Perceptions Of Barriers To High-Quality Palliative Care In Hospitals

Lack of financial reimbursement has created an environment in which end-of-life care is not a top priority for U.S. hospitals.

by Christine K. Cassel, John M. Ludden, and Grace M. Moon

Palliative care is defined by the World Health Organization as “the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families.”¹ According to the Institute of Medicine (IOM), four basic elements are required for the care of dying patients: understanding the physical, psychological, spiritual, and practical dimensions of caregiving; identifying and communicating diagnosis and prognosis; establishing goals and plans; and fitting palliative and other care to these goals.²

The quality of end-of-life palliative care has been receiving an increasing amount of attention in response to public and professional pressures and to deficiencies cited by a number of research and policy studies.³ As a result, a growing number of initiatives have been developed to improve care for patients at the end of life. Until recently most palliative care experts have focused their research and advocacy on the hospice model, which is primarily based on home care, and have neglected much of hospital-based end-of-life palliative care.

An increasing awareness of the large number of deaths occurring in U.S. institutions has spurred research on the quality of end-of-life care in hospitals. A large number of deaths occur in institutions, although in-hospital mortality rates vary geographically. According to the Dartmouth Atlas of Health Care, 1999, the rate of in-hospital mortality among Medicare enrollees during 1995–1996 varied from below 20 percent in some areas of the western and northwestern states to more than 50 percent in the eastern and southern states.⁴ However, the percentage of total deaths of all ages that occur in hospitals is much higher, about 60 percent.⁵

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) is largely responsible for stimulating research efforts to improve end-of-life palliative care in hospitals. The SUPPORT study began in 1988 in an attempt to improve prognostication and decision making for seriously ill patients.⁶ It reported on an extensive intervention trial to improve care for 10,000 patients with critical illnesses who were hospitalized at academic medical centers (AMCs). The intervention was unsuccessful, and professionals and communities...
have responded by attempting to improve end-of-life care and identifying hospitalized patients at special risk.

The absence of a stable and explicit financing mechanism to pay for palliative care for dying patients in hospitals may be a barrier to improving their care. Several studies suggest that Medicare payment policy may encourage hospitals to discharge older, dying patients quickly and thus limit beneficial treatments such as palliative care. A 1997 IOM report also suggests that physicians may be encouraged to limit time spent with dying patients because the current payment system does not recognize the resources, such as a longer evaluation and management time and interdisciplinary teams, needed to provide high-quality palliative care. Based on these findings, the IOM recommended policy changes, including revising financing mechanisms for end-of-life palliative care to encourage high-quality care and to sustain a coordinated system of care; and creating a palliative care medical specialty.

**Study Findings**

**Perceptions of financing palliative care.**

Two distinct perspectives emerged regarding financing end-of-life palliative care: a “budget” perspective and a “reimbursement” perspective.

The “budget” perspective views such care as already implicitly included in the current reimbursement system and, therefore, part of its core programs. Interviewees from this perspective viewed it as their responsibility to figure out how to provide this care within budget by “moving the money around.” One interviewee from an IDS in the Pacific region made it sound simple: “Good palliative care is a matter of getting the right care in the right place at the right time.”

This perspective was voiced most clearly by leaders in full-risk, capitated environments, mostly located in western states. Most of these programs have included hospice care as part of their system for many years. These interviewees believed that their institutions had a low percentage of in-hospital deaths, which is consistent with Dartmouth Atlas data. In general, the “budget” perspective emerges from a financing system in which funds are taken into an organization at the “top” and allocated to program areas according to their needs. A prepaid group practice is the clearest example of this financing system. Within such a system, palliative care programs are funded in order to provide a service. To gain or keep this funding, programs need to demonstrate their continuing contribution to overall care. Such a contribution may be based on utilization goals and efficiency, or it...
may be based on broad clinical goals.

In contrast, the “reimbursement” perspective views end-of-life palliative care as a “new” service that is not reimbursed under the current financing system. Managers holding this perspective tend to believe that they are not responsible for providing this care. A common goal within this group is to quickly move dying patients out of expensive intensive care units (ICUs) and into less costly hospital units, or out of the hospital completely and into nursing homes, hospice, or other types of less costly care. This view was articulated by an interviewee from a large teaching hospital: “Hospitals are not responsible for dying patients. They should all go to nursing homes that love them to death.”

The “reimbursement” perspective is seen most clearly in fee-for-service (FFS) environments, where payments are made by Medicare DRG directly or through an insurance plan with various utilization and/or “benefit” controls. The “reimbursement” system commonly creates organizations where the financial control system is based on the notion of “every tub on its own bottom.” In such a system the reimbursement of specific services is carefully monitored, and the success of each program is evaluated in terms of its own costs and reimbursements. Services that are not reimbursed are perceived as money losers.

Leaders from this perspective complained that lack of financial resources for end-of-life palliative care is a “huge problem” and “creates barriers to providing optimal end-of-life care.” They firmly believed that palliative care services need their own explicit funding source.

Most of the “reimbursement” institutions serve large numbers of uninsured and Medicaid patients. They rely heavily on FFS Medicare business plans, and many are in precarious financial states. The leaders from these institutions felt that current financial problems have created an environment in which innovative programs, like end-of-life palliative care, are “not on their list of top priorities.”

There was a strong perception among this group that programs need to prove their value to receive enough institutional support to remain in operation. The few of these interviewees involved with palliative care programs noted high pressures to justify internally their programs’ existence, by demonstrating improvements in overall quality of care or by generating cost savings.

Looking deeper: CEO versus clinician. Of the interviewees, 83 percent held executive management positions, while 17 percent were clinicians in charge of palliative care services. The perspectives of leaders in these roles differed, even within the same type of organization, and sometimes even within the same institution.

“Budget” perspective. A majority of interviewees in this group perceived no major, direct financial problems relating specifically to end-of-life care. A few who felt that financing such care was a problem pointed to the severely stretched overall funding of health care, especially for chronically ill elderly persons.

In several cases, we interviewed both executive managers and clinicians responsible for palliative care in the same institutions. They perceived financing problems differently. Executive officers saw the financial pressure as a result of forces “outside” the institution, such as Medicare’s and other insurers’ reimbursement systems or the marketplace. Clinicians described their financial struggles as partially the result of internal stinginess within their organization.

These clinicians’ stories indicate that palliative care programs in “budget” perspective institutions are not free from financial concerns. They compete with other clinical programs for resources and are constrained by the perception that they increase hospital length-of-stay (and cost). A provider from an integrated delivery system with a “budget” perspective remarked, “They [senior executives and accountants] are always asking, ‘What’s the value added?’”

Whereas “budget” perspective executives spoke about their institutional commitment to palliative care, clinician-managers were highly concerned about the availability of start-up and ongoing funding and were often
caught between the institutional rhetoric and what they see as their stressful reality. They voiced their concerns even as they repeated their institution’s rhetorical stance that end-of-life palliative care is of clinical and institutional value. For instance, one clinician could not reconcile the dueling facts that he could not secure funding for a half-time nurse (which would make the program possible) and that the company’s chief executive officer (CEO) was supposedly in support of the palliative care program. Moreover, program managers repeatedly spoke of problems finding funding for nonbillable (but low-cost) services such as nursing, chaplaincy, or social work.

“Reimbursement” perspective. Interviewees at all levels in this group viewed financing for end-of-life palliative care as a direct impediment: “We don’t do it because they don’t pay for it.” One CEO told a palliative care expert, “You are providing a service we cannot afford.” A primary concern for some was the retroactive reimbursement denials from insurance companies regarding end-of-life palliative care. An interviewee from one AMC noted, “[For] patients who require hospital admission for acute symptom control, pain, delirium, and agitation, the hospital is denied payment because [the insurance company] feels that this does not require an acute care hospital admission.” A leader from another AMC echoed this belief: “If a patient is [admitted to a hospital because he/she is] highly symptomatic, requiring intensive physician and nurse activity, but has a Do Not Resuscitate order, insurance companies automatically deny the payment for hospital care.” Others spoke of the need to manipulate the documentation of diagnosis to ensure payment from insurance companies: “The nurses or billers create ‘stories’ to get an approval” from health plans. These leaders viewed insurance benefit boundaries as excluding in-hospital palliative care.

Several interviewees from the “reimbursement” group identified a lack of internal resources and support for palliative end-of-life care programs as an additional major barrier to provision of this care. A CEO from an AMC in the Northeast described his experience: “At a time when hospitals are facing deficits, projected to be $15 billion in the next twenty years, the financial crisis has had a negative impact on hospice programs, and people [in management] are perceiving this care as less than imperative because it is not a core service in the sense that it will help us survive.”

- **Perceived nonfinancial barriers.** The two groups agree that some nonfinancial factors add to the underdeveloped and undervalued status of end-of-life palliative care in U.S. health care institutions. Although interviewees described these factors as being nonfinancial, their words suggest that financing does play an important role. For instance, interviewees identified the American cultural reluctance to dealing with death as a major nonfinancial barrier in delivering optimal end-of-life palliative care. They repeatedly cited examples in which both doctor and patient resort to aggressive, futile treatments rather than accepting death’s imminence, but in the same breath they reiterated that life-prolonging attempts pay better. In fact, aggressive procedures are better reimbursed than palliative care treatments are. Equally importantly, aggressive treatments have explicit reimbursement mechanisms, which hospital-based palliative care lacks.

- **Perceived quality problems.** There was a consensus among interviewees that problems exist in the quality of end-of-life palliative care provided in hospitals. Most agreed that hospitals are not an ideal place to provide such care: “Patients should be transferred out of the high-technology, negative en-
environment [of hospitals] to patients’ homes, if at all possible.”

Interviewees seem to feel differently about the magnitude of this problem depending on whether they believe that their organization has control over how it delivers end-of-life palliative care. Those who perceived few problems in the quality of such care were mostly from “budget”-perspective environments with either in-house programs or contractual arrangements for transferring patients out of the hospital to alternative settings, such as hospice and home care. Because such options are available, these respondents believed that they have control over their spectrum of care and process of care delivery and can closely monitor the quality of patient services. This sense of control is reflected in a statement from a doctor in one medical group: “If the end-of-life care needs an intervention, just go ahead and do it.”

On the other hand, those who perceived serious problems in the quality of end-of-life palliative care were most often from the “reimbursement” perspective, especially large AMCs in FFS environments, whose priorities are to teach, do research, and provide interventions predominantly to save lives, and where there is no identifiable revenue stream for care of the dying. Because the concept of palliative care does not mesh with these priorities, institutions may allow the quality of such care to suffer.

Leaders in these organizations underscored their sense of having little control over the care processes of their patients. Many of these organizations serve a large number of Medicaid and uninsured patients who live alone. Therefore, the option of transferring dying patients to substitute settings may be impossible because of the lack of informal caregivers and financial support. This may cause providers to feel powerless to improve the quality of care.

Policy Recommendations

In interviewing health care leaders about their perceptions of the degree to which financing impedes the improvement of end-of-life care for hospitalized patients, we found substantial agreement that financial barriers could be reduced. Interviewees were asked to discuss their ideas and opinions regarding the following three policy options, which are being debated widely in the palliative care community as ways to ease these barriers: (1) develop measures of the quality of end-of-life palliative care and incorporate quality measures in hospital accreditation; (2) develop a Medicare DRG code specifically for end-of-life palliative care; and (3) establish palliative care as a recognized medical specialty.

Quality-of-care standards. An accountability system must be developed to create incentives for health care organizations to improve care for patients at the end of life. Quality measurement and accompanying accreditation standards that are monitored and enforced by accreditation bodies such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) or the National Committee for Quality Assurance (NCQA) would provide incentives for organizations and providers to improve the quality of end-of-life palliative care.

Health care organizations are now required to meet the Conditions of Participation to be accredited by the JCAHO. Except for hospice programs within the category of home care organizations, the JCAHO does not suggest specific measures to be used for patients at the end of life, although it does require documentation of pain management. As a result, individual providers and hospitals are left to measure and monitor quality improvement efforts on their own, with no system to guide them in evaluating and improving their processes and performance.10

A number of initiatives have begun to address the need to develop such quality measurements. Among them are work by the American Geriatrics Society (AGS) and the Tool Kit of Instruments to Measure End of Life Care (TIME).11 The Picker Institute also is further developing these survey tools to assess the quality of care at the end of life.12

Accreditation of hospital-based palliative care programs would validate appropriate in-
patient care and establish utilization review protocols that would describe reimbursable palliative care services (specifying type of specialty, diagnoses, and treatments) and could serve as a guideline for insurance companies to use for reimbursement purposes.

Valid, reliable, comparable, meaningful, and publicly available quality measures for treatment of dying patients would provide evidence-based, uniform measures for organizations to compare their performance with others and serve as an educational tool for providers and organizations.

Palliative care practitioners from the “budget” perspective were particularly supportive of this recommendation, because quality standards would give their institutions a strong incentive to invest in their palliative care programs in an effort to compete in the marketplace. As one CEO put it, “How do you know whether we are doing the right job with this population of patients? I mean, what metrics can I look at?”

According to the “reimbursement” perspective, quality measures and standards would force hospital administration to make end-of-life palliative care a higher priority, because hospitals would be publicly judged against these standards.

Palliative care DRG. A designated DRG code for end-of-life palliative care would greatly help to remove the external financial barriers perceived by the “reimbursement” perspective by allowing providers and organizations to render such services without fearing denials of payment by insurers. The explicit designation of palliative care also would help to legitimize it as appropriate in-hospital care. Furthermore, incentives for accurate documentation of end-of-life palliative care could influence the hospital culture to acknowledge this care as valuable, which would help to remove many internal barriers.

It may be advisable to use a modifier of primary DRG classification, since resource use may vary depending on the underlying illness. For instance, a patient dying of lung cancer with metastasis to the brain may have very different needs than a patient dying of end-stage liver failure. A secondary International Classification of Diseases, Ninth Revision (ICD-9) code for end-of-life palliative care developed in 1996 (V-66.7) was an important step in acknowledging end-of-life palliative care as a part of legitimate in-hospital care. The goal in creating this code was to gather data to study the feasibility of creating a DRG for hospital-based palliative care.13 However, the code was rarely used by providers because of the absence of monetary reimbursement for it and the lack of resources to educate providers and hospitals about its availability.14 As a result, the Health Care Financing Administration (HCFA) could not perform a reliable assessment of the financial implications of explicit payment categories for this care. HCFA also was unable to assess the costs of such in-hospital palliative care. Two current studies, supported by the Robert Wood Johnson Foundation and the Milbank Memorial Fund, are attempting to quantify these costs.

With a few exceptions, interviewees from both groups thought that an explicit DRG or modifier code representing palliative care services for hospitalized patients would be a good idea. The few interviewees who were skeptical of this policy came from fully capitated environments in which end-of-life palliative care services are provided under the current financing system. A few of the skeptics, but not all, voiced concern that a new DRG could create incentives for unnecessary hospitalization, to “gain revenue by encouraging people to be institutionalized when we should be encouraging payment strategies that encourage the right kinds of services in other appropriate settings.” Another concern was that a DRG code for this service could foster mistrust by consumers who would fear that their hospital endorses “a speedy death rather than a good death.”

Palliative care specialty. Most interviewees perceived that the creation of a medical specialty for end-of-life palliative care would likely improve this care. A recognized specialty would further legitimize and validate palliative medicine as an integral part of health care. Furthermore, it would help to
eliminate some of the financial barriers by allowing qualified physicians to bill for their services and consultations. For example, geriatricians or general internists who practice palliative medicine cannot bill Medicare for consultations because they are considered primary care physicians, not specialists. If they had specialist status, they could work with patients’ primary care internists or geriatricians, and both physicians could bill for their services.

More importantly, according to the IOM, most providers do not have the skills to deliver appropriate end-of-life care. A dedicated specialty that teaches palliative medicine would engender the necessary expertise to properly assess and manage the care that dying patients need. In addition, specialty status would encourage leadership in medical education and in research efforts that would continuously improve the quality of care.

Not all interviewees supported the idea of creating a specialty. Those not in favor were concerned that yet another specialty would further fragment today’s medical care system and contribute to the lack of care coordination among providers.

Dying is at once a fact of life and a profound mystery,” the IOM report states. “Death comes to all, yet each person experiences it in ways that are only partly accessible to the physician or family member, the philosopher or researcher.” Despite the lack of empirical evidence on improving care for dying patients, most would agree that suffering at the end of life can and should be relieved by appropriate expertise and a supportive context of care.

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NOTES
2. Institute of Medicine, Approaching Death: Improving Care at the End of Life (Washington: National Academy Press, 1997).
8. IOM, Approaching Death.
9. Ibid.
15. IOM, Approaching Death.
16. Ibid., 1.