of hospice election in the continuous nursing home population may indicate that diagnoses associated with long-term care are not as appropriate for the Medicare hospice benefit, as compared to diagnoses for beneficiaries with at least some residency in the community during their calendar year of death. It may also be the case that nursing home residents are receiving adequate care in their facility, or that they and their families are unaware of the hospice option or eligibility for it.

A recent report to Congress states that beneficiaries today generally have greater access to hospice care than in the early 1990s, as evidenced by increases in both the use of hospice services and the supply of providers (MedPAC, 2002). The availability and use of hospice care varies geographically. States with the largest per-beneficiary enrollment in hospice are Arizona (15 per 1,000), Florida (13 per 1,000) and Colorado (12 per 1,000) (Gage and Dao, 2000).⁴ States with low rates of hospice use per beneficiary are Alaska, Maine and Utah—each with fewer than 4 per 1,000. Recent research shows that although

in rural areas the use of hospice care is growing faster than in urban areas, the rate of rural beneficiaries using hospice is 25 percent lower than that of urban beneficiaries (MedPAC, 2002). The number of hospices participating in Medicare increased by 89 percent from 1992 to 2002 (MedPAC, 2002). Gage and Dao (2002) found that the West North Central region has the highest number of hospice agencies per beneficiary (9.8 per 100,000) while the Middle Atlantic region has the lowest (3.7 per 100,000). However, these calculations do not account for the size of the hospice agency, so these numbers can offer only limited comparisons about the availability of services by region.

End-of-Life Care for Medicare Beneficiaries Outside Hospice Settings

To the extent that dying beneficiaries receive *some* form of health care prior to death,⁵ the majority receive end-of-life care in settings other than hospice—either because beneficiaries are unaware of the hospice benefit, or do not choose to participate in it, or because they are not considered eligible, given the lengthy or unpredictable course of their illness. The services these beneficiaries receive—and those that Medicare covers—depend heavily on the site where the services are rendered. By provider type, Table 1 lists those Medicare-covered services that may be considered end-of-life care when provided to terminally ill patients. The provider types include hospice, home health, skilled nursing facility (SNF) and hospital. Eligibility rules for recipients and cost-sharing liabilities are also listed in this table. Beneficiaries receiving end-of-life care outside the hospice benefit probably experience more cost-sharing than if they were in hospice care (depending on their individual circumstances).

The Home Health Benefit—While both a terminally ill hospice patient and a terminally ill home health patient may reside at home, each is eligible for a different set of services, as listed

in Table 1. Under the home health benefit, Medicare covers skilled nursing care, rehabilitative therapies, nursing aide services and durable medical equipment. To qualify for the home health benefit, beneficiaries must be considered generally homebound.

While Medicare's home health benefit includes many services that terminally ill beneficiaries need, there are several palliative care services it does not cover. For example, home health does not include the comprehensive coordinated care that is a hallmark of hospice, such as 24-hour access to care. The home health benefit also does not cover bereavement counseling for the patient and/or the patient's family, nor most oral prescription drugs, including those for pain. Respite care that could assist informal family caregivers with short breaks is not covered under Medicare's home health benefit, nor are home-making services, custodial care and nutritional counseling.⁶

Due to legislative and regulatory changes over time, the home health benefit has gradually become an alternative to hospice care for some beneficiaries with chronic and long-term care needs. For instance, in 1989, after a period of tight regulatory control, beneficiaries became eligible to receive *daily* home health visits, rather than being restricted to *intermittent* care. This benefit change allowed people with chronic and ongoing medical problems to receive home health services—transforming Medicare's home health benefit from one focused on patients needing short-term, post-acute care to one that also served patients who needed longer-term care.

Despite these eligibility increases, evidence is mounting that indicates that access to home health services has decreased, especially for Medicare patients with chronic illnesses (Stoner et al., 1999). Reasons for this decrease may relate to changes in Medicare's method of payment to home health agencies. A discussion

of Medicare's reimbursement systems follows in the next section.

The Skilled Nursing Facility (SNF) Benefit—

Beneficiaries with terminal illnesses, who have been discharged from a hospital (after a stay of three days or more) may receive services in a skilled nursing facility if they require inpatient skilled nursing or rehabilitative service. This benefit, though, is not designed for people who will require these services for more than three weeks; beneficiary cost-sharing increases dramatically on the 21st day. The SNF benefit covers continuous nursing care, rehabilitative therapies, prescription drugs, medical supplies and equipment. As noted in Table 1, it does not cover bereavement and pastoral care either for the patient who is dying or for his or her family members.

Medicare also covers room and board under the SNF benefit, whereas under the hospice benefit the beneficiary is normally liable for these costs. This distinction creates the financial incentive for terminally ill patients discharged from a hospital to choose—at least initially—the SNF benefit, despite its curative and rehabilitative nature, over the hospice benefit (Zerzan et al., 2000). They may still elect hospice care, however, at a later date. In theory, dually eligible beneficiaries do not encounter this incentive because Medicaid pays hospice providers for room and board in nursing facilities; in practice, however, there may be barriers to electing hospice care while in a Medicaid nursing facility (see Tilly and Wiener, 2001).

The Hospital Benefit—Forty-four percent of Medicare decedents die in hospitals—making the hospital the care site with the largest share of Medicare beneficiary deaths (Hogan, 2001). This means that although hospitals are designed to provide intensive curative treatment, they are also frequently in a position to provide end-of-life care. In hospitals, Medicare beneficiaries are

covered for the same end-of-life care services as they are under the SNF benefit (Table 1). These include continuous nursing, prescription drugs, nutritionist services, durable medical equipment and supplies, and room and board. As in the SNF benefit, Medicare does not specifically cover be-

reavement and pastoral care for the hospital in-patient or the family. In 2002, beneficiaries are liable for an \$812 deductible for the hospital stay and increased per day cost-sharing after the 60th day in the hospital.

III. Payment Methods and Spending

Medicare Payment Rates and Methods

Across health care settings, Medicare relies on different payment methods and payment rates to cover the cost of end-of-life care. Table 3 provides a summary of payment systems for hospice and non-hospice care. Some of the financial incentives associated with payment methods are discussed in the section that follows.

Hospice Rates—Medicare pays hospice providers a fixed amount on a per diem basis. For hospice services that are provided in the

home, the rate is usually \$110 per day in 2002.⁷ This payment applies to more than 95 percent of all Medicare hospice patients (NHPCO, 2001). When extra services are required, such as an in-patient hospital stay, Medicare reimburses at one of three other higher payment rates, up to \$644 per day. These per diem payments are intended to cover the providers' costs of furnishing all the services included in the Medicare hospice benefit, *on average*. For some patients—such as those requiring expensive medications—the cost of providing care may exceed the amount

Table 3: Medicare Payment Methods, by Type of Provider, 2002

	Hospice	Home Health	Skilled Nursing Facility	Hospital
Unit of Payment	Per day	Per 60-day episode of care	Per day	Per qualifying admission
Patient/Payment Classification	<p>4 payment rates corresponding to the level of care provided:*</p> <ul style="list-style-type: none"> • Routine home care (\$110) • Continuous home care (\$644) • Inpatient respite care (\$114) • General inpatient care (\$491) 	<p>80 Home Health Resource Groups (HHRGs) corresponding to the patient's clinical status and functional needs</p>	<p>44 Resource Utilization Groups (RUGs) corresponding to predicted use of nursing and rehab services for the patient</p>	<p>About 500 diagnosis-related groups (DRGs) corresponding to the patient's medical condition and treatment plan</p>

* These are base payments for fiscal year 2002. They do not include later payment adjustments made to reflect geographic differences in health care wages.

Source: Medicare Program Memoranda and applicable Congressional Federal Registers.

Medicare pays the agency per day. However, for others who require less costly treatments, the hospice agency may spend less than the amount it receives from Medicare per day. The agency is free to keep these excess payments as they are intended to help offset the expense of caring for the more costly patients.

As with any prospective payment system, this payment mechanism encourages the agency to streamline costs, but it also implicitly creates financial incentives to avoid costly patients and to limit extremely expensive services. Unlike SNF, home health, and hospital payments, Medicare's hospice reimbursement system does not include a case-mix adjuster—a mechanism for basing reimbursement rates on patient characteristics, such as diagnosis. Case-mix adjusters are designed to pay providers higher amounts for patients who are expected to be costlier to treat, and thus reduce, to some extent, the provider's incentive to avoid these patients.

Hospice agencies report that another concern with Medicare's system for reimbursing hospice care is that it creates problems covering the costs of patients with short lengths of stay. These people have high overall costs because the initial and final days in hospice care are the most expensive days for the hospice agency to provide. This problem is compounded by the increasing numbers of hospice patients who die within one week of admission. In 2000, this was the case for 30 percent of Medicare hospice beneficiaries (Hogan, 2002 in MedPAC, 2002).

SNF, Home Health and Hospital Payment Method—Like Medicare's hospice payments, the SNF prospective payment system also pays a fixed amount on a per diem basis. But SNF patients are classified into some 40 case-mix groups to determine their daily payment rates, based on their anticipated service use. Home health providers are also paid through a prospective payment system. Home health

agencies are paid a fixed amount over 60-day time periods. Recent research (Stoner et al., 1999) has begun to document that this payment system, introduced in the Balanced Budget Act of 1997, created an incentive for home health agencies to avoid patients who have chronic care needs. Hospital admissions are paid a pre-determined fixed amount based primarily on the patient's diagnosis. Because the home health and hospital payment systems are not based on per diem payments, shorter episodes of care within each payment group are generally more profitable for the provider, whereas just the opposite is true for hospice and SNF.

Payment and Coverage of End-of-Life Care for Beneficiaries in Managed Care (Medicare+Choice and PACE)

Medicare+Choice—Medicare beneficiaries enrolled in a private plan—usually an HMO—through the Medicare+Choice (M+C) program may choose to receive end-of-life care under the Medicare hospice benefit while still remaining in the HMO, because Medicare's hospice benefit may have lower cost-sharing and include more services for treating terminal illness than are offered by their HMO. In cases where a patient's HMO covers services over and above those covered by traditional Medicare, enrollees may retain access to those additional services (as well as curative treatment unrelated to their terminal condition) through their HMO, even when they elect to participate in Medicare hospice. If they wish, however, hospice beneficiaries can disenroll from their HMO, unlike other beneficiaries who are scheduled to be “locked in” for at least part of the year beginning in 2005. Disenrollment may be preferable for terminally ill beneficiaries in plans with monthly premiums because they may no longer want or need the extra benefits provided by the HMO (e.g., dental and drug coverage). However, beneficiaries who have other health complications (e.g., diabetes) may wish to continue in the HMO for treatment of symptoms unrelated to their terminal illness.



PACE is a community-based managed care system that offers comprehensive health care and social services to frail, elderly adults, usually for the last two or three years of an enrollee's life.

When an HMO enrollee elects the Medicare hospice benefit, and remains in the HMO, the patient's selected hospice agency, not the patient's HMO, becomes responsible for all costs associated with the terminal illness. The hospice agency is paid directly by Medicare on the same basis as described earlier. HMOs, therefore, have a financial incentive to encourage their terminally ill enrollees to elect Medicare's hospice benefit, especially if the HMO anticipates that caring for the terminal illness will be expensive. Further, if the HMO does not expect the patient to use many services unrelated to the terminal illness (e.g., vision care), the HMO has a financial incentive to retain the enrollment in order to continue receiving a portion of its Medicare monthly payments for that beneficiary.

Given both provider and beneficiary incentives, it is not surprising that over a four-year period, 26 percent of M+C decedents used hospice, 11 percentage points more than Medicare decedents who were not enrolled in HMOs (see Table 2).⁸ Other research has found that Medicare hospice users who were enrolled in an HMO had longer lengths of stay in the hospice than those not enrolled in an HMO (Vernig et al., 1999). It could also be that a greater interest in hospice care within the M+C population may reflect the HMO enrollees' higher rate of acceptance of a "managed" approach to medical care—somewhat consistent with the set of palliative care services offered by the Medicare hospice benefit.

The PACE Program—If it is available in their area, frail, elderly nursing-home-eligible beneficiaries have the option of enrolling in the Program of All-inclusive Care for the Elderly (PACE). PACE is a community-based managed care system that offers comprehensive health care and social services to frail, elderly adults, usually for the last two or three years of an enrollee's life. Since PACE enrollees usually remain in the program until death, they often transition to end-of-life palliative care within the PACE program.

Among PACE enrollees who died in 2000, almost half (47 percent) were able to die at home (NPA, 2002). Unlike the Medicare+Choice program, PACE enrollees may not take part in the Medicare hospice program unless they disenroll from PACE.⁹ However, PACE patients virtually never choose to drop their PACE enrollment in order to receive the Medicare hospice services because PACE has a more generous benefit package (Fitzgerald, 2001). For example, PACE-covered benefits include extensive counseling options, prescription and non-prescription drugs, eye and dental care, and transportation services. Also, PACE enrollees in nursing homes are able to transition smoothly from curative to palliative care while remaining in the same facility, and receiving care from the same team of interdisciplinary caregivers—a comfort to beneficiaries who are nearing the end of life.

PACE receives fixed per-member per-month payments from Medicare, Medicaid and private payers for all recipients, regardless of their health status (although participants must be quite frail to enroll initially). PACE programs assume full financial risk for all enrollees, and therefore have the financial incentive to prevent costly hospitalizations. The amount Medicare pays PACE programs is based on Medicare's payment to HMOs in the enrollee's county, multiplied by 2.39 to account for the increased cost of treating frail, elderly participants. Medicare's median monthly payment in 2000 was \$1,321; Medicaid's was \$2,422 (NPA, 2002). Enrollment in PACE programs is gradually increasing. Total average daily census in 2000 was 6,575 PACE enrollees with an additional 1,121 in organizations currently applying to Medicare for PACE certification (NPA, 2002). Due to the high long-term-care costs for frail, elderly individuals, most PACE enrollees qualify for Medicaid benefits (in addition to Medicare).

Issues Unique to Dual Eligibles

Medicare beneficiaries with incomes low enough to be eligible for Medicaid face a

number of unique circumstances with respect to end-of-life care. For example, many dually eligible beneficiaries have Medicaid access to drug coverage for the treatment of all diseases subject to state formulary restrictions (Tilly and Wiener, 2001). Thus the advantage of having access to drug coverage in hospice may not offer extra financial help to them. The PACE program, for example, can serve these needs for frail dual eligibles. Additionally, depending on state Medicaid programs, some dually eligible beneficiaries have access to home and community care (Tilly and Wiener, 2001). All these factors may help to explain why fewer dual eligible beneficiaries receive hospice care.

For those dual eligibles participating in the Medicare hospice program, Medicaid typically covers the beneficiary's Medicare cost-sharing, such as the \$5 copayment for prescription drugs, and facility room and board costs, if needed. Research has shown that Medicaid-covered hospice beneficiaries remain in hospice longer (Gage and Dao, 2000). This finding may suggest that dually covered beneficiaries enter hospice care with longer life expectancies associated with progressively degenerative diagnoses, such as dementia and frailty. Indeed, often their eligibility for Medicaid has resulted from extended time spent in a nursing home prior to electing hospice care. Six states do not offer Medicaid hospice benefits. Further research is needed on how the absence of a Medicaid hospice program affects low-income Medicare beneficiaries.

Nursing Home Hospice Patients—When a terminally ill, dually eligible nursing home resident elects hospice (and remains in the nursing home), the nursing home no longer bills the state Medicaid program for that patient's care. Instead, the nursing home bills and receives payment from the hospice agency elected by the patient. The hospice then bills its state Medicaid agency for the patient's room and board, in addition to billing Medicare for the patient's hospice care. The state Medicaid agency

is obligated to pay the hospice agency at least 95 percent of what it would have paid the nursing home had the patient not elected hospice (potentially saving the state some money). The hospice agency is then free to pay the nursing home whatever amount was negotiated in the contract between the nursing home and the hospice for room and board and services provided to hospice patients. Tilly and Wiener (2001) indicate that refusal by many nursing homes to accept lower payments may discourage hospices from working in this environment. However, a 1997 report by the Office of the Inspector General for the Department of Health and Human Services expressed concerns that nursing homes could be receiving room and board payments for hospice patients that exceed what Medicaid would have otherwise paid, implicitly raising the issue of potential kickbacks and overuse of the hospice benefit. Better understanding of the relationship between hospice organizations and nursing homes is needed.

Prescription Drug Coverage

Important differences in Medicare's coverage of prescription drugs exist across settings and benefit structures. Under the Medicare hospice benefit, prescription drugs are covered for palliative purposes only and are limited to the treatment of the terminal condition. Such drugs typically include those that assist with pain management and symptom control, including psychological distress.¹⁰ Recent research has found that beneficiaries who require very expensive medications (e.g., palliative chemotherapy, new brand-name pain medications) may face barriers in accessing hospice agencies because the agencies must bear the cost of the drugs out of their fixed daily payment from Medicare (Huskamp et al., 2001; Mahoney, 2002 cited in MedPAC, 2002).

For non-hospice beneficiaries living at home, the Medicare fee-for-service program does not generally cover outpatient drugs—whether they

are considered palliative or curative—although a small number of outpatient drugs, specified individually by legislation, are covered by Medicare under Part B. These drugs include, among others, those that are not self-administered (e.g., infusion drugs such as chemotherapy, and intravenous pain medications), oral antinausea drugs for people receiving chemotherapy, and inhalation drugs requiring the use of a nebulizer.¹¹ While these covered drugs are important to many beneficiaries who are dying from diseases such as cancer and chronic obstructive pulmonary disease, many palliative drugs are missing from this list—specifically, topical ointments for common skin ulcerations, and effective oral drugs for acute pain, bladder and bowel problems, and psychological distress. As a result, terminally ill patients who do not elect hospice, or are not eligible for hospice care, are liable for the cost of these outpatient drugs, as are all Medicare beneficiaries. In some cases, they may have supplemental coverage for prescription drugs—a fact that may affect their interest in hospice.

Medicare provides full drug coverage to terminally ill hospital inpatients. In general, these patients may be hospitalized as a result of the acute medical event that caused their terminal prognosis (e.g., heart attack), or they may be readmitted sporadically due to exacerbations of their ongoing terminal condition (e.g., chronic obstructive pulmonary disease). In many cases, the patient may not be able to afford the appropriate outpatient drug therapy at home that could help prevent these hospitalizations. Medicare's home health benefit does not cover most outpatient drugs.

Medicare Spending on End-of-Life Care

Contrary to claims that Medicare spending over time has increased disproportionately for those who are dying, the ratio of spending on beneficiaries during their last year of life has remained stable for two decades. Medicare

spending for decedents accounts for 28 percent of Medicare's total annual spending. Research examining completed Medicare claims during the last year of life estimates that average per-beneficiary Medicare payments during the last year of a beneficiary's life amounted to \$26,000 (in 1997 dollars), approximately six times higher than Medicare's average annual spending per individual for surviving beneficiaries (Hogan et al., 2001). This finding is not surprising, given that dying people are generally sicker. Moreover, this represents spending of all types and is not limited to costs of providing palliative care.

We found that among those beneficiaries whose 1998 Medicare costs ranked in the top 5 percent of per-beneficiary spending, fewer than a quarter were decedents. And among those who were both top spenders and decedents, hospice users represented only 6 percent. This finding indicates that extraordinarily expensive health care is most often spent on Medicare survivors, and is not limited to end-of-life measures. Other research suggests that end-of-life care for the very old is not as medically aggressive as that for younger Medicare patients. In the last two years of life, Medicare spends, on average (in 1996 dollars), \$37,000 for 75-year-old decedents, compared to \$21,000 for those who died at the age of 95 (Spillman and Lubitz, 2000).

The Medicare hospice program accounts for about 1 percent of Medicare's annual payments. From inception, its mission has not been to be a Medicare cost-reducer, but rather a program that provides appropriate care for dying patients. As such, Table 4 shows that average Medicare spending in the last calendar year of life on a decedent who used hospice care (\$19,950) is not dramatically different from the amount spent on a decedent who did not use hospice care (\$17,790).¹² Though Medicare spending on hospice users is somewhat higher, these figures are quite close considering that some portion of the decedents who did not elect hospice died

Table 4: Spending in Last Calendar Year of Life

Medicare Spending				
Beneficiaries	Total Spending	Hospice Care	Hospital Inpatient Care	All Other Services*
Used hospice	\$19,950	\$4,186	\$9,257	\$6,506
Did not use hospice	\$17,790	\$0	\$11,188	\$6,602
All Payer Spending				
Used hospice	\$27,202	\$4,186	\$10,618	\$12,398
Did not use hospice	\$26,047	\$0	\$12,292	\$13,755

* Includes services provided to hospice patients by nonhospice-affiliated physicians.

Note: Excludes Medicare beneficiaries in managed care.

Source: Urban Institute analysis of 1995–1998 MCBS Cost and Use Files.

relatively suddenly and therefore used few medical services—very different from hospice patients who typically require a considerable amount of medical services before conceding the terminal nature of their illness. Additionally, lower spending on inpatient hospitalizations for decedents who elected hospice care, as shown in Table 4, suggests that hospital care is likely to be associated with the curative treatment protocols that hospice patients have agreed to forgo.

In addition to Medicare, other sources of payment enter into the total expenditures for beneficiaries' end-of-life care. For example, out-of-pocket spending accounts for 18 percent of total spending in the last year of life, Medicaid for almost 10 percent, and other payers for 12 percent, leaving Medicare spending to cover a little more than 60 percent of decedents' costs

(Hogan et al., 2001). Table 4 shows that total health care expenditures in the calendar year of death for hospice decedents (\$27,202) are also somewhat higher than for non-hospice decedents (\$26,047), by an amount very similar to the difference in Medicare payments for hospice and non-hospice decedents.¹³

Out-of-pocket expenses for Medicare beneficiaries in their last year of life vary by setting and type of care they receive. For example, hospice beneficiaries face very few cost-sharing requirements. Beneficiaries with home health are responsible for coinsurance only on durable medical equipment and are fully liable for most outpatient medications. Non-hospice beneficiaries who require sporadic hospitalizations have greater out-of-pocket expenses because they are liable for deductibles (\$812 per hospital admission in 2002).

IV. Best Practices and Potential Improvements in End-of-Life Care

Best Practices

While Medicare has made some inroads in improving care at the end of life, the examples of current best practices affect only a small proportion of those beneficiaries who are nearing the end of their lives. About 2 million Medicare beneficiaries die each year, most of whom receive care in more traditional settings and programs that may not meet their needs. It is useful to summarize some of the positive steps that have been taken and to consider other ways to move constructively in the direction of better care.

Medicare supports several useful programs that address end-of-life care for terminally ill beneficiaries. As it currently exists, the Medicare hospice benefit offers a generally appropriate method for financing end-of-life care for people with terminal illnesses, such as cancer, that are characterized by functional declines and suffering primarily in the last several months of their lives. With these caveats, hospice offers comprehensive care that is sensitive to the needs of patients and their families. Its continued growth over time—averaging annual increases of 16 percent between 1992 and 2000—attests to its success. The per diem method of payment for hospice care provides flexibility to deliver the services most needed by the patient (Huskamp et al., 2001). This flexibility could allow some hospices to work creatively with the Medicare benefit to go beyond the required services.¹⁴ In general, however, Medicaid has more flexibility than Medicare to experiment with alternative approaches (Tilly and Wiener, 2001).

In addition to its hospice benefit, Medicare contributes to the financing of frail, elderly patients through PACE programs. Though the

PACE program is founded on a long-term-care model, its arrangement allows patients to receive end-of-life services that are based more on their individual functional status and acuity level than on their life expectancy, as is the case with hospice care. As a result, chronically ill Medicare beneficiaries in the PACE program may receive appropriate palliative services earlier than Medicare hospice patients. Once they are in PACE, this occurs without a break in the coordinated care management that they are receiving. In Wisconsin, the Wellspring Program has also found a way to provide quality care to terminally ill Medicare beneficiaries outside the hospice program.¹⁵ These two programs highlight what can be done in a more coordinated environment, but PACE in particular has not expanded as rapidly as many of its supporters had hoped it would.

Also supporting end-of-life care is Medicare's fee-for-service payment policy which covers advance care planning—discussions between physicians and their patients that identify the circumstances in which the patient would prefer palliative care versus curative treatment. If advance care planning constitutes the principal part (more than 50 percent) of a physician visit, physicians may bill for it. Physicians who are knowledgeable about this policy now have an incentive to spend time with a patient to discuss advance care planning. This consultation may allow patients to consider formal options such as hospice as well as less formal, but planned courses of future care. Not covered in regular Medicare, however, are the social and supportive services that may be extremely important for many terminally ill Medicare beneficiaries.

Finally, HMOs are free to be creative in designing new approaches to treating terminally ill



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patients. Since the coordinated care environment is often well suited for managing chronic illnesses such as lung and heart disease, Medicare may want to find ways to encourage HMO involvement in treating terminal illnesses. In general, however, current financial incentives exist for HMOs to refer terminally ill enrollees to hospice care. Also, Medicare beneficiaries with multiple care needs have had low participation rates in managed care organizations (GAO, 2000).

What Else Can Be Done?

A number of changes—many of them quite modest—could be made to the Medicare program to increase access to care offered near the end of life and improve some of the care that is now available. Improvements could be made for both hospice and non-hospice patients who need palliative care.

The Precepts of Palliative Care—These fundamental principles, developed by *Last Acts*, were mentioned earlier in the introduction. These simple, basic precepts for providing good palliative care—respecting patient preferences, providing comprehensive care, maximizing interdisciplinary resources, acknowledging caregiver concerns, and creating flexible health care systems—can provide future researchers with useful means for assessing the quality of end-of-life care.

Medicare could encourage the application of these fundamental principles in a number of ways that are described below. Equally important is the need for education of both providers and patients. For example, Medicare could fund provider seminars and continuing education courses to clarify hospice benefit regulations and also introduce the Precepts of Palliative Care in all care settings. To encourage beneficiaries to take part in achieving the best care possible, Medicare could print the *Last Acts* definition of good palliative care in its *Medicare Guide to*

Hospice—a guidebook distributed to people taking part in the hospice benefit—and on its Web site, which is accessed by Medicare consumers across the country.

Improvements to the Hospice Benefit—

Hospices face several challenges that might be addressed with adjustments in payment policy and eligibility policy. With respect to payment issues, hospice organizations argue that fixed per diem payments work best for hospice agencies that care for patients with lengthier stays because care during the first and last several days of a patient's stay are the costliest for the hospice to provide. In addition, lengthier hospice stays allow the patient and family to benefit most fully from the hospice services that Medicare covers, such as bereavement counseling. This implies two types of needs: first, finding ways to encourage patients to enter hospice earlier (often through earlier physician referrals), and second, ensuring that payments for those who have very short stays are adequate for their more intensive needs. In the first instance, careful attention to how patients are certified and better education of the physicians who counsel such patients may be in order. Hospice care remains a foreign concept for many people, doctors included. In addition, more flexible eligibility rules could allow hospice care to be available to a wider range of Medicare beneficiaries. To address the second issue, a minimum total payment or a higher per diem in the last seven to ten days of life might be appropriate.

Another potential problem related to hospice financing is the expense of some palliative treatments. Radiation or chemotherapy for pain relief, for example, can be very expensive. If the hospice is expected to absorb this in its per diem payments, less of this type of care may be furnished to the patient, even if it might improve patient comfort. While one of the advantages of hospice care is access to outpatient prescription drugs, this benefit is less clear in

areas where regular Medicare also provides coverage, such as chemotherapy and intravenous pain management.¹⁶

The Centers for Medicare & Medicaid Services (CMS) should continue its efforts to make better information about Medicare coverage and eligibility rules available to patients who have terminal illnesses and to the physicians who are treating them. For example, Medicare's current allowance that permits beneficiaries to re-elect hospice care if their terminal illness runs a more gradual course than originally expected is advantageous both for the patient and for hospice providers. Unfortunately, physicians are often unaware that legally, they may recertify a patient for hospice care, even after the patient has been in hospice care for six months, provided that the patient maintains a reasonable prognosis of six months or less to live. Improving communication to physicians about their ability to recertify patients for hospice care would be helpful because many physicians may be concerned about being accused of Medicare fraud if their patients remain in hospice care longer than six months. There is no indication that the recertification process is unusually cumbersome; CMS reports that its denial rate for hospice benefit certification (including both initial and recertifications) is less than 1 percent (Community-State Partnerships, 2001).

Also with respect to eligibility, there should be an investigation into whether the six-month prognosis is the best means for determining appropriateness for hospice care. Hospice has proven to work well for people with very predictable life expectancies, such as cancer patients, but its limited time frame may not fit the needs of patients whose end-of-life course is much less predictable (Lynn, 2001). Although the number of non-cancer diagnoses (such as Parkinson's disease) in hospice care has grown considerably in recent years, cancer still accounts for the majority (51 percent) of all Medicare-covered hospice diagnoses (Hogan,

2002 cited in MedPAC, 2002). Potentially, one reason for the comparably lower rate of non-cancer diagnoses is the difficulty physicians face in making life expectancy prognoses for many of these non-cancer diagnoses. More flexible eligibility rules could allow hospice care to be available to a wider range of Medicare beneficiaries. Is it just the six-month prognosis that needs attention? Eligibility measures other than time constraints could be considered, as well.

Improvements Outside the Hospice

Benefit—At the inception of the Medicare hospice program, much of the early emphasis on offering extra services at the end of life only in the hospice setting was to avoid the high costs of providing a new set of benefits that would constitute a major expansion of Medicare coverage. In fact, this has not become a major problem; instead, the question is whether the majority of beneficiaries who realistically will remain outside hospice are getting reasonable care. Indeed, the basic Medicare benefit does little to facilitate end-of-life or palliative care outside the formal environments where such care is recognized, such as hospice.

A further issue is whether hospice is the preferred environment for all individuals nearing the end of their lives, or whether it is more reasonable for many to remain in the standard Medicare program, but perhaps receive some additional services and/or a slightly different mix of services. Another reason for beneficiaries with grim prognoses to resist hospice treatment is their unwillingness to give up on curative care, especially when the curative treatment is not particularly painful. For example, recent improvements in medical treatments (in chemotherapy, for example) translate to less patient discomfort. Consequently, beneficiaries may be more likely to postpone hospice, even when they would be considered eligible (Mahoney, 2002 cited in MedPAC, 2002). Medicare's traditional fee-for-service program may never achieve the coordination and comprehensiveness of services

such as hospice or PACE. However, small changes to care outside hospice could nonetheless be extremely important for those facing death.

For end-of-life and other palliative care issues to be taken seriously, they have to be recognized in Medicare's rules and payment systems. For example, a 1999 MedPAC study found that the rule allowing physicians to be reimbursed explicitly for end-of-life planning is not widely known, even by experts in end-of-life care. CMS could clarify and publicize to physicians the availability of Medicare payment for advance care planning under the Medicare Fee Schedule. Medicare also needs to communicate its recent policy of recognizing pain management as a physician specialty. This policy enables geriatricians and internists who specialize in pain management to bill Medicare for consultations requested by the patient's primary care physician. Although this billing policy may help patients to receive better pain relief at the end of their lives, Medicare still does not recognize the more comprehensive field of *palliative care* as a specialty. Establishing a palliative care specialty would raise awareness and could boost the quality of care for seriously ill and dying patients through increases in medical education on palliative care and potential research opportunities (Cassel, 2000).

The inclusion of palliative care coursework in Medicare-funded medical education could also be required. Teaching hospitals provide medical students with a natural learning environment for care of the dying elderly, given their large share of Medicare patients. However, instruction on palliative care should extend to other settings, such as nursing facilities and homes.

Modest service expansions could also help. For example, a discrete number of counseling sessions with social workers or others who take a more complete view of planning for the end of life might be covered, in conjunction with certain types of hospital stays or with advance

planning counseling from a physician. This modest step could help in achieving one of the precepts of palliative care—a team approach—without requiring that beneficiaries become involved in a full-scale hospice program. The most problematic change needed in this regard, however, is coverage of prescription drugs. It would be difficult to extend coverage for such drugs to some but not all Medicare beneficiaries in the regular program. The likelihood of a universal drug benefit under Medicare has declined with the events of 2001, although for beneficiaries in need of palliative care as well as many others, this is an important omission from the current Medicare benefit package (see Ault and Hash, 2001).

Not all provision of palliative care needs to be thought of as an additional benefit adding to Medicare's costs. Rather, the issue is whether appropriate care is offered in hospitals, skilled nursing facilities and home health. In these settings, where prospective payment provides some incentives to offer less care, it is important to ensure that guidelines for discharge decisions, for example, require that palliative care needs be taken into account. Discharging a patient just a few hours or days before death should be viewed as inappropriate if that individual has substantial palliative care needs. Such a discharge is likely to be against both the patient's and the family's wishes. Hospitals have the flexibility to keep patients longer and guidelines for their peer review organizations could be developed to encourage it as part of appropriate end-of-life care. In home health, the new prospective payment system needs to be examined for its use and effectiveness at the end of life.

Further, for patients who do not choose hospice, the hospital may well be the de facto best site in which to offer additional services such as counseling and advance planning. A more proactive effort in this regard could help to avoid taking actions against patients' wishes while they are hospitalized. Better coordination



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of care for hospitalized patients would go a long way to improving end-of-life care for those who are not in formal programs. For example, such emphasis might well help patients with chronic lung and heart disease—who are likely to face multiple episodes of hospitalization—plan for a course of treatment and make decisions ahead of time.

Controversy over payment levels in the Medicare+Choice program may also be an area where explicit attention to end-of-life care is relevant. That is, end-of-life care should be part of any policy debate on how to encourage private health plans to enroll patients with substantial health care problems (including terminal illnesses).

The Department of Health and Human Services (DHHS) has several mechanisms that can support further research on best practices for palliative care. For example, DHHS could fund demonstration projects that test the use of modified benefit designs for meeting the various needs of dying patients depending on their medical characteristics and acuity level. Patients with

Alzheimer's disease or chronic obstructive pulmonary disease, for instance, might be managed better if they received a combination of home health and hospice care services, or if they were admitted to hospice programs without a life-expectancy restriction.

Conclusion

In sum, much remains to be done to move the palliative care needs of people at the end of their lives to a more mainstream position within Medicare. Most Americans who die are being served by the Medicare program, yet Medicare's attention to end-of-life issues is largely confined to hospice, a small, but growing program. A careful look at end-of-life care ought to explore both hospice and traditional care settings to find areas of improvement. The list of best practices remains limited; the small number of physicians and patients who are knowledgeable about these issues constitutes a major barrier. Even with attention to budget constraints, however, a number of improvements could be made through either regulatory or legislative changes on a modest scale.

Endnotes

1. These precepts have been endorsed by more than 150 organizations that deal with end-of-life care issues. For further information on these Precepts of Palliative Care, go to www.lastacts.org.

2. For medical problems unrelated to their terminal illness, hospice patients are eligible to receive Medicare-covered curative and/or rehabilitative services. For example, if a Medicare cancer patient in the hospice benefit sustains a hip fracture, then Medicare will cover the patient's hip treatment, independent from the hospice care.

3. Included in the percentage of Medicare+Choice decedents who elected hospice care (26 percent) are decedents who may have withdrawn from their HMO as well as those who remained in their private plan.

4. Gage and Dao (2000) point out that these states similarly have the highest proportion of beneficiaries enrolled in HMOs.

5. Our research shows that less than 2 percent of Medicare decedents have no health care spending in the last calendar year of life. This figure does not account for services received that are unrelated to the cause of death.

6. An exception is made for patients with end-stage renal disease and those with diabetes.

7. Each Medicare hospice payment rate is adjusted for geographic difference in health care wages.

8. Similar results were also reported by Hogan et al. (2001). Note that this percentage includes beneficiaries who disenroll from the HMO once they go into hospice.

9. Though PACE programs provide palliative care to Medicare beneficiaries, PACE programs are not Medicare-certified hospice providers.

10. Beneficiaries are liable for a maximum co-payment of \$5 per prescription.

11. Beneficiaries receiving these drugs are liable for a 20 percent coinsurance which, in light of recent government reports, can be expensive given the retail markup for many of these drugs (GAO, 2001).

12. Our calculations were based on the last calendar year of life rather than the last year of life because of dataset and project limitations. The findings should not be used as a means

for measuring precise costs of hospice care as compared to other treatments, since many other adjustments to the data would be needed to do so.

13. When decedents were categorized by income levels, we found no clear pattern relating income to spending in the last calendar year of life.

14. As an example, Tilly and Wiener (2001) present a case study of The Hospice of the Florida Suncoast, but as the authors note, much of the creative work, such as providing palliative care even to those who are still receiving curative services, is funded by the Medicaid program.

15. The Wellspring Program is an alliance of 11 nonprofit nursing facilities in Wisconsin explicitly formed to address public and payer concerns about the quality of nursing home care. Staff empowerment and frequent resident assessments play a major role in Wellspring's goal of providing high standards of care.

16. Chemotherapy drug costs have become a highly controversial issue; when revisiting the costs of this treatment, it might be appropriate to examine whether an adjustment for hospice also needs to be part of the discussion.

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Medicare and End-of-Life Care

Marilyn Moon and Cristina Boccuti

September 2002

Last Acts National Program Office
1620 Eye Street, N.W.
Washington, D.C. 20006-4017
Phone: (800) 341-0050
Fax: (202) 296-8352
Karen Orloff Kaplan, ScD
Director

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