

# Providing Care At The End Of Life: Do Medicare Rules Impede Good Care?

*A study of end-of-life care providers reveals some shortcomings.*

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MEDICARE SPENDS more than a quarter of its annual budget on care for those in their last year of life and covers more than 80 percent of decedents.<sup>1</sup> Studies have documented poor quality of care, gaps in care, and patient and family dissatisfaction with care received by dying patients.<sup>2</sup> Nineteen percent of Medicare decedents, nearly 360,000 beneficiaries, used the Medicare hospice benefit in 1998.<sup>3</sup>

In recent years we have heard providers report anecdotes about cases in which Medicare coverage and reimbursement rules may have impeded the delivery of high-quality end-of-life care to terminally ill Medicare beneficiaries. Among these anecdotes are that (1) skilled nursing facilities (SNFs) are transferring dying patients to hospitals in part so that the SNF does not incur the costs of the intensive treatments that the patients might need; (2) hospitals are discharging dying patients in response to diagnosis-related group (DRG) payment incentives; (3) patients are being dissuaded from electing hospice if they need particularly high-cost palliative care; (4) hospices and home health agencies are avoiding patients without caregivers in the home or with high levels of need for home care; and (5) physicians are not referring patients (particu-

larly noncancer patients) to hospice because they fear that they will be charged with fraud if the referred patients do not die within six months. No information has been systematically gathered about the extent to which Medicare coverage and reimbursement methods have affected care or how widespread these issues may be.

In this study we assess problems faced by several types of providers delivering end-of-life services under fee-for-service (FFS) Medicare. We identify important ways in which Medicare benefit design and financing rules both facilitate and create barriers to effective end-of-life care.

## Overview Of Current Medicare Payment Systems

Medicare's FFS payment systems for end-of-life care vary by provider type (Exhibit 1). In an attempt to control Medicare spending and provide greater incentives for efficiency, the Medicare FFS program has been systematically eliminating the use of cost-based reimbursement over the past two decades. However, this can create adverse selection and stinting, which often result in restricted access to care and/or decreases in quality.<sup>4</sup>

Medicare also contracts with managed

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**EXHIBIT 1****Principal Medicare Fee-For-Service Program Provider Payment Methods Relevant To End-Of-Life Care, By Provider Type**

<b>Provider type</b>	<b>Payment unit</b>	<b>Payment adjustments</b>	<b>Services included</b>	<b>Eligibility for benefit</b>
Hospital	Discharge	Diagnosis category; outlier system	Nursing care, bed and board, use of hospital facilities, medical social services, drugs, biologics, supplies, appliances, equipment, diagnostic and therapeutic services	Medically necessary
Physicians	Visit, service	Relative value of type of visit or procedure performed	Physician consultations, medical and surgical procedures	Medically necessary
Hospice	Day (or hour for continuous care)	4 rates: routine home care; continuous home care; general inpatient care; and inpatient respite care	Nursing care, social work, therapy, home health aide and homemaker services, durable medical equipment and supplies, drugs, counseling, physician services, inpatient and respite care	Must have a prognosis of 6 months or less to live and give up coverage of curative treatment for the terminal illness
Home health	Day; transitioning to 60-day episode as mandated by the Balanced Budget Act of 1997	System at time of site visits: per visit payment based on allowable portion of historical costs; current system: pay for episodes, case-mix-adjusted, with outlier system and per visit payments for episodes with 5 or fewer visits	Skilled nursing care, therapy, home health aide care, durable medical equipment and supplies	Must be homebound and require part-time or intermittent skilled nursing care
Skilled nursing facility	Day	Case-mix-adjusted for severity	Nursing care, bed and board, therapy, drugs, biologics, supplies, appliances, and equipment	Must have a prior 3-day hospitalization and require inpatient skilled nursing or rehab services daily

**SOURCE:** Office of the Federal Register, National Archives and Records Administration, Code of Federal Regulations, Title 42, U.S. Government Printing Office, revised 1 October 2000.

care organizations (MCOs), which have their own internal payment systems, to provide coverage to Medicare enrollees. These MCOs are paid a monthly risk-adjusted capitated amount but are not responsible for hospice care, which is carved out to the FFS program.

### Study Design

To identify problems with the Medicare financing system, we conducted visits to six sites across the country: five urban sites selected from the Center for Studying Health

System Change's (HSC's) Health Tracking project (Boston; Cleveland; Greenville, South Carolina; Miami; and Seattle) and one rural site from the Health Tracking Snapshot series (the area around Fargo, North Dakota/Moorhead, Minnesota). These sites were chosen to maximize diversity in rates of use of various types of end-of-life care (for example, percentage of Medicare deaths occurring in hospitals), geography, and market characteristics and to take advantage of HSC contacts.

From lists of these contacts, we randomly

selected a contact person from a different type of organization that provides end-of-life care services in each market and used a “snowball” technique to identify interviewees at other organizations throughout the market. We conducted structured in-person interviews of at least one person in a hospital, hospice agency, home health agency, skilled nursing facility, and physician practice in most sites. We sought to interview a range of types of providers such as for-profit and nonprofit entities and teaching and community hospitals and, within these organizations, a variety of clinical and administrative staff such as medical directors, primary care and specialty physicians, discharge planners, social workers, nurses, financing/contracting specialists, and chief executive officers (CEOs) or executive directors. A previous study by Christine Cassel and colleagues reported the views of CEOs and other leaders of hospitals, integrated delivery systems, and medical groups on factors affecting hospital-based palliative care quality.<sup>5</sup> Because we were aware of that ongoing study, we chose not to interview the same types of individuals.

The interview protocol consisted of three primary sections: (1) characteristics of the organization, (2) how Medicare reimbursement methods and rules influence the provision of end-of-life care, and (3) how Medicare benefit design influences the provision of end-of-life care. “Patients at the end of life” were defined in the interviews as “patients who have a progressive, incurable illness that will end in death despite good treatment, and who are sick enough that you would not be surprised if they died within six months.”

With only six sites represented, we used our judgment about the importance and generalizability of each issue raised when selecting the areas of concern presented below.

## Hospice

■ **Reimbursement rates.** While most interviewees praised the comprehensiveness of the Medicare hospice benefit, many stated that the level of the hospice per diem rates (\$98.96 per routine home care day) makes it difficult

for hospices to provide expensive medications, procedures such as palliative radiation or chemotherapy, certain types of durable medical equipment (DME), and blood transfusions and products.

In several markets we found evidence of access problems for patients with high-cost needs. Some hospices will not admit these patients, or they will admit them but inform them in advance that the hospice will not provide the high-cost item(s) and may discharge them to receive certain types of high-cost care.

In addition, several physicians reported that they choose not to refer patients with high-cost needs who might benefit from hospice care because of concerns about the potential strain on the hospice’s budget. For example, one physician reported that he does not refer patients who need expensive supportive treatments that will ease pain and perhaps extend life but not cure a terminal condition. Such treatments include erythropoietin (EPO, a glycoprotein that can decrease anemia and transfusion requirements for cancer patients), pamidronate (used to decrease calcium levels in persons with bone metastases and relieve problems such as confusion, nausea, and pain), or leuprolide (which decreases pain and tumor load in prostate cancer patients). A Veterans Affairs (VA) physician reported supplying expensive drugs and supplies through the VA system to his Medicare hospice patients because he felt that hospices could not afford these items. This was less of a problem for larger hospices and hospice chains that use exclusive contracting arrangements with distributors. These arrangements allow them to negotiate better prices with suppliers in exchange for volume. Interviewees also noted that the current reimbursement rates were insufficient to provide the amount of nursing care required for hospice patients to remain in their homes until death, and room and board for hospice patients is not covered.

Overall, interviewees expressed the view that per diem payment is an appropriate method of reimbursing hospices and provides flexibility to deliver the services most needed

by the patient, but current rates do not adequately reflect current hospice treatment patterns. The design of the hospice benefit, first implemented in 1982, reflects the prevailing treatment model for cancer at that time, focusing on the provision of nursing and supportive care. From 1989 to 1993 the hospice per diem reimbursement system was updated using the hospital market basket; since 1993 it has been updated using the hospital market basket less some amount, ranging from 0.25 to 2.0 percentage points of the hospital market basket.<sup>6</sup> Over the past two decades a broad range of new curative treatments and palliative care options have become available, and they have changed the population of hospice users. Also, the use of hospice for a number of chronic, terminal conditions (such as congestive heart failure and chronic obstructive pulmonary disease) whose disease patterns differ from cancer has increased, and some interviewees felt that these changes should be reflected in an updated rate.

#### ■ Shorter stays and payment system.

Most of the hospices we visited had experienced sizable declines in mean length-of-stay over the past few years, ranging from a decrease of 17 percent over the past five years to a decrease of 50 percent over the past three years. Nationally, average length-of-stay declined 27 percent from 1992 to 1998.<sup>7</sup>

Per day expenses are typically higher for the first days of a hospice stay, because of the costs associated with creating a care plan and arranging the necessary services and equipment. Costs are also higher for the last days of a stay, because of the more intensive use of emotional support services and nursing care.

In the past, hospices were able to average higher-cost days at the beginning and end of a stay with relatively lower-cost days in the middle of the stay. Shorter lengths-of-stay have meant that hospices have a greater proportion of higher-cost days, which has contributed to budget shortfalls of 5–12 percent of operating expenses in recent years for eight of the ten hospices interviewed. The two that did not report recent shortfalls were part of large, for-profit hospice chains. Budget short-

falls for hospital-based hospices were typically subsidized by their affiliated hospital or through some combination of donations and hospital subsidies; freestanding nonprofit hospices relied on donations.

Interviewees in some markets felt that increased scrutiny of the hospice eligibility rule of a prognosis of six months or less, through recent efforts to reduce Medicare fraud and abuse, such as the Clinton administration's Operation Restore Trust (ORT) initiative, had contributed to the trend toward later referrals (closer to death) and shorter hospice stays. The U.S. Department of Health and Human Services implemented ORT in 1995 to reduce errors and systematic fraud and abuse in the home health, SNF, hospice, and direct medical education (DME) benefits of the Medicare and Medicaid programs. To combat the perception that stays of more than six months were illegal, the former Health Care Financing Administration (HCFA) administrator sent a letter to hospices stating that "nothing can be further from the truth."<sup>8</sup>

#### ■ Rural/urban per diem differential.

Hospices serving rural areas noted that the reimbursement rate is lower for patients residing in rural areas than for those in urban areas. The cost of travel to serve rural patients, including mileage and staff time, can be high for these hospices, and today's reimbursement formula does not consider travel distance.

■ Hospice "thrivers." A few hospice administrators and clinicians noted that some persons with a prognosis of six months or less to live improve after hospice admission, perhaps because of the specialized care they receive. Hospice regulations require that a patient be discharged from hospice once his or her prognosis is longer than six months, often resulting in discontinuity of care. However, interviewees noted that such patients often "crash" once they are discharged from hospice and are readmitted once their prognosis has shortened to six months or less. Hospice interviewees stated that these "thrivers" represented a relatively small proportion of their caseload and argued that total Medicare costs for these patients were likely to be higher

when the hospice was forced to discharge them. The financial implications of covering some level of hospice services or related care for these patients are uncertain, however, because there is no evidence that total Medicare costs would be offset by doing so.

■ **Insufficient reimbursement for inpatient respite care.** Several clinicians and administrators across markets noted that finding hospitals and nursing homes willing to accept the inpatient respite per diem rate of approximately \$100 for a hospice patient can be extremely difficult. This suggests that the respite per diem does not reflect the marginal costs of treating respite patients, although such patients likely require a lower level of care than do patients with acute care needs.

## Home Health

■ **Impact of new payment arrangements on quality.** Several interviewees from hospitals and home health agencies (HHAs) expressed concern about the impact of the interim payment system (IPS) and the likely impact of the newly implemented prospective payment system (PPS) mandated under the Balanced Budget Act (BBA) of 1997. Discharge planners in one public hospital felt that local HHAs were providing lower-quality care, discharging patients sooner than appropriate, and increasing family burden under the IPS. The IPS set payment limits that reduced revenues to agencies with above-average costs for their region during the period before the introduction of the episode-based system. One hospice interviewee felt that such changes were resulting in the dumping of sicker home health patients into the hospice program.

■ **Use of infusion therapy to qualify for home health.** Interviewees reported that infusion therapy is sometimes provided as a way to obtain coverage for home health services for end-of-life patients who otherwise would not meet Medicare coverage criteria.

■ **Uncovered services.** Interviewees reported that they would like to be able to provide home nutrition visits, symptom management consultations by a hospice consultation team, and end-of-life counseling services by

social workers for patients at the end of life but not enrolled in hospice.

## Physicians

■ **Billing by nonattending physicians.** By regulation, only the hospice patient's attending physician of record can bill Medicare Part B directly for services rendered. The hospice must bill Medicare for the services of other physicians that are related to the terminal condition. We discovered that some physicians and hospices are unaware of this rule and find that physician claims submitted to Part B for hospice services are denied. One physician felt that the confusion resulted in an access problem for Medicare hospice patients because some nonattending physicians who had had Part B claims denied were no longer willing to treat hospice patients.

## Hospitals

■ **Early discharge.** To confirm previously reported anecdotes of patients being discharged from the hospital when death was imminent, we asked hospital representatives if their hospital had a compassionate nondischarge policy. While few hospitals had a formal policy to this effect, many felt that not discharging such patients was standard practice. One of the physicians interviewed stated that "dumping" of patients by hospitals to SNFs at the very end of life occurred because of the financial incentives faced by hospitals under the PPS, but no other interviewees reported this behavior on the part of hospitals.

■ **Unnecessary hospitalization for medication coverage.** Some interviewees reported that hospital admission was sometimes used as a way to obtain coverage of expensive pain medication or other medications for Medicare enrollees who do not have supplemental drug coverage.

## Skilled Nursing Facilities

■ **RUG-based payment system.** The current Medicare per diem reimbursement method for SNFs, based on the resource utilization group (RUG)-III classification system, reflects differences in time spent delivering

nursing and therapy services to groups of patients. The method does not reflect differences in the use of certain ancillary services, including drugs, infusion therapy, respiratory therapy, lab tests, imaging services, and transportation.<sup>9</sup> As a result, SNFs serving patients who need relatively high levels of these services are underreimbursed, which creates an incentive for SNFs to avoid such patients.

Several interviewees noted that SNFs are sometimes unwilling to admit patients with high-cost medical needs. For example, a discharge planner from a public hospital said that local SNFs are not willing to admit patients with end-stage liver disease or who are ventilator dependent. Another interviewee noted that local SNFs would not accept cancer patients recovering between rounds of chemotherapy because of the high costs of chemotherapy that they would be forced to absorb. Another mentioned that local SNFs regularly send patients by ambulance to an oncologist's office to receive EPO injections so that the oncologist will bill Part B for the cost of the injection.

In response to findings from a recent HCFA study of variation in ancillary costs across RUG-III categories, HCFA released a notice of proposed rule making in April 2000 that outlined a change in the SNF per diem methodology to reflect differences in ancillary service use. Under the proposed rule, SNF payments for several RUG-III categories would be adjusted by an ancillary service index based on clinical information obtained from the Minimum Data Set (MDS) reporting system. However, HCFA decided not to implement the rule, noting that further research was needed to create an appropriate index.

■ **Use of infusion therapy to qualify for SNF stay.** As with home health, interviewees reported that infusion therapy is sometimes provided as a way to obtain coverage of SNF stays for end-of-life patients who otherwise would not meet Medicare coverage criteria.

■ **SNF transfers of dying patients to hospitals.** The director of case management at one community hospital stated that local SNFs sometimes attempt to discharge a pa-

tient to the hospital when the patient's death is imminent. One SNF administrator stated that dying patients with complex and extremely high-cost needs (such as total parenteral nutrition, or TPN) are sometimes discharged to hospitals.

## Medicare Versus Private Coverage

In the six markets studied, we found that coverage of and eligibility for end-of-life services were similar in most commercial health plans and FFS Medicare. However, a minority of commercial plans use benefit caps on hospice and other end-of-life services, and a very small minority of plans do not cover hospice care at all.

Many interviewees reported that commercial plans are sometimes more flexible with coverage, allowing end-of-life care providers to negotiate the coverage of certain items (such as additional home health visits if such visits are likely to prevent a hospitalization) through the utilization review (UR) process. Some complained that along with this potential for flexibility came administrative hassle. They also noted that commercial plans are sometimes less willing to pay for psychosocial services for patients at the end of life.

The levels of Medicare FFS and commercial plan per diem hospice rates were comparable within each market we visited. However, commercial plans sometimes carve out certain high-cost services—such as radiation, oral/enteral nutritional supplements, palliative chemotherapy, and certain pharmaceuticals—from the per diem rate and pay separately for them. This practice is in contrast with the all-inclusive hospice per diem paid under FFS Medicare (with the exception of attending physician consultations, which are reimbursed by Part B) and results in hospices' being paid effectively higher rates by these commercial plans.

Despite these differences, Medicare rules and policies are the dominant influence on hospice policies and revenues because of the high share of Medicare enrollees at hospices. Of the ten hospices studied, all reported that more than half of their patients were Medi-

care enrollees, and eight of the ten had 80 percent or higher Medicare enrollment.

## Recommendations For Changing Medicare Policy

In making recommendations to improve end-of-life care for Medicare beneficiaries, we kept to those that could be budget-neutral, although, in some cases, we suggest studies of the possible cost implications of benefit or payment changes that are not likely to be budget-neutral.

■ **Adopt a patient-level outlier policy for high-cost hospice cases.** For these stays, Medicare would reimburse the hospice a pre-determined percentage of expenditures exceeding some threshold.<sup>10</sup> The percentage should be based on some notion of marginal cost for hospices. For example, the Medicare hospital outlier system reimburses 80 percent of expenses above the hospital threshold, a number based on estimates of marginal costs for a hospital. Given the high proportion of labor as inputs in hospice care relative to hospital care, the corresponding number for hospice may be higher than 80 percent. If budget neutrality were desired, such a change could be financed by reducing the current per diems and distributing the funds to hospices with high-cost outlier patients. The current distribution of hospice expenditures could be studied to assist in determining the threshold and percentage to be used.<sup>11</sup>

■ **Explore the need for rebasing hospice rates.** We suggest that a study be conducted to determine how well current hospice per diem rates account for changes in treatment patterns over the years since the hospice benefit was implemented, including the increasing use of drugs and other palliative technologies. We expect that such a study, which would use data from hospice cost reports, would shed light on the appropriateness of previous updating methods and outline other possible approaches to updating for the future. Ultimately, however, the level of rates reflects a public policy choice about the level and quality of hospice care.

■ **Pay a higher per diem for the first and**

**last days of a hospice stay.** Paying a higher per diem for the first and last days could be kept budget-neutral by reducing the current per diems to cover expenditures associated with increasing the first and last days' rate.<sup>12</sup>

■ **Explore the level of variation in hospice travel costs.** If there is large variation in travel costs, hospice per diem rates could be adjusted to reflect these costs, as they are adjusted for local wage differences.<sup>13</sup>

■ **Estimate the net cost of adding some key services.** These should include room-and-board coverage for hospice patients with no caregiver; lower-level coverage of hospice-type services for hospice thrivers; and home nutrition visits, symptom management consultations, and end-of-life counseling for patients who do not elect hospice. Because adding these services to the Medicare benefit is not likely to be budget-neutral, we recommend that a study be conducted to estimate the associated costs. The decision of whether to add coverage of these items and the level of coverage that might be added could be made after determining expected costs.

■ **Consider the interaction of hospice per diem rates and Medicare drug benefit.** If a new Medicare outpatient drug benefit is enacted, we recommend a study to estimate the distribution of outpatient drug spending within the hospice benefit, to shed light on whether or how hospice per diems should be changed to reflect new drug coverage.

■ **Monitor implementation of the new Medicare home health payment system.** We recommend a study of the impact of the new home health payment system on severely ill and dying patients.

■ **Engage in further study of key issues.** We suggest further investigation of the following: (1) SNF access problems for end-of-life patients with high-cost ancillary service needs; (2) access problems for patients needing inpatient respite care under the hospice benefit; and (3) discharges from SNFs to hospitals and from hospitals to SNFs when death is imminent.

Several of the recommendations would require detailed data on hospice costs. The BBA

requires implementation of hospice cost reports beginning on or after 1 April 1999. The first year of data should be available in 2001, although the level of quality of these initial data is uncertain at this point. Additional data items may need to be added in future cost reports to address some of the issues raised.

OUR RECOMMENDATIONS are largely confined to changes that could be made within the context of existing Medicare provider payment systems. They emphasize changes that could be made to the hospice payment system because of the disproportionate emphasis of interviewees on hospice issues. During our interviews it became clear, however, that some patients do not fit well into the hospice model, because the course of their illness is unpredictable, because they cannot or do not wish to be maintained in their homes, or because they wish to continue curative treatment. Also, some Medicare enrollees at the end of life would prefer to adopt a palliative strategy sooner than the hospice benefit allows, at least as it is used in current practice. We heard support from several interviewees for an eligibility model like that used for the MediCaring demonstration, which bases hospice eligibility on disease severity and disability rather than prognosis, but there are no data available at this point on the impact of such a system.<sup>14</sup> More dramatic changes to the Medicare hospice benefit, through either a MediCaring-type model or another approach, should continue to be investigated in the future.

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## NOTES

1. C. Hogan et al., "Medicare Beneficiaries' Costs and Use of Care in the Last Year of Life," Medicare Payment Advisory Commission Contract Research Series no. 00-1 (Washington: MedPAC, May 2000).
2. Institute of Medicine, *Approaching Death: Improving Care at the End of Life* (Washington: National Academy Press, 1997).
3. Hogan et al., "Medicare Beneficiaries' Costs and Use of Care."
4. J. Newhouse, "Reimbursing Health Plans and Health Providers: Selection versus Efficiency in Production," *Journal of Economic Literature* (September 1996): 1236-1263.
5. C. Cassel, J. Ludden, and G. Moon, "Perceptions of Barriers to High-Quality Palliative Care in Hospitals," *Health Affairs* (Sep/Oct 2000): 166-172.
6. While the per diem rate is updated using some form of the hospital market basket, the aggregate facility cap is updated using the medical care expenditure component of the Consumer Price Index-Urban (CPI-U).
7. U.S. General Accounting Office, *Medicare: More Beneficiaries Use Hospice but for Fewer Days of Care*, GAO/HEHS-00-182 (Washington: GAO, September 2000).
8. L. Lagnado, "Medicare Head Tackles Criticism on Deadline-Oriented Hospice Care," *Wall Street Journal*, 15 September 2000.
9. MedPAC, *Report to the Congress: Medicare Payment Policy* (Washington: MedPAC, March 2000).
10. The threshold could be set, for example, at a certain number of standard deviations from the mean of per patient expenditures.
11. One of two types of hospice reporting systems would be required for this study: (1) a bill-reporting system that included information on services used and the cost of providing those services; or (2) a utilization-reporting system. If the latter option were used, information on cost could be estimated using a standard formula to convert utilization to cost.
12. To calculate an adjustment to the per diem rate, data on costs from each day of a hospice stay are needed. Such information could be obtained from a random sample of hospice patients rather than from all hospice users.
13. To adjust hospice rates for travel costs, Medicare would need to be able to disaggregate labor costs on the hospice cost report to allow one to distinguish labor costs associated with service provision from those associated with travel.
14. J. Lynn et al., "Capitated Risk-Bearing Managed Care Systems Improve End-of-Life Care," *Journal of the American Geriatrics Society* (March 1998): 322-330.