

## Managing Advanced Illness: A Quality and Cost Challenge to Medicare, Medicaid, and Private Insurers

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**OVERVIEW** — *This background paper examines approaches to delivering and financing health services for persons with advanced chronic illness. Recognizing that the Medicare program is the major insurer of such services and that its share is likely to increase due to the aging of the population, the paper focuses on the nature and structure of Medicare hospice—and, to a very limited extent, palliative-care—benefits. It also explores Medicaid benefits, as well as coverage through private insurance, including indemnity, point-of-service, and preferred-provider-organization products. In addition to giving descriptive information on the various programs, the paper looks at quality concerns and cost and payment considerations.*

# Managing Advanced Illness: A Quality and Cost Challenge to Medicare, Medicaid, and Private Insurers

Advanced illness is a challenge to this country's "cure-all" culture of high-technology procedures and newly discovered drugs. Persons with advanced chronic diseases that will soon end their lives tend to represent failure to the health care system. But as the population ages, the definition of "success" in caring for persons with advanced illness is gradually taking on new meaning: the degree to which the quality of patients' lives is enhanced and their suffering relieved.

Educating patients about the disease process and prognosis is integral to success, so that treatment can be provided throughout the care continuum according to the preferences of patients and family members. When advanced illness means that death in the near term is likely, understanding how patients want to spend the rest of their lives is crucial. This is true not only for the patients themselves but also for the providers responsible for recommending and implementing patient care plans and the payers responsible for managing the plans' costs. It is also important for policymakers in both the public and private sectors, as they change their focus from a procedure- and pharmacy-oriented inpatient and outpatient health care system to a continuum of preventive, ambulatory, inpatient, and post-acute care for those with chronic illness.

While advanced illness obviously is not limited to those 65 years of age and older, the 65-plus population consumes one-third of health care spending and one-half of physician time in the United States, according to the Alliance for Aging Research. Nearly three-quarters of the people who die each year in this country are in that age group. For most, the cause of death is a chronic disease, with heart disease, cancer, stroke, and chronic obstructive pulmonary disease (COPD) topping the list. Despite medical advances, death from advanced chronic illness takes its toll, although the age of death is being extended.<sup>1</sup> By the time the baby-boom generation, consisting of those born between 1946 and 1964, starts reaching age 65, "the 35 million Americans over 65 today will double in size, approaching one quarter of the population." By mid-century, the number of those over 85 will nearly quadruple.<sup>2</sup>

"The elderly with chronic diseases often face a period of decline in health and function before death that—with the exception of cancer—varies

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significantly in duration and symptomology from patient to patient,” James Lubitz, Ph.D., of the Centers for Medicare and Medicaid Services (CMS) indicates. Pointing out that some persons want “continued intensive, invasive efforts,” while others reject them, he goes to the crux of the matter: “I would prefer to see a financing system that was capable of respecting both courses of action—one that allows for this kind of patient-directed action.”<sup>3</sup>

In a recent study, “persons who were 60 years of age or older and who had a limited life expectancy due to cancer, congestive heart failure (CHF), or COPD,” gave their preferences based on their understanding of the outcomes of treatment. If treatment placed a low burden on them and restored their health, 98.7 percent said they would choose to receive it. However, if the treatment resulted in their survival but with severe functional impairment, 74.4 percent indicated they would not choose it. If the treatment meant they would survive but with severe cognitive impairment, an even higher proportion—88.8 percent—would choose not to have it.<sup>4</sup>

Even those who reject “intensive, invasive efforts” if the likelihood of cognitive or functional impairment is high may wish to have a menu of choices, a range of options regarding their care. This half of the equation tends to be forgotten, implying that the opposite of turning down intensive, invasive measures is a void. While some patients’ care may be restricted to symptom management, prescribing and monitoring of medications, and provision of psychological and social support, others’ treatment may include “interventions designed to improve their physical, functional, emotional, and social well-being.” This was the case in clinical trials of seriously ill cancer patients at the University of California at Davis. The patients received both investigational chemotherapy and palliative care. According to Frederick J. Meyer, M.D., professor and chair of internal medicine at UC Davis, “In the past, it’s been an either-or situation....In our opinion, that’s not an acceptable choice. Why can’t patients have both?”<sup>5</sup>

Some patient advocates, health professionals, and health plan administrators have addressed the need to help patients and families thread their way—through various transitions—toward appropriate end-of-life care. They have redefined success in caring for those with advanced illness in innovative ways that strive for continuity of patient education, continuity of patient care, and continuity of patient and family support. The models that they have developed, however, face numerous barriers in the delivery and financing of services because of the compartmentalization and rigidity of the health care infrastructure itself. Rather than encouraging continuous and simultaneous services that address the needs of patients—services that may modify patients’ courses of illness without being curative—delivery and payment policies tend to discourage them. Such barriers raise important questions for policymakers: How can the health “system,” known for its fragmentation and inflexibility, respond to patients who clearly are concerned with the quality of the time they

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have remaining? How can health care financing—particularly Medicare, which pays for most end-of-life services—allow for such quality to be recognized and supported?

## **HOSPICE: FORERUNNER OF A BROADER PALLIATIVE-CARE BENEFIT?**

For the past 25 years or so, end-of-life care has largely been associated with hospice services, even though only about a fifth of those who die of advanced illness actually avail themselves of hospice benefits through Medicare, Medicaid, or private insurance. While hospice itself is a far-reaching concept, the hospice benefit—as offered by public and private insurers—tends to be fairly restrictive. Hospice is defined by the National Hospice and Palliative Care Organization (NHPCO) as

a team-oriented approach of expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's wishes. Emotional and spiritual support also is extended to the family and loved ones. Generally, this care is provided in the patient's home or in a home-like setting operated by a hospice program.<sup>6</sup>

### **Some Background**

From a public policy standpoint, federal research and development of standards and payments for hospice care were the first acknowledgments of the need for a new approach to care of the dying in this country. Federal support for hospice dates to the mid- to late 1970s, when the National Cancer Institute funded studies at the Connecticut Hospice in New Haven and at hospices in Arizona, California, and New Jersey. A federal task force issued a report in 1978 on the role of the federal government in providing hospice services and, that same year, the Health Care Financing Administration (HCFA), now CMS, of the U.S. Department of Health and Human Services (DHHS), announced that it would support demonstration projects on providing health services to persons with terminal illnesses. The U.S. General Accounting Office (GAO) followed up in 1979 with a report profiling hospice services and outlining requirements for them, particularly under HCFA programs. In 1980, under Medicare and Medicaid waivers, HCFA began paying 26 hospice providers for home health services, as well as for bereavement counseling and pain-control drugs.

Charitable foundations played a large role in these early developments. The Robert Wood Johnson Foundation (RWJF) and the John A. Hartford Foundation helped finance the assessment of HCFA's demonstration program, and the W. K. Kellogg Foundation provided funding to the Joint Commission on Accreditation of Hospitals (now the Joint Commission on Accreditation of Healthcare Organizations) for preparation of a hospice standards manual and an assessment and survey guide, both of which were published in 1983.

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By 1983, relying on charitable contributions, private insurance dollars, and self-pay patients, 1,145 programs had defined themselves as hospices. (In 2000, there were 3,100 programs, which admitted 700,000 patients, according to NHPCO.)<sup>7</sup> On November 1, 1983, the federal government started to pay for hospice services. Without waiting for the final results of the assessment and research studies, Congress had authorized hospice coverage under Medicare in the Tax Equity and Fiscal Responsibility Act of 1982, with an expiration date of October 1, 1986. Subsequent legislation, the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA), eliminated the sunset clause.

The Medicare hospice provisions served as guidelines for hospice services under Medicaid, the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS), and the Veterans Administration (now the Department of Veterans Affairs). COBRA authorized hospice coverage as an optional state benefit for Medicaid, and a Department of Defense measure that became law in 1991 provided for hospice care in military hospitals for active-duty personnel and in the CHAMPUS program for military dependents. Around the same time, the Veterans Administration began offering hospice services.

### Medicare Hospice Benefit as Model

As the Medicare hospice benefit evolved over the years, it took on the following standards:<sup>8</sup>

- It is available as a benefit under Part A of the Medicare program. Under the benefit, “beneficiaries elect to receive non-curative treatment and services for their terminal illness by

### HOSPICE STATISTICS 2000

(For 3,100 Operational Hospice Programs in the United States, Including the District of Columbia, Puerto Rico, and Guam)

<b>Hospice Ownership</b>	
Nonprofit	73%
For-Profit	20%
Government-Operated	7%
<b>Hospice Medicare Certification</b>	
Certified	91%
Not Certified	9%
<b>Freestanding, Affiliated, and Other Hospices<sup>a</sup></b>	
Freestanding	37%
Affiliated	66%
With Hospitals	35%
With Home Health Agencies	22%
With Hospital Systems	9%
Other	6%
<b>Hospice Geographic Location</b>	
Rural	49%
Urban and Rural	38%
Urban	13%
<b>Hospice Days of Service<sup>b</sup></b>	
Routine Home Care	96%
Inpatient Care	3%
Respite Care	0.3%
Continuous Home Care	0.3%
<b>Hospice Days of Service by Payer<sup>b, c</sup></b>	
Medicare	79%
Private Insurance	13%
Medicaid	5%
Alternative Sources	3%
Self-Pays	1%

<sup>a</sup> Does not add up to 100% due to an overlap.

<sup>b</sup> Does not add up to 100% due to rounding.

<sup>c</sup> Hospice providers gained additional funds from charitable contributions.

Source: National Hospice and Palliative Care Organization, “NHPCO Facts and Figures”; accessed May 24, 2002, at <http://www.nhpco.org/>.

waiving the standard Medicare benefits for treatment of a terminal illness." Beneficiaries may, however, still receive standard Medicare benefits for the treatment of conditions that are not related to the terminal illness.

■ It is accessible to Medicare beneficiaries who "are certified by their doctor and the hospice medical director as terminally ill" and who "have a life expectancy of six months or less." A beneficiary must sign a statement choosing the benefit over curative treatment and enroll in a Medicare-approved hospice program.

■ It mandates services relating to the terminal diagnosis, as outlined in the beneficiary's care plan, by physicians for medical direction of the patient's care, registered and licensed practical nurses through regular home care visits, home health aides and homemakers, and chaplains. It also includes social work and counseling services, bereavement counseling, medical equipment, medical supplies, drugs for symptom control and pain relief, volunteer support, medical rehabilitation services (by physical and occupational therapists and speech pathologists), and dietary counseling. The inclusion of outpatient prescription drugs is unique for a Medicare benefit. A family member or other person who is significant to the patient serves as the primary caregiver and, when appropriate, helps make decisions for the patient. Hospice staff members are on call 24 hours a day, seven days a week.

■ While mainly provided in a home setting, it reimburses for services delivered in freestanding hospice facilities and hospitals, as well as in nursing homes and other long-term-care facilities. Medicare provides a capitated per diem payment for almost all services the patient receives. The patient is responsible for a 5 percent copayment for respite care and up to \$5 for each prescription. Medicare does not cover room and board, but Medicaid may pick up those costs for its beneficiaries.

■ In statutory language, it lasts as long as the patient's physician recertifies the terminal illness. As long as the patient is eligible, two 90-day periods of care are followed by an unlimited number of 60-day periods. CMS, however, has the policy of continuing the benefit "as long as the patient shows objective evidence of clinical decline," which has to be documented.<sup>9</sup> Because the prognosis is expected to be six months or less, extensive stays tend to garner suspicion from federal inspectors.

### Inherent Problems

While hospice was first heralded as the gold standard of end-of-life care, it soon encountered criticism from hospice providers and patients, who found the benefit too rigid, and from government, which undertook fraud investigations. Providers of end-of-life care are concerned about what they call "the irrational choice" patients face in being required to forgo

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curative care in order to access hospice services. “The either-or approach that was adopted as a cost containment measure imposes a simplistic binary-decision model that is not consistent with either the clinical or emotional reality of the hospice process for patients and their families,” according to David Rehm, president and chief executive officer of VistaCare Hospice Foundation.<sup>10</sup>

“When patients are most vulnerable, they have to choose between a hospice model that can cut them off from the professionals who are treating them and a curative model that may be highly inappropriate for their care,” Diane Meier, M.D., director of the Mount Sinai School of Medicine Center to Advance Palliative Care, indicates. “The rational approach would be to continue disease-modifying treatment as well as palliative care. The same professionals, the same team, would continue caring for the patient and the transitions would be seamless.”<sup>11</sup>

The DHHS Office of Inspector General (OIG), on the other hand, has been concerned about enforcement of hospice rules, particularly of the six-month prognosis requirement. The OIG conducted numerous audits of Medicare hospice services during the mid- to late 1990s to see if the rules were being followed. The office’s concerns centered on whether or not the beneficiaries, especially those with diagnoses other than cancer, met the definition of “terminally ill” when they enrolled in hospice programs.<sup>12</sup> Critics of the OIG have accused the office of unreasonably expecting “people to die on time.” For example, the *Wall Street Journal* headlined a 2000 story: “Rules Are Rules: Hospice’s Patients Beat the Odds, So Medicare Decides to Crack Down.”<sup>13</sup>

The Balanced Budget Act of 1997 addressed some of the OIG concerns by permitting hospices to discharge patients who improved, without eliminating their future benefits, and by requiring recertification of hospice patients every 60 days (after the first 180 days). However, these provisions did not dispel criticism by hospice providers and their advocacy groups that the hospice benefit, as defined, was inflexible. Hospice providers—such as the National Hospice Work Group, a national organization of major not-for-profit hospice providers—contend that the benefit, as defined, is not working as it was intended. Because of the six-month prognosis requirement, hospice predominately draws those with advanced chronic illnesses with fairly certain trajectories, such as certain cancers, and not those—such as persons with COPD—with less predictable courses of illness.

Probably because of the “either-or” hospice option and the difficulty of predicting death with exactitude, dying persons are entering into hospice too late, providers believe. While NHPCO cited an average length of service of 64 days in its 1992 census, it indicates that the mean fell to 48 days in 2000. NHPCO contends that the median length of service, which was 25 days in 2000, is more accurate because of the high frequency of short periods of service. A third of those who were served by hospice in

## HOSPICE DEMOGRAPHICS IN 2000

Gender	
Female	55.0%
Male	45.0%
Age*	
17 & younger	0.4%
18-34	1.0%
35-64	17.0%
65-74	24.0%
75-84	33.0%
85 & older	25.0%
Race / National Origin	
White/Anglo	82.0%
Black/African-American	8.0%
Latino/Hispanic	2.0%
Other	2.0%
Not Classified	6.0%

\* Slightly over 100% due to rounding.

Source: National Hospice and Palliative Care Organization, “NHPCO Facts and Figures”; accessed May 24, 2002, at <http://www.nhpco.org/>.

2000 died in seven days or fewer.<sup>14</sup> Moreover, a GAO study issued in 2000 indicates that, “although more beneficiaries are choosing hospice, many are doing so closer to the time of death. Half of Medicare hospice users are enrolled for 19 or fewer days, and service periods of one week or less are common.”<sup>15</sup> In publicizing these numbers, providers say that the OIG assessments were skewed, because the OIG audits targeted lengths of service over 210 days (and largely in nursing facilities, where Medicare hospice services are available only to patients who are also eligible for Medicaid or who have private-pay status).

Providers also express concern that OIG activities have had a chilling effect on physicians unfamiliar with the hospice concept or reluctant to refer patients to hospice. They cite the lack of training in palliative medicine at both the undergraduate and graduate levels and the absence of requirements to mandate it. In addition, they have asserted that the per diem rates and aggregate caps on hospice payments, while encouraging cost-effective care, may be inadequate for certain patients. “The development of many new higher-cost and higher-technology pain and symptom treatments that were never anticipated in the cost structure of the original benefit has exerted cost pressure on the per diem rates,” Rehm of VistaCare indicates. “The result of this antiquated cost structure is that many smaller hospice providers are forced to limit admission to those that are unlikely to require these treatments.”<sup>16</sup>

Providers that are involved in both hospice and palliative care have indicated that, if the restrictive barriers to fuller utilization of the hospice service system were corrected, the hospice program would be considerably more effective. While they see the need for an expanded palliative care benefit, they think it should be paired with improvement of hospice, because most palliative care to date has been hospital-based.<sup>17</sup> Cynthia Pan, M.D., assistant professor of geriatrics at Mount Sinai, has identified over 400 hospitals with palliative care programs.

## The Palliative Care Approach

While some leading providers in the field of end-of-life care are committed to improving the hospice benefit, others prefer a broader palliative care program. One of the original advocates of palliative care, the Cleveland Clinic, defines the term in this way:

The word palliative is derived from the Latin *pallium*, a cloak or cover. Thus, palliative care is a form of care that (a) recognizes that cure or long-term control is not possible, (b) is concerned with the quality rather than quantity of life, and (c) cloaks troublesome and distressing symptoms with treatments whose primary or sole aim is the highest possible measure of patient comfort...

The goal of palliative care is fully realized, however, only if attention is given to all of the following: (a) relief for the patient from pain and other distressing symptoms, (b) psychological and spiritual care for

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the patient, (c) a support system to help the patient live as actively as possible in the face of impending death, and (d) a support system to sustain the patient's family during the illness and bereavement.<sup>18</sup>

A study by the Mount Sinai School of Medicine Center to Advance Palliative Care—supported by RWJF—indicates that such a program would be available to “the chronically sick with conditions such as heart or lung disease who are not expected to survive more than a few years,” as well as to “the ‘actively dying,’ whose anticipated life expectancy is measured in days or weeks.” Ironically, as those urging a broader model seek to break the bonds that the hospice benefit imposes on them, they recognize that Medicare “currently pays for palliative care services per se only within the hospice benefit.”<sup>19</sup> According to Meier, of the Mount Sinai School of Medicine Center to Advance Palliative Care,

The biggest challenge—and one that continues to plague even successful palliative care programs like that at Mount Sinai—is money, or rather the lack thereof. Only about 15 percent of physician and nursing salaries at Mount Sinai's palliative care institute are paid through clinical billing. To date, the institute has survived on philanthropy, grants, and some institutional support—a piecing together of financing that can hardly be viewed as a sustainable model.<sup>20</sup>

Meier adds, however, that Mount Sinai has chosen to provide support for the palliative care program because patients who receive services under it have shorter lengths of inpatient stay and lower pharmacy costs. Studies have shown that subsidizing the salaries of the palliative care interdisciplinary team saves money in other areas, she points out.<sup>21</sup>

Admittedly, there are no clear definitional lines between hospice and palliative care, which NHPCO acknowledged in 2000 when it changed its name from the National Hospice Organization, founded in 1978, to the National Hospice and Palliative Care Organization.<sup>22</sup> (Palliative care originally was a hospital-based model, and its leadership still comes largely from the hospital sector, but the term seems to have expanded to apply to other settings, including the home.) To those who receive, provide, and pay for services to address advanced illness, the term that is used may not be as important as the quality of life that is achieved and the cost resources that are allocated. From a policy standpoint, access to a broader benefit may well depend upon how well advocates of a new advanced-illness care model are able to document that it would have a positive effect on patients' quality of life and be a cost-effective approach for public and private insurers.

In linking services to payment, some point to the federal government's 1996 addition of a new diagnosis code for palliative care to the *International Classification of Diseases, 9<sup>th</sup> Revision, Clinical Modification*, to enable hospital coders to indicate that palliative care is provided to a dying patient during a hospital stay. The code is for research, not payment, so it does not provide incentives for hospitals to provide palliative care. Moreover, those, such as Meier, who back a comprehensive, integrated model

of palliative care object to the limitations that one code denotes. The Center to Advance Palliative Care would like to see development of “a code for an extended visit in an office, in a hospital, or in a nursing home for planning end-of-life care (to be paid with appropriate limits on the frequency of use for any one patient).”<sup>23</sup>

Addressing Medicare inpatient payment policy, Charles F. von Gunten, M.D., Ph.D., and several colleagues recently suggested adjusting “hospital payments to include essential palliative care services for hospitalized patients in pertinent diagnosis-related groups.” Rejecting a new DRG for palliative care because it would label patients as “palliative” rather than identify their needs, they present the following argument:

When looking at contemporary patterns of hospitalization, it is clear that large numbers of patients are admitted because of complications of advanced progressive chronic illnesses that are incurable and will ultimately contribute to their death. It is time to acknowledge this, define the best approaches, and make the relief of suffering and the provision of palliative care an explicit part of reimbursed hospitalization for relevant DRGs under Medicare.<sup>24</sup>

## QUALITY OF CARE, QUALITY OF LIFE

### The SUPPORT Study and a Change of Course

Whether the term or concept is “hospice,” “palliative care,” or something else, such as “transition management,” recognizing and enhancing the patient’s quality of life is a major feature. The major work on quality of care and quality of life consists of the “Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment” (SUPPORT) and a companion study, “The Hospitalized Elderly Longitudinal Project” (HELP). Initiated in the early 1980s, SUPPORT, developed by Joanne Lynn, M.D., and William Knaus, M.D., centered on

diagnoses that were common, caused high mortality, engendered important decisions during hospitalizations (a consideration that eliminated end stage renal failure), and had fairly stable treatment possibilities so that prognostic estimates would be expected to be fairly stable over the length of the study (a consideration that eliminated HIV/AIDS). Severity criteria were set so that patients’ average six-month survival would be 50 percent. Selected diagnoses included acute respiratory failure, COPD, CHF, coma, cirrhosis, advanced colon or non-small cell lung cancer, and multi-organ system failure, with sepsis or malignancy.<sup>25</sup>

By the end of 1999, SUPPORT and HELP had produced extensive data, including 67 papers published in peer-reviewed journals, on improving care of those with the diagnoses under study. Additional papers on end-of-life care were published in 2000, including one on why “an intervention intended to improve decision-making was completely ineffectual.”

SUPPORT's thesis was that a patient's course of care was the result of interaction between the person's illness and the decisions—largely made by physicians—about that care, so that improving decision making at the patient level would enhance both the process and the outcome for the patient. Lynn and nine co-authors concluded that

SUPPORT's intervention may have failed to have an impact because strong psychological and social forces underlie present practices. System-level innovation and quality improvement in routine care may offer more powerful opportunities for improvement.<sup>26</sup>

The conclusion that “the course of care may be determined largely by pre-existing routine, that patient-centered decision-making is often difficult to implement, and that improving the experience of patients might best be achieved by changing institutional and professional routines”<sup>27</sup> seems to be guiding experts in end-of-life care now. There is an ongoing reexamination of “the institutional and professional routines” of those who care for persons with advanced illness (whether the providers are primary-care practitioners or specialist physicians) and development of new models to reform those routines.

### Clinician Problems and Ways to Address Them

The study by the Mount Sinai Center to Advance Palliative Care indicates that many clinicians (a) “are uncomfortable talking to their patients about the inability of contemporary medicine to achieve cure or remission of their conditions”; (b) “do not manage pain well” and may have difficulty in managing certain other symptoms (such as “shortness of breath, anxiety, depression, nausea, and vomiting”); and (c) “are rarely able to facilitate effective grieving and bereavement for both dying patients and their families.”<sup>28</sup> Because these problems obviously have an adverse impact on the quality of life of the clinicians' patients, the authors recommend certain actions:

- That DHHS modify the Medicare conditions of participation for hospitals, nursing homes, and home health agencies and that the Joint Commission on Accreditation of Healthcare Organizations strengthen its standards for hospitals and other organizations under its purview to “create an environment in which palliative care is widely understood and practiced.” That the emphasis be on desired outcomes rather than on the means by which the outcomes are achieved. That exposure to standardized end-of-life educational programs for physicians and nurses should be strongly encouraged or required.
- That the National Forum for Quality Measurement and Reporting assure that its measures of hospital quality are consistent with those developed by the NHPCO for Medicare hospice use.
- That best practices in the field be identified and disseminated.
- That Medicare quality improvement organizations (formerly professional review organizations) “include at least one expert in palliative

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care on their boards” or have at least one member of the board attend a recognized palliative-care training program. That the CMS Practicing Physicians Advisory Council and Medicare carrier advisory committees also include experts (or in the latter case, train persons) in palliative care. That CMS advisory committees be evaluated in terms of whether palliative-care experts should be added.<sup>29</sup>

The National Consensus Project on Quality Palliative Care is in the process of drafting a document on norms and standards for palliative care and establishing a methodology for diffusion, review, and feedback on the document. A coalition of five organizations—the American Academy of Hospice and Palliative Medicine, Center to Advance Palliative Care, Hospice and Palliative Nurses Association, Partnership for Caring, and NHPCO—the project has an 18- to 24-month timetable.

### Various Collaborations

In the mid-1990s, the American Geriatrics Society developed “domains” for measuring the quality of care provided to persons at the end of life. Among them were physical and emotional symptoms, support of function and autonomy, advance planning, type of care near death (in terms of the site of death, cardiopulmonary resuscitation, and hospitalization), patient and family satisfaction, global quality of life (patient’s assessment of overall well-being), family burden, survival time, provider continuity and skill, and bereavement.<sup>30</sup>

Various efforts are now underway to define quality in end-of-life care. The Outcomes Forum—a joint effort of NHPCO and the National Hospice Work Group—is piloting some outcome measures for hospice that target “safe and comfortable dying,” “self-determined life closure,” and “effective grieving.”<sup>31</sup> For another example, the United Hospital Fund is partnering with RAND’s Institute for Healthcare Improvement on the Palliative Care Quality Improvement Collaborative. The collaborative is working with 21 hospitals, nursing homes, hospices, and home health agencies “to improve each organization’s ability to care effectively for persons with advanced chronic illnesses and those at the end of life.” The project is targeting pain reduction in palliative-care patients, improved advance-care planning, better continuity of care between hospital and nursing home, and better follow-up on referrals for hospice care, through a process of goal identification, definition of practices to be changed, and quantifiable measurement of the effectiveness of changes made.<sup>32</sup>

RWJF has been prominent in funding at least a score of initiatives aimed at improving end-of-life care, including “Last Acts,” a national coalition of organizations involved in education, discussion, collaboration, and dissemination of information to improve services for people who are dying and their families.<sup>33</sup> Numerous other charitable and voluntary organizations also are working in the field.

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## Some Models

Renewed interest in improving the care of persons with chronic illnesses, particularly those with prognoses of short life expectancies, has stimulated the development of various care models. The Medicare Payment Advisory Commission (MedPAC) included a chapter on "Care for People at the End of Life" in its 1998 *Report to the Congress: Context for a Changing Medicare Program*, which reviewed some innovative models. The chapter was innovative in itself, because it represented the commission's first treatment of the topic. In presenting the chapter, MedPAC indicated:

There is widespread agreement that the quality of care provided at the end of life is poor. Many studies have found that people do not get the care they want and that many suffer from high levels of pain due to miscommunication. Studies also suggest that current payment policies fail to provide adequate incentives for the provision of palliative care.<sup>34</sup>

MedPAC cited the United Hospital Fund's Hospital Palliative Care Initiative, a precursor of the fund's Palliative Care Quality Improvement Collaborative (in partnership with RAND). The initiative was aimed at improving hospital services for persons who were dying and to encourage hospital-based palliative-care programs. It also highlighted the Congestive Heart Failure Case Management Program sponsored by Kaiser Permanente in Bellflower, California; the multidisciplinary OPTIONS program developed by the HealthCare Partners Medical Group in Los Angeles; and the Complex Case Management Program operated by Franklin Health, Inc., for very ill persons enrolled in managed care plans.

MedPAC also featured MediCaring, a more comprehensive system of managed care that was proposed by Lynn at the Center to Improve Care of the Dying, formerly at George Washington University and now at RAND. Featured in a December 1997 National Health Policy Forum meeting, MediCaring focuses on supportive community-based services that take into account a patient's personal preferences, the family's need for counseling and support, and the patient's medical needs.<sup>35</sup> It is based on the premise that good care of the dying calls for interdisciplinary teams, continuity and coordination of care, integration of diverse services delivered in a variety of settings, and changes in the orientation of providers.

A model under development at Sutter VNA and Hospice relies on home-based "transition management" of high-risk, chronically ill patients, in order to give them better continuity of services until they are eligible and ready for hospice. If the patients do not elect the hospice benefit or if their referral is refused, transition management can manage their care. Designed to fill the gap between the inpatient hospital setting and hospice care (generally at home), transition management draws upon home-care services "to help patients with advanced chronic illness transition smoothly from acute life-sustaining treatment toward supportive care at home."<sup>36</sup> Brad Stuart, M.D., medical director of Sutter VNA and Hospice indicates:

**Renewed interest in improving the care of persons with advanced illnesses has stimulated the development of various care models.**

Although many hospice providers (including myself) have tried unsuccessfully to help hospice to expand into this role, home care's potential has not yet been explored. Many patients with advanced illness are already on home care, yet still need medical services that hospice cannot easily provide. Hospice will continue to grow, but home care will probably be where "transition management" will be based, if regulations are changed to allow it.<sup>37</sup>

Stuart explains that a Medicare-certified home health agency provides home health services to patients with late-stage illness (or to any other patients) if they meet the following eligibility criteria: the patient must be recovering, must be home-bound, and must have a skilled nursing need. The agency cannot provide hospice services unless it is separately licensed as a Medicare-certified hospice. (Sutter is both.) However, home health can follow the patient until he or she no longer has a skilled need, at which point the agency has to discharge the patient. The patient may be sufficiently ill to require re-hospitalization or to die within weeks to months, but may not be "hospice-appropriate." The reasons for lack of entry into hospice include having a noncancer diagnosis for which prognosis is uncertain, not being willing to give up all life-sustaining care, and associating "hospice" with dying.

Just as there is a chasm between "medical model" inpatient treatment and the Medicare hospice benefit, there is a chasm between home health and hospice, Stuart indicates. "Home health and hospice regulations are purposely designed to make these two service lines entirely discrete and discontinuous. Between them lies a chasm of unfilled need."

In addition, a collection of exemplary hospital-based models appears in *Pioneer Programs in Palliative Care: Nine Case Studies*, sponsored by RWJF and Milbank Memorial Fund. In the report, clinicians at hospitals in Alabama, Illinois, Massachusetts (two), New York (two), Ohio, Pennsylvania, and Virginia describe the establishment of palliative-care programs in their institutions.<sup>38</sup>

The developers of some of the models have been urging Congress and CMS to develop a demonstration project so that they can test their approaches. This would mean waiving Medicare—and possibly Medicaid—regulations, with the goal of making care of those with advanced illness more continuous and bridging acute and end-of-life care.

## COST AND PAYMENT CONSIDERATIONS

### Medicare

In 2000, the last year for which data are available, the Medicare program spent \$224 billion for health services.<sup>39</sup> While the Alliance for Aging Research has estimated that Medicare beneficiaries in the last year of life account for over one-fourth of total Medicare expenditures,<sup>40</sup> the percentage of the total Medicare Part A budget spent on hospice (an

**Just as there is a chasm between "medical model" inpatient treatment and the Medicare hospice benefit, there is a chasm between home health and hospice.**

estimated \$2.8 billion, or 1.3 percent) is quite small. (The estimated amount for the limited Medicare skilled-nursing-facility [SNF] benefit was \$10.6 billion, or 4.9 percent. Home health accounted for \$4.6 billion, or 2.1 percent.) HCFA has indicated that, by percent of outlays, free-standing hospice accounts for 55.5 percent, hospital-based programs 17.2 percent, SNFs 0.8 percent, and home health agencies 26.5 percent. A 1998 comparison of average charges per day in different settings indicated \$2,177 for hospital inpatient facilities, \$482 for SNFs, and \$113 for hospice services.<sup>41</sup> As noted earlier, only a small percentage of palliative-care services are paid for under Medicare, because, by its very nature, palliative care blurs Medicare's structured payment boundaries.<sup>42</sup>

A lot of the research on end-of-life care has centered on studies comparing expenditures for persons who elect hospice with those for people who stay with intensive approaches, the health costs of the last year of life with those of previous years, the health costs of persons 85 years of age and older with those of people 65 to 84 years of age, the health costs of one diagnosis with that of another, and similar studies. Because Medicare is the major payer of end-of-life care, whether in the acute or post-acute setting, most of the studies use Medicare data, although some work has been done on Medicaid and private insurance as well.

As indicated in other parts of this background paper, Medicare, as the major payer of and model for hospice care, is the target of various criticisms of the way it funds services for those with advanced illness, including those who are dying. On one hand, the program is criticized because of the restrictions on the hospice benefit, primarily the requirements to waive standard Medicare benefits and to have a life expectancy of less than six months. On the other hand, it is criticized for its incentives for intensive acute services and its silos of post-acute services that act as barriers to a seamless continuum in the last stages of life.

In recognition of the current debate over a Medicare outpatient prescription-drug benefit, it is important to note the issue's relevance to hospice or palliative care. Because pharmaceuticals are so important to the treatment of persons with advanced chronic illness, especially for pain control and symptom management, they are central to the debate over enactment of a prescription-drug benefit. While drugs are covered, along with necessary medical supplies, under the capitated Medicare hospice payment, they compete with work force costs, short-term inpatient stays, and counseling for a share of the payment, according to Tom Ault and Michael Hash, who recently analyzed Medicare prescription-drug coverage issues in end-of-life care for Last Acts.<sup>43</sup>

## Medicaid

Federal and state Medicaid spending for health services (without the State Children's Health Insurance Program) totaled \$202 billion in 2000.<sup>44</sup>

**Medicare is criticized for its incentives for intensive acute services and its silos of post-acute services that act as barriers to a seamless continuum in the last stages of life.**

A breakdown for 1998, the last year for which Medicaid hospice information is available, indicates that hospice payments were \$325 million, or 0.2 percent of total spending. ("The federal share of Medicaid's hospice spending was \$185.7 million, or 57.1 percent of the total FY 1998 Medicaid hospice payments," according to HCFA's Division of Medical Statistics, as quoted on the Web site of the National Association for Home Care.) Forty-four states offered the hospice option.<sup>45</sup>

As with other health services in this federal-state program, there was considerable variation in the duration, amount, and scope of services, according to Jane Tilly and Joshua Wiener, who analyzed Medicaid end-of-life care for Last Acts. For example, "in 1998, the total number of Medicaid hospice patients ranged from only 4 in Arizona to 7,583 in Florida."<sup>46</sup> They identify three major payment issues:

First, according to most nongovernmental experts, the current hospice rate for routine home care is too low to enable hospices to provide the most advanced types of pain relief, such as chemotherapy and radiation treatments. Another reason the payment level is considered low is that hospices tend to serve patients in the last few weeks before death when care can be particularly expensive and the payment rates do not adequately adjust for case mix.

Second, payment rates are based on very old cost experience that no longer reflects current expenses. Data from hospice demonstration projects conducted during the early 1980s were used to calculate the initial Medicare hospice rates, upon which both current Medicare and Medicaid rates are based [The rates are periodically increased by an update factor.]...

Third, the way in which Medicaid pays nursing homes for hospice patients causes a great deal of confusion. In these circumstances, the hospice is the primary caregiver for the resident and the nursing home supplies room and board....State Medicaid programs must pay at least 95 percent of the nursing home rate for room and board directly to the hospice, which in turn pays the nursing home....Reportedly, nursing homes rarely accept less than 100 percent of the Medicaid room and board payment. As a result, hospices generally pay full room and board costs, which means that they suffer a financial loss.<sup>47</sup>

## Private Insurance

Most private insurance plans offer hospice benefits, according to a 2000 study for DHHS by The MEDSTAT Group. The study used the organization's proprietary MarketScanR database, which includes approximately 70 employers and 200 insurance carriers and claims administrators (covering about four million privately insured persons). It showed that 84.4 percent of indemnity plans, 90.0 percent of point-of-service (POS) plans, and 100 percent of preferred-provider-organization (PPO) plans offered a hospice benefit.

**Most private insurance plans offer hospice benefits.**



However, when characteristics of the benefit were broken down by indemnity, POS, and PPO, there was a great deal of variation. While the great majority required precertification, only 55.6 percent of the indemnity, 66.7 percent of the POS, and 20.0 percent of the PPO plans included a specified definition of terminal illness. Deductible and coinsurance provisions varied significantly as well. Coverage for hospital-based hospice services ranged from 81.5 percent of indemnity and 77.8 percent of POS to only 40.0 percent of PPO plans, while in-home hospice coverage was somewhat over or a little under 70 percent for all three types of plans. In terms of covered services, the indemnity and POS plans were more liberal than the PPO plans, across the board.<sup>48</sup>

While cost and payment considerations often override other issues in health care debates, quality and cost seem to be on fairly even footing in discussions on services for patients with “advancing” advanced illness, who are near the end of life. While the field of end-of-life care was criticized for years for not having hard data, public and private organizations now generate a steady flow of studies and analyses, many funded by philanthropy. Whether the aging of the population or attention to a continuum of services is bringing special urgency to the development and acceptance of compassionate, cost-effective treatment plans for persons with chronic advanced illness, the bell seems to be tolling for patients, providers, payers—and policymakers—alike.

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## ENDNOTES

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diagnostic categories spelled out in the NHPCO 'Medical Guidelines for Non-Cancer Disease.' Later on, the RHHI medical directors met again to establish parameters to measure 'clinical decline' so that this could be documented by hospice clinicians in a standardized way. Both of these sets of negotiations were carried out with CMS' blessing. Current policy is that 'clinical decline' must be documented in the clinical record in order for a hospice patient to be re-certified for any Medicare hospice benefit period beyond the first one. Congress's recent legislative language (passed at the urging of the hospice industry) states that the patient is eligible as long as the primary physician says he or she is eligible. CMS made it clear that the agency would not tell the RHHIs to change their policy for approving or denying claims because of this legislation. Therefore, a patient cannot be kept on the benefit if he or she is clinically stable or improving for long periods, even if the patient's physician insists the patient is 'terminal.'" (In a May 24, 2002 letter to NHPCO, CMS Administrator Thomas Scully stated that "Medicare regulations use the terms 'expectancy' and 'if the terminal illness runs its normal course' ...to indicate that it is entirely possible for hospice services to be needed for more than a six-month period. The Medicare program recognizes that terminal illnesses do not have entirely predictable courses. In further recognition of the difficulty in making exact predictions, physicians certifying Medicare patients for hospice are expected only to use their best 'clinical judgment regarding the normal course of the individual's illness.' ")

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