



IMPORTANT QUESTIONS FOR HOSPICE IN THE NEXT CENTURY

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**U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy**

Office of the Assistant Secretary for Planning and Evaluation

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This report was prepared under contract #100-97-0010 between the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy and the MEDSTAT Group. For additional information about this subject, you can visit the DALTCP home page at <http://aspe.hhs.gov/daltcp/home.htm> or contact the ASPE Project Officer, Jennie Harvell, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. Her e-mail address is: jharvell@osaspe.dhhs.gov.

The goal of ASPE's Medicare Hospice Benefit study is to provide general information on the role of the Medicare hospice benefit and more specific information about how end of life care is provided to institutionalized beneficiaries. Six reports have been produced from this study:

Synthesis and Analysis of Medicare's Hospice Benefit: Executive Summary and Recommendations (report 1) briefly summarizes the methods used for each report and the findings and recommendations that emerged from each of the following reports under this study.

Important Questions for Hospice in the Next Century (report 2), synthesizes the literature related to the Medicare hospice benefit and summarizes discussions with key informants on the use of hospice in nursing homes.

Medicare's Hospice Benefit: Use and Expenditures (report 3), analyzes Medicare utilization and payments for hospice users in 1996.

Use of Medicare's Hospice Benefit by Nursing Facility Residents (report 4), examines differences in hospice utilization and expenditures as a function of when nursing facility residents started using hospice services (i.e., before or during a nursing home stay).

Outcomes and Utilization for Hospice and Non-Hospice Nursing Facility Decedents, (report 5) compares pain management and types of services provided to dying nursing home residents receiving hospice compared to other dying residents who did not receive hospice.

Hospice Benefits and Utilization in the Large Employer Market (report 6), reports on how hospice services are provided by 52 large employers and used by their employees, and identifies alternative approaches to designing and administering hospice benefits.

All of these reports are available on ASPE's Office of Disability, Aging and Long-Term Care Policy website (<http://aspe.hhs.gov/daltcp/home.htm>). Copies can be mailed out by contacting the Office of Disability, Aging and Long-Term Care Policy, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C., by fax at 202-401-7733, or by email at DAITCP2@osaspe.dhhs.gov.

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Appendices

The MEDSTAT Group

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Important Questions for Hospice in the Next Century

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TABLE OF CONTENTS

EXECUTIVE SUMMARY.....		III
ACRONYMS		IX
1. INTRODUCTION		1
2. THE MEDICARE HOSPICE BENEFIT.....		3
HISTORY OF THE BENEFIT		3
TODAY’S MEDICARE HOSPICE BENEFIT		7
3. MEDICARE HMO ENROLLEES AND HOSPICE ELECTION.....		11
4. MEDICAID’S HOSPICE BENEFIT.....		13
5. EMPLOYER-BASED HOSPICE BENEFITS.....		16
6. MEDICARE HOSPICE BENEFICIARIES		17
MEDICARE HOSPICE BENEFICIARIES		17
MEDICARE HOSPICE BENEFICIARIES IN NURSING FACILITIES.....		20
7. HOSPICE PROVIDERS		21
VOLUME AND GEOGRAPHIC DISTRIBUTION		21
NURSING FACILITIES WITH MEDICARE HOSPICE BENEFICIARIES		22
CONTRACTUAL RELATIONSHIPS BETWEEN HOSPICES AND NURSING FACILITIES		23
8. UTILIZATION OF THE MEDICARE HOSPICE BENEFIT		25
HOSPICE LENGTHS OF STAY.....		25
OFFICE OF INSPECTOR GENERAL RELATED INVESTIGATIONS.....		25
9. MEDICARE EXPENDITURES AND HOSPICE CARE.....		31
SPENDING ON HOSPICE.....		31
END-OF-LIFE COSTS AND MEDICARE’S HOSPICE BENEFIT: LESSONS FROM THE LITERATURE		32
10. ISSUES REGARDING ACCESS TO THE MEDICARE HOSPICE BENEFIT.....		38
GEOGRAPHIC ACCESS.....		38
MINORITY ACCESS		40
ACCESS FOR PERSONS WITHOUT CAREGIVERS OR ELIGIBLE FOR MEDICARE SKILLED NURSING FACILITY CARE.....		41
ACCESS TO HOSPICE FOR AIDS PATIENTS		42
ACCESS BY DIAGNOSIS - PROGNOSIS IN NON-ONCOLOGIC DISEASE MODELS		43
11. RESEARCH ON THE QUALITY OF HOSPICE CARE.....		47
PATIENT OUTCOMES AND FAMILY OUTCOMES		48
12. THE DYING EXPERIENCE OF NURSING FACILITY RESIDENTS		53
13. RECENT END-OF-LIFE INITIATIVES AND DEMONSTRATION PROJECTS		55
14. DISCUSSIONS WITH INDUSTRY AND STATE REPRESENTATIVES		58

INDUSTRY AND STATE CERTIFICATION REPRESENTATIVES	59
STATE MEDICAID PROGRAM OFFICIALS	64
15. A SUMMARY OF ISSUES RELATED TO THE MEDICARE HOSPICE BENEFIT AND ITS USE IN A NURSING FACILITY	66
16. CONCLUSION.....	71
REFERENCES	74

TABLES AND FIGURES

Table 1. Balanced Budget Act of 1997: Provisions Related to Hospice Services	82
Table 2. Hospice Reimbursement Rates From 11/01/83 - 9/30/98.....	84
Table 3. Medicare Hospice Payments and Use by Level of Care, 1997	85
Table 4. Medicare Hospice Payments and Use by Type of Hospice Affiliation, 1997	86
Table 5. Demographics of Hospice Beneficiaries by Type of Hospice Affiliation, 1987-1990	87
Table 6. Characteristics of Discharged Hospice Patients in the 1994 and 1996 National Home and Hospice Care Surveys.....	88
Table 7. Number of Medicare-Certified Hospices by Type of Provider Affiliation.....	89
Table 8. Lengths of Stay by Hospice Provider Affiliation, 1987-1990.....	90
Table 9. Average Number of Visits per Week by Type of Service.....	91
Table 10. Adjusted ¹ Medicare Reimbursement Saved per Dollar of Hospice Expenditure by Length of Enrollment and Month ³	92
Table 11. Adjusted Medicare Part A Reimbursement Saved per Dollar of Hospice Expenditures, by Length of Enrollment and Month, 1992*	93
Table 12. Adjusted Medicare Part A and Part B Reimbursement Saved per Dollar of Hospice Expenditures, by Length of Enrollment and Month, 1992*	94
Figure 1. Number of Medicare and Non-Medicare Hospice Patients	97
Figure 2. Number of Medicare and Non-Medicare Certified Hospice Providers	98
Figure 3. Distribution of Medicare Benefit Payments by Type of Service, FY 1997	99
Figure 4. Comparison of Rate of Growth to Projected Rate of Growth in Medicare Benefit Payments per Enrollee by Type of Service.....	100

Appendix A – Literature Review Methodology

Appendix B – National Hospice Organization’s Sample Contract

Appendix C – Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases and Hospice Enrollment Criteria for End-Stage Dementia Patients

Appendix D – Wisconsin State Guidelines for Medicare Hospice Care Provision In the Nursing Home

EXECUTIVE SUMMARY

This work was conducted under the auspices of the Office of the Assistant Secretary for Planning and Evaluation (ASPE) as part of a larger ASPE study titled “Synthesis and Analysis of Medicare’s Hospice Benefit.” The ASPE study goal is to inform policy makers about the role of the Medicare hospice benefit, in general, and specifically about its contribution to end-of-life care for institutionalized beneficiaries.

This report contains six main sections. The first focuses on hospice coverage policies and reviews the history of the Medicare hospice benefit, its current structure, and its influence on care of the dying. Also included is a description of hospice care covered by other insurers including state Medicaid programs and private employers. The second section provides a literature review of the issues surrounding access to hospice and the provision of hospice care in nursing facilities. This is followed by a brief description of current end of life initiatives to improve care of the terminally ill. The next section summarizes discussions with hospice and nursing facility providers, federal and state certification surveyors, and state Medicaid officials regarding overlapping areas in caring for the terminally ill. Last, section 6 summarizes the issues and provides a framework for the four subsequent reports in this study, Medicare’s Hospice Benefit: Use and Expenditures, Use of Medicare’s Hospice Benefit Use by Nursing Facility Residents, Outcomes and Utilization for Hospice and Non-Hospice Nursing Facility Decedents, and Hospice Benefits and Utilization in the Large Employer Market.

Congress established the Medicare hospice benefit as both a cost-containment mechanism to limit the program’s high costs for beneficiaries in their last year of life and a quality improvement tool to improve care for the dying. Medicare pays hospices a capitated per diem in exchange for delivering almost all services needed in a day to treat the patient’s terminal illness. Excluded from this payment are room and

board costs for a beneficiary who lives in a nursing facility and any costs for attending physicians who are not hospice staff. Hospices coordinate the care of the terminally ill acting as a gatekeeper to manage treatment of the terminal condition. They specialize in pain and symptom management and provide greater levels of aide services than otherwise available under Medicare. In addition, Medicare's hospice benefit also covers counseling and bereavement services for beneficiaries' family members.¹

Medicare is the primary payer for hospice services covering 77 percent of all hospice expenditures. The rest is paid for by Medicaid (4 percent), private insurance (12 percent) or other sources (7 percent). In 1997, Medicare covered 374,723 hospice enrollees at a cost of \$2.02 billion (MedPAC, 1998). Average length of coverage was 50 days, although that varied by provider type. For instance, beneficiaries served by free-standing hospices had the longest episodes (53 days per person) in contrast to those treated in skilled nursing facilities (SNFs) whose episodes of care lasted only 39 days per person, on average (HCFA, 1998a). Most hospice enrollees live at home or in a private residence, but an estimated 12 percent may be nursing facility residents (Gage, 1998).

While hospice is a relatively new Medicare benefit, it has been studied extensively. Early research, which focused on the benefit's implementation and use, found cancer patients are the most common hospice users (Mor and Kidder, 1985), although people with other terminal illnesses also are choosing hospice as the program matures (Banaszak-Holl and Mor, 1996). The National Hospice Study evaluated the benefit's cost effectiveness and found hospice achieved program savings (Kidder, 1992). These lower patient costs were due to patients having lower inpatient hospital costs, particularly in the last months of life. A more

¹ Although health maintenance organizations may cover some outpatient drugs, this benefit varies by plan and generally is more limited than the pain medications covered under hospice.

recent study which updated the NHS arrived at similar conclusions although this study focused only on cancer patients (Lewin, 1995).

High-cost hospice users – and the adequacy of Medicare’s payment rates for their care—were the focus of yet another study. This study showed that higher expenses were due to longer enrollment periods, not higher daily costs (HCFA, 1993). As a result, the Secretary concluded that the per diem payment rates were adequate for covering this population because they adjusted for volume.

Another study which looked at coverage policies, analyzed the effect of removing the 210-day lifetime limit on Medicare hospice coverage (Banaszak-Holl and Mor, 1996). This study showed that for most cases, length of use did not go up substantially without the limit. However, patients with illnesses other than cancer were most likely to gain from the longer allowable enrollment periods because they tended to have longer episodes of hospice care.

In addition to these national program studies, hospice use is also profiled regularly by the National Center for Health Statistics (NCHS) (NCHS, 1998). These ongoing surveys, which describe hospice use by all insured populations, underscore the important role Medicare plays in covering hospice care. Almost 80 percent of all hospice users are 65 or older, suggesting these probably are Medicare-covered enrollments.

In 1998, the Office of the Inspector General (OIG) in the Department of Health and Human Services (HHS) raised questions about the role of the hospice benefit for dually covered Medicare beneficiaries living in nursing facilities. While Medicare is the primary payer when both programs cover a benefit, the state Medicaid program covers room and board for the nursing facility resident in addition to the Medicare-covered hospice services. The OIG was concerned about the financial relationships between hospices and nursing facilities. Better information was needed about the role of the Medicare hospice

benefit, in general, and its contribution to end-of-life care for institutionalized beneficiaries. Specifically, the OIG wanted to know if hospice changed the cost or quality of services provided to dying beneficiaries in nursing facilities. Also at issue was Medicaid's role in covering these nursing facility residents. These matters raised additional questions, including how other payers, like Medicaid and private insurers, cover their terminally ill populations and whether their hospice patients had to waive other use of hospital, skilled nursing facility and home health services as required by Medicare (Program manuals, section 144.4).

This study of Medicare's hospice benefit addresses these and other questions. Funded by the Office of the Assistant Secretary for Planning and Evaluation (ASPE), this report describes Medicare hospice eligibility, coverage and payment policies, and selected Medicaid (Title XIX) and private insurance programs. It also presents information on costs, utilization, and quality of care in Medicare's hospice program. These materials are supplemented with anecdotal reports from hospice representatives, nursing facility providers, and state Medicaid officials. These discussions focused on Medicare's hospice benefit in general, and issues around coordinating the staff, services, and payments for hospice enrollees living in nursing facilities. In addition, issues raised by program survey officials are included to describe the problems in assessing quality of care for hospice patients who live in nursing facilities. For example, because the goals of curative and palliative treatment differ, malnourished residents in a nursing facility may be perceived as either neglected or as exercising their right to refuse food, depending on whether they are hospice enrollees.

Hospice's influence on the costs and quality of care for dying Medicare beneficiaries is still being debated. Hospice may well save Medicare dollars, but because of inadequate study designs—including the lack of adequate control for selection bias – accurate estimates of savings are not available. Studies in the 1980s found few differences in the quality of life or symptoms measured at the end of life between hospice and non-hospice patients. The limited number of studies conducted since the 1980s appear to add very little

support to the arguments that hospice care is superior to conventional care for patient and family outcomes. However, the need for better measurement has become evident in the literature, and research efforts are now addressing this need. Further, the changing populations enrolling in hospice raise questions about whether study findings that are largely based on cancer patients are applicable to other terminally ill populations. No study has yet compared the processes and outcomes of care for hospice and non-hospice beneficiaries in nursing facilities. Such research, to the extent possible, is now being conducted as part of this study.

Key questions addressed in this study include:

- Who uses Medicare's hospice benefit? Has this population changed over time? Are enrollees in health maintenance organizations (HMOs) just as likely to use it as those in fee-for-service?
- How do Medicare's eligibility guidelines affect the types of terminally ill patients who enroll in hospice?
- How do nursing facility residents elect and use hospice? Are their choices affected by their institutional residency?
- Are there differences in resources used by residents who are on hospice versus terminally ill residents who are not enrolled?
- Are there differences in the processes of care and the outcomes (e.g., the quality of symptom management) of dying nursing facility residents who have elected hospice compared to those who have not?
- What can we learn from other hospice benefit programs?

This report is the first in a series which analyze Medicare's hospice benefit today and its use in nursing facilities. The other reports in this study for ASPE use Medicare administrative data to analyze total Medicare use and expenditures for hospice patients during, and in the 6 months prior to, enrollment in the

benefit in 1996 (Medicare's Hospice Benefit: Use and Expenditures). In addition, nursing facility data and Medicare Part A claims data from five states is examined to contrast the enrollees (Medicare's Hospice Benefit Use by Nursing Facility Residents) and expenditures, processes, and outcomes for hospice and non-hospice enrollees in nursing facilities (Outcomes and Utilization for Hospice and Non-Hospice Nursing Facility Decedents). And last, administrative data from employer-based insurance claims is used to compare differences in the benefits, use, and cost of covering hospice in the private sector (Hospice Benefits and Utilization in the Large Employer Market). Findings from these analyses will inform the policy debate regarding the provision of hospice care for different types of beneficiaries, including those in nursing facilities. Study conclusions and recommendations reflecting findings from these analyses and this literature review are forthcoming in the final report of this ASPE-funded study.

ACRONYMS

The following acronyms are used in this report.

AHCPR	Agency for Health Care Policy and Research
AIDS	Acquired Immune Deficiency Syndrome
ASPE	Office of the Assistant Secretary for Planning and Evaluation
BBA	Balanced Budget Act of 1997
CHF	Congestive Heart Failure
COPD	Cardiopulmonary Disease
COBRA	Consolidated Omnibus Budget Reconciliation Act of 1985
CPT	Current Procedural Terminology
FAST	Functional Assessment Staging Criteria
GAO	General Accounting Office
HAA	Hospice Association of America
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
HMO	Health Maintenance Organization
IOM	Institute of Medicine
MDS	Minimum Data Set
MedPAC	Medicare Payment Advisory Committee
NAHC	National Association for Home Care
NCHS	National Center for Health Statistics
NHHCS	National Home and Hospice Care Survey
NHO	National Hospice Organization
NHOPP	National Hospice Outcomes Planning Project
NHS	National Hospice Study
OBRA	Omnibus Budget Reconciliation Act of 1987
OIG	Office of the Inspector General
OSCAR	Online Survey and Certification Automated Record
RWJ	Robert Wood Johnson Foundation
SNF	Skilled Nursing Facility
TEFRA	Tax Equity and Fiscal Responsibility Act of 1982
VA	Department of Veterans Affairs

1. INTRODUCTION

Hospice offers palliative care to the terminally ill, focusing on managing pain and other symptoms related to that illness, rather than on providing curative treatments. Congress added a hospice benefit to the Medicare program in 1982 for beneficiaries with six months or less to live.² Beneficiaries who enroll in Medicare's hospice program waive their right to other inpatient and home health services although they may disenroll from hospice at any time. Still, the benefit is intended to provide better, more cost-effective care to dying beneficiaries.

Medicare's hospice benefit has had a dramatic effect on the provision of hospice care in the United States. Increases in the number of Medicare beneficiaries who elect hospice and the number of participating providers continue into the sixteenth year of the benefit's implementation, with Medicare now paying for 77 percent of all hospice care in the United States. Almost 18 percent of all elderly people who die are enrolled in hospice. Still, concerns abound that the structure of the Medicare benefit and its eligibility requirements may discourage access to hospice care for certain groups of dying persons, particularly those for whom accurate prognoses are difficult to make.

While most hospice is delivered in the community, nursing facility residents are increasingly enrolling in the benefit. The proportion of residents with non-cancer diagnoses who enroll in hospice has been growing although they are still proportionately less likely than cancer patients to choose hospice.

Despite the increased enrollments, nursing facility residents may still have limited access to hospice. According to anecdotal reports, access to hospice care in the nursing facility may have become more difficult since the Office of Inspector General (OIG) of the Department of Health and Human Services

² The hospice benefit was established under the Tax Equity and Fiscal Responsibility Act of 1982.

questioned the hospice lengths of stay and eligibility of beneficiaries residing in nursing facilities (USDHHS, 1997). In addition, facilities that do not contract with a participating hospice may not make the benefit available to their residents. Access is further contingent on the facility's encouragement of hospice use. And in the case of residents recently discharged from the hospital, nursing facilities have a financial incentive to encourage the beneficiary to use their SNF benefit instead of the hospice benefit. Access to providers also differs dramatically by state and region.

Hospice patients in nursing facilities also encounter other issues because the two types of providers deliver similar services but have very different treatment orientations. Hospice and nursing facility services need to be coordinated yet often lack the benefit of clear guidance and regulation at the federal and state levels. In fact, differences between hospice and nursing facility conditions of participation (and enforcement of such) heighten differences in staff perceptions of what is considered appropriate care. Although individual providers and surveyors seem to address many of these issues and differences, a regulatory and survey environment that fosters the nursing facility-hospice alliance does not yet exist.

Also at issue is the process for paying nursing facilities when dually-covered beneficiaries enroll in Medicare's hospice benefit but reside in a Medicaid-covered nursing facility bed. For these beneficiaries, Medicaid passes the nursing home payment to the hospice which then passes it through to the nursing facility. According to anecdotal reports, this method is problematic and overly burdensome for both hospice and nursing facility providers.

Another important question raised by the OIG is whether hospice costs for routine home care in the nursing facility are lower than when provided in the community (HHS, 1997). Currently, no data are available to examine the difference in hospice costs although hospices are required to submit cost report data for cost reporting periods beginning in 1999 (BBA, 1997). Nonetheless, the overriding question

relating to the provision of hospice care in nursing facilities—whether this care reduces costs and improves end-of-life care—has yet to be answered.

This report is the first in this study that considers how hospice is used by the general Medicare population, by nursing facility residents, and by private sector enrollees. This first report will summarize the existing published and anecdotal information on these issues while the remaining reports will present analyses of several data sources. First, this report provides an overview of Medicare, Medicaid and select private insurance policies for hospice coverage. Second, it provides a literature review of hospice use, payments and quality of care issues. Third, a brief description of other end of life initiatives is included. And last, discussions with providers, certification and statistics officials are summarized.

2. THE MEDICARE HOSPICE BENEFIT

HISTORY OF THE BENEFIT

Hospice was introduced as a Medicare benefit in 1982 under the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), about 10 years after hospice had emerged in the United States as a new type of formal service. The first standards for hospice care were formulated in 1974 by a committee of the International Work Group on Death and Dying (Kastenbaum, 1975). At about the same time, hospice also was being introduced in Canada, with the establishment of the Palliative Care Unit at Montreal's Royal Victoria Hospital (Mount, 1976). In 1977, the National Hospice Organization (NHO) was formed in the United States. It advocated for the hospice philosophy of care for the dying, educated the public, and provided a resource and structure for information exchange among the burgeoning number of hospices in this country.

Governmental initiatives and not-for-profit foundation funding bolstered the spread of hospices here. In 1978, the National Cancer Institute awarded grants to three hospices as demonstration projects to investigate the costs associated with care and to describe the actual manner in which care was provided to patients. Shortly thereafter, the Health Care Financing Administration (HCFA) was charged by Congress and the Carter Administration to initiate a research and demonstration study to examine the costs, benefits, and feasibility of having Medicare pay for hospice care. Existing hospice programs were invited to apply. Of 233 applicants, 26 hospices with diverse organizational arrangements were chosen (Greer et al. 1983; Mor et al., 1988; Mor and Masterson-Allen, 1987). The Robert Wood Johnson Foundation (RWJ) and the John A. Hartford Foundation also supported this research project. The W.K. Kellogg Foundation in 1981 awarded a grant to the Joint Commission on the Accreditation of Hospitals to investigate the status of hospice in the United States and to develop standards for accreditation (McCann, 1983).

Congress in 1982 introduced hospice into the Medicare program as a cost-savings provision after a Congressional Budget Office study asserted that hospice would result in sizable savings over conventional hospital care (Mor and Masterson-Allen, 1987). Because the benefit was created so quickly and represented a new area of health care, two special provisions were included in the legislation. First, a sunset provision stipulated that without congressional intervention, the law would expire in November 1986. Second, an evaluation of the impact of the benefit was mandated.

Initially, Medicare's hospice benefit consisted of three benefit periods with a lifetime limit of 210 days of coverage. Patients who lived longer but who still required hospice services were to be cared for by the hospice without charge to Medicare or the patient as a condition of providers' participation in the program. Further, if patients were unable to pay for services, the hospice was not allowed to discharge them

on that basis (Hoyer, 1998). Putting the providers at risk for delivering services after the 210th day gave them an incentive to enroll only seriously ill beneficiaries despite the difficulties of predicting survival.

The benefit was limited to 210 lifetime days for several reasons. First, this limit was consistent with results from the National Hospice Study (NHS), which found that more than 95 percent of the 15,000 patients in the study were on hospice for fewer than 210 days. (Fully 90 percent of the participants had a primary diagnosis of cancer, and thus the shorter length of stay is consistent with hospice care for cancer patients.) Secondly, hospice was cost effective for shorter episodes (those lasting up to 100 days) but not for longer ones. That is, savings associated with reduced hospital use in the last weeks of life were offset by the cost of additional services in longer hospice episodes. Recognizing the difficulty of making a prognosis of six months or less, Congress later repealed the 210-day limit for services furnished on or after Jan 1, 1990. Four benefit periods replaced the 210 days: The first two were limited to 90 days each and the third period to 30 days, while the fourth period was unlimited. However, beneficiaries could have no more than four benefit periods.

TEFRA 1982 hospice legislation also established four, graduating levels of hospice care which are still used today. These four levels include routine home care, continuous home care, inpatient respite care, and general inpatient care (see page 10 for a complete description of these levels.) Most covered days are routine home care days except for the days when the enrollee has a higher level of hospice care coverage.

To manage the patient's care, TEFRA also required an interdisciplinary team. That team includes a physician, registered nurse, social worker, and pastoral or other spiritual counselor. Collectively the team— together with the patient, the patient's family, and the patient's primary or attending physician—assesses, coordinates, and provides the appropriate palliative and supportive care to hospice patients and their families. Additionally, the hospice team helps establish the patient's plan of care, providing or supervising

hospice care and services, and periodically reviewing and updating the care plan. The team also manages the patient's discomfort and symptom relief. Implicit in the interdisciplinary team concept is the idea that team members will have stable relationships among themselves vis à vis the patient and thereby enhance continuity of care. Unlike multidisciplinary care where each area decides what is best practice in its own discipline, everyone on the hospice interdisciplinary team offers input on all issues facing a patient.

The original hospice legislation not only required hospices to use volunteers, but also mandated records on their use, cost savings, and the expansion of care and services achieved by doing so. Volunteers were considered key to the hospice movement. Although the number of volunteers hospices used varied markedly, proponents thought that their continuous involvement was important to preserving the hospice philosophy. The final hospice regulations contained a requirement that volunteer efforts should account for at least 5 percent of total hospice personnel efforts. This requirement was added because HCFA believed the intent of the law was to develop standards to monitor the level of volunteer activity so to prevent substantial diminution of the proportion of volunteers.

The Title XVIII hospice benefit was designed so that most services were provided in the patient's home. To support this focus, TEFRA contained a 20/80 provision, which limited a provider's total inpatient care days to 20 percent of all care delivered during a year by a given hospice. This provision did not apply to each individual, since some patients might need to stay far longer in an inpatient setting. The provision was intended to control costs, prevent the program from becoming an exclusively inpatient model, and preserve hospice's philosophy of care in a home environment.

Another major provision of the original Medicare hospice legislation was that hospices assess families' bereavement needs. Although Title XVIII payment stops at the time of death, hospice providers

must provide bereavement services for up to one year afterwards. Hospice proponents maintained that they made a difference and thus families should continue to receive these services after the patient's death.

In 1986, the Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985 was signed into law. Besides repealing the sunset provision for Medicare's hospice benefit, it stated that terminally ill patients residing in nursing facilities could elect Medicare hospice care. For every day of care, hospices would be paid Medicare's routine home care rate. COBRA also gave states the option of adding a hospice benefit to their Medicaid programs.

TODAY'S MEDICARE HOSPICE BENEFIT

Today, Medicare Part A insurance provides virtually unlimited hospice coverage to eligible beneficiaries who are terminally ill. Patients must be certified by their physician and the hospice medical director as having a life expectancy of six months or less (if the disease runs its normal course). They must also sign a statement choosing hospice in lieu of standard treatments for their terminal illness, and be treated by a Medicare-certified hospice. Even though they must waive their rights to all other inpatient hospital, skilled nursing facility, and home health services for the terminal illness, beneficiaries may still be treated for other medical problems under the regular Medicare program. For example, if a cancer patient breaks a hip, Medicare will cover hip treatment (and payments) independent of hospice care.

The Balanced Budget Act of 1997 (BBA) established unlimited coverage for beneficiaries by changing the four hospice benefit periods to two 90-day periods, followed by an unlimited number of 60-day periods (Table 1). Benefit periods do not need to be consecutive as long as the patient is certified as terminally ill at the beginning of each one. Hospice election can be canceled at any time and reelected at a later date. Inasmuch as predicting death is difficult and the practice of medicine is changing rapidly, this

policy was designed to ensure that access to hospice would always be available. However, so that eligibility would be reviewed more frequently, the law increased the number of times hospice beneficiaries had to be recertified to every 60 days. This change in coverage recognizes that certain conditions may stabilize and that certain complications may require significant medical intervention. Patients can be discharged from hospice during these periods and still be re-admitted into their next hospice benefit period when their condition warrants it.

Medicare's hospice benefit includes services not available under other parts of the program. Among these are extensive coverage of non-IV therapy outpatient prescription drugs for pain relief and symptom management, homemaker services, and bereavement counseling for both the patient and their family members. Although hospices are required to make family counseling available for up to one year after the patient's death, as noted earlier, payment ceases on the patient's death. The hospice benefit also comprises physician management services and nursing care; medical supplies and appliances; short-term inpatient care, including respite care; home health aides; physical and occupational therapy; speech language pathology services; medical social services; dietary and other counseling; and any other Medicare-covered service in the patient's plan of care. Attending physicians who are not associated with the hospice may continue caring for the patient as part of the hospice team, but their visits are not covered by the hospice payment. Instead, they are covered by Medicare's traditional Part B physician benefit. In addition, other physician services may be provided on a consultation basis and paid under Part B.

Generally, a hospice patient's primary caregiver is a family member or "significant other." Each patient has a team consisting of family members, nurses, physicians, social workers, dietitians, counselors, clergy and volunteers who make regular home visits. Speech language pathologists and other therapists are

provided on an as-needed basis. Further, the hospice physician and nurse are on-call 24 hours a day, seven days a week to provide advice by phone or visit when necessary.

While most hospice enrollees live at home, an estimated 12 percent live in a nursing facility (Gage, 1998). If a patient lives in a nursing facility, the facility is considered to be the home and the staff members are regarded as family or the patient's primary caregivers. The room and board costs of the nursing facility stay are not included in the hospice benefit.

Medicare uses four payment rates, reflecting different levels of care (Table 2). Payments are capitated, all-inclusive, prospectively set per diems. The amount does not change regardless of the volume or intensity of services provided during the day. These national payment rates are adjusted by the hospital wage index to reflect geographic variations in cost. The four payment levels include:

- ***Routine home care.*** Patients are at home (or living in a nursing facility), under the care of the hospice, receiving fewer than eight hours of care per day. Payments for routine home care in fiscal year 1999 were \$97.11 a day. About 87 percent of all payments in 1997 were for routine home care totalling \$1.8 billion dollars (Table 3). This is the default payment rate for each day a beneficiary is enrolled in hospice and not receiving a higher level of care.
- ***Continuous home care.*** This care is furnished only during brief periods of crisis and only as necessary to maintain patients at home. A continuous home care day is at least eight hours long and consists predominantly of continuous nursing care, although home health aide and homemaker services may also be provided on a continuous basis. The payment rate is \$566.82 for 24 hours of care. These payments accounted for \$29 million or 1 percent of the hospice expenditures in 1997.
- ***Inpatient respite care.*** With this care, hospice patients may receive care in approved facilities on a short-term basis (not more than five days at a time) as respite for their caregivers. The payment rate for this level is \$100.46 a day. Inpatient respite days represented less than one percent of hospice payments and accounted for only \$4.8 million in 1997.
- ***General inpatient care.*** With this care, patients may be admitted to approved facilities for pain control or acute or chronic symptom management that cannot be achieved in other settings. This level of care may be provided in a hospital, a hospice with its own inpatient

facility, or a skilled nursing facility. The payment rate for this level is \$432.01 a day. General inpatient care is the second most frequently used hospice care accounting for 11 percent of hospice expenditures, or \$210 million dollars.

Individual beneficiaries have an unlimited number of inpatient days (including both respite and general inpatient). However, as mentioned earlier, the total inpatient days per year provided by any one hospice can not be greater than 20 percent of all hospice days provided by that facility. Restricting the total share of inpatient days allows providers to give sicker beneficiaries more inpatient days, while offsetting that with patients who use less than 20 percent of days in inpatient care. Hospices are paid a routine home care rate for inpatient days that exceed the 20 percent limit so they have an incentive to limit inpatient use rates.

Total provider payments also are limited to an annual per capita spending cap that is updated annually by the Consumer Price Index. For fiscal year 1999, the cap was \$15,313. Facility payments are limited to the product of the cap times the unduplicated number of patients served, although few agencies have ever been restricted by this cap. This cap is essentially a proxy for the cost of care for the last six months of life under the traditional Medicare program (Hoyer, 1998).

Like Medicare hospital payments, hospice payments are updated each year by some portion of the increase in the hospital market basket. For fiscal years 1998 through 2002, the BBA set payments at market basket minus one percentage point for each fiscal year. The BBA also requires hospices to submit cost reports beginning in fiscal year 1999. These data will be important for analyzing the types of costs incurred by hospices. This information will be increasingly important as cancer becomes less dominant in the hospice population. Such information also will be useful to understand differences in costs associated with varying types of hospice ownership and affiliations (for instance, whether the hospice is hospital-based, SNF-based, home-health-agency-based, or free-standing); for various levels of treatment (routine home

care, continuous home care, general inpatient, or respite inpatient care); and for various care settings (e.g., home care in a community setting versus in a nursing or assisted living facility).

Beneficiaries have limited copayments for outpatient drugs or biologicals and inpatient respite stays. The drug co-payment is 5 percent of the cost of the drug to the hospice or \$5 per prescription item, whichever is less. The inpatient hospital deductible (\$764 in 1998) is the annual limit for respite copayments.

To be covered, services must be provided by a Medicare-certified hospice. Certified providers must be engaged primarily in providing hospice care and make services available on a 24-hour basis. About 94 percent of all hospices are certified to participate in Medicare, Medicaid, or both; 89 percent of all hospices are dually certified (NCHS, 1998). Beneficiaries may change providers once during an election period.

3. MEDICARE HMO ENROLLEES AND HOSPICE ELECTION

Beneficiaries enrolled in hospice also may enroll in managed care arrangements. That was not so before the BBA passed in 1997, however, when beneficiaries on hospice could not enroll in an HMO. Also, because of the BBA, HMO enrollees who elected hospice are no longer required to disenroll from the HMO because of their choice.

Medicare payments for HMO enrollees who elect hospice are similar to payments for other hospice cases. When an enrollee elects hospice coverage, the hospice is paid the appropriate per diem amount for the hospice care and the HMO payment is reduced to 1/12 of the prior monthly capitation which covers any additional benefits the HMO offers to its enrollees. As in FFS, the HMO submits fee-for-service bills for costs not related to the terminal illness.

Very few empirical studies have looked at the relationships between HMO and hospice enrollment as they affect cost, utilization or quality of care. Those studies that have been done were based on limited samples – either members of one specific plan or residents of one limited geographic area – but they provide some information. One study compared the differences in cost for dying frail elders who were enrolled in an HMO or remained in fee-for-service in California and found no differences in expenditures (Experton, 1996). A second study compared the use of hospice between two groups of Cancer patients in 1992 in South Florida and found that HMO enrollees had a longer length of stay in hospice (20 days compared to 14 days for nonHMO enrollees). Similarly, a larger proportion of HMO enrollees than fee-for-service nonenrollees survived in hospice for longer than 180 days (Vernig, 1999).

More recently, HMO managers were interviewed to find out about their end-of-life care program, including their relationships with hospice providers. While this also was a limited sample – only 19 managers were interviewed – the findings may be instructive since they are a geographically mixed group of nonprofit HMOs, for-profit HMOs, IPAs, health systems, and others (Fox, 1999). Most stated that referrals to hospices were “too infrequent and often late -only a few days before death.” A few of the HMOs owned their own hospices. Some instituted physician education programs to teach physicians about hospice and some have established end of life committees. Others had developed palliative care teams. The interviewees suggested that few HMOs have addressed end of life needs beyond those required by the federal government. Most saw the target population as Cancer patients rather than other terminally ill populations.

Fox found hospices were criticized because of perceptions of poor communications between hospices and plan administrators, physicians, and case managers resulting in poorly coordinated services. The interviewees were concerned about their community image and whether the establishment of end of life

programs might be perceived as a means of managing the costs of high cost populations rather than improving the quality of care for dying enrollees. Last, the interviewees were asked whether referring beneficiaries to hospice was financially advantageous. The responses varied widely and only two groups had data - each of which lead to opposite conclusions. Some felt that most of the expensive interventions had already occurred before patients were transferred to hospice.

4. MEDICAID'S HOSPICE BENEFIT

While Medicare pays for most hospice care, Medicaid also may offer hospice coverage as an optional benefit under the Title XIX program. All but 17 states offered this benefit in 1998. State Medicaid hospice programs must include, at minimum, the same services as Medicare, although more types of services may come under the hospice umbrella. Eligibility, payment, and conditions of participation rules mirror Medicare's. As in Medicare, most Medicaid hospice care is routine home care, whether it is actually provided at home or in a nursing facility.

Medicaid per diem payment rates may vary by state and differ from Medicare's. If a Medicaid recipient lives in a nursing facility but enrolls in Medicaid's hospice benefit, Medicaid pays the hospice two amounts – one for Medicaid hospice coverage and the other for room and board at the nursing facility. For room and board, the state must pay at least 95 percent of the nursing facility rate. Hospices, in turn, must pay nursing facilities at least 95 percent up to 100 percent of Medicaid's room and board rate. (Any amount greater than 100 percent suggests hospices are paying above fair market value (FR, October 1999). If the beneficiary is dually eligible—that is, on Medicaid and Medicare—Medicare pays for hospice care while Medicaid pays the hospice for nursing facility room and board.

Medicaid uses the same program rules for hospice that Medicare uses. A care plan must be established before services are provided. If a state Medicaid program offers hospice, it must cover the same services as Medicare: nursing care; medical social services; physicians' services; counseling services; home health aide; medical appliances and supplies, including drugs and biologicals; and physical and occupational therapy. In general, the services must be related to the palliation or management of the patient's terminal illness, or symptom control, or to enable the individual to maintain activities of daily living and basic functional skills.

In addition, both programs use the same payment methodology as specified in the Social Security Act (section 1907 (a)(13)(D) and cover the same four definitions of care—routine home care, continuous home care for crisis periods, short-term inpatient care if needed, and short-term inpatient respite care to relieve at-home caregivers. As with Medicare's benefit, Medicaid's respite inpatient care is allowable only on an occasional basis and cannot be covered for more than five consecutive days.

Also as in Medicare, Medicaid's inpatient payments to a hospice are limited to 20 percent of the aggregate total number of hospice days provided per facility. The one exception is in the Medicaid program's treatment of the acquired immune deficiency syndrome (AIDS) population. Under Medicaid, AIDS patients may have more than 20 percent of their days as inpatient days. AIDS patients' inpatient days also are excluded from the count of the total inpatient days provided by a hospice. Both these provisions were authorized under the Omnibus Budget Reconciliation Act of 1987 (OBRA 87).

Title XIX has covered hospice services since 1985, when COBRA allowed states to cover hospice as an optional service for Medicaid recipients who waived their rights to other services. OBRA 86 clarified the rules for dually eligible recipients who resided in nursing facilities, elected Medicare hospice coverage, and lived in a state that did not cover hospice services under its optional Medicaid program. In these cases,

hospices were still responsible for all costs of hospice enrollees. Medicare would pay them for the hospice benefit coverage, and the state would pay nursing facility room and board plus coinsurance. The state's payment would equal what Medicaid allocated for room and board plus coinsurance amounts. The nursing facility had to have a written agreement with the hospice, identifying the hospice as fully responsible for managing the patient's hospice care while the nursing facility provided room and board.

OBRA 1986 also defined nursing facility room and board to comprise "performance of personal care services, including assistance with activities of daily living, in socializing activities, administration of medication, maintaining the cleanliness of the resident's room, and supervising and assisting in the use of durable medical equipment and prescribed therapies." OBRA 90 (section 4705(a)(4)) deleted this definition.

OBRA 89 added a requirement that the state's payment amount for dual eligibles must equal at least 95 percent of the rate it would have paid the facility if the beneficiary had not elected hospice. This payment is made to the hospice, along with Medicare's per diem for hospice routine care for each day of a nursing home resident's enrollment. Hospices, in turn, must pay nursing facilities for room and board and daily care. That amount must be at least what they receive from the state.

OBRA 90 modified the coverage provisions. Before that legislation, Medicaid-eligible individuals electing the Medicaid hospice benefit waived their right to Medicaid coverage for services other than those described earlier. Under OBRA 90, recipients can receive Medicaid coverage for services related to treating their terminal condition and to other services like personal care that Medicare does not cover.

In general, Medicaid acts as a wraparound benefit for dually covered Medicare beneficiaries, particularly those in nursing facilities. Dually eligible hospice beneficiaries living in the community can use their Medicaid coverage only if the state covers some service, such as personal care or prescription drugs,

not covered by Medicare's hospice benefit. By contrast, Medicaid will cover room and board and coinsurance of beneficiaries who live in nursing facilities while Medicare will pay for their hospice services. The exact number of dually-eligible beneficiaries in nursing facilities is unknown.

5. EMPLOYER-BASED HOSPICE BENEFITS

A small proportion of hospice enrollees are privately insured. A recent study of large firms (200 or more employees) found that 83 percent of employees are in firms that offer hospice coverage (Gabel et al., 1998). And the opportunity to choose this benefit increases with firm size—growing from 68 percent of employees in firms with 299-999 employees to 89 percent in firms with 5,000 or more employees.

The availability of hospice benefits also varies by plan type. While 86 percent of conventional fee-for-service, preferred provider organization, and point-of-service plans have hospice as an explicit benefit, only 78 percent of the HMO plans do. Even so, many of the HMOs offer hospice implicitly through their case management programs.

Benefits also vary widely based on geographic region. Whereas about 28 percent of employees in all large firms have dollar caps on their hospice coverage, in the West, 38 percent have caps. By contrast, only 23 percent of the firms located in the northeast and south have caps. Nearly a third (31 percent) of the firms limit length of stay. These limits are found most often in firms located in the northeast and Midwest. Eligibility generally is based on diagnosis of terminal illness by the patient's physician. Nearly half (48 percent) of employees must have a doctor's prognosis of six months or fewer to live, a requirement that varies little by firm size. Less than 1 percent decide eligibility on a case-by-case basis. Little information is available on cost and use of hospice in the private insurance market although some information will be provided by the analyses in the second half of this study.

6. MEDICARE HOSPICE BENEFICIARIES

MEDICARE HOSPICE BENEFICIARIES

Medicare beneficiaries have grown rapidly as a share of the total hospice population, increasing more than seven-fold during the last decade, from 40,356 in 1988 to 302,608, in 1995 (HAA, 1997). In 1995, Medicare covered 78 percent of all hospice users, up from 22 percent in 1988 (Figure 1).

Routine hospice home care is the most widely used benefit. Beneficiaries received 18.2 million days of such care in 1997, accounting for \$1.8 billion or 89 percent of total hospice expenditures (Table 3). General inpatient care, by contrast, represented 10 percent of Medicare expenditures (HCFA, 1998a).

Most patients received services from free-standing hospice programs or from hospice programs based in home health agencies (52 percent and 29 percent, respectively).³ These patients also have the most days on hospice, on average, and account for 82 percent of the expenditures (Table 4). The highest average costs per case are for patients treated by free-standing facilities (\$5,796, on average, per beneficiary) or by providers based in SNFs (\$5,079). Only 17 percent of the hospice expenditures were for patients treated by hospital-based hospices (HCFA, 1998a). (Hospices affiliated with nursing facilities and hospitals deliver hospice care in home and institutional settings. The level of care specifies whether the patient was treated as an inpatient.)

Banaszak-Holl and Mor (1996) examined characteristics of Medicare hospice enrollees between 1987 and 1990. They were in a variety of settings: free-standing hospices as well as in hospitals, SNFs, and

³ This reference is to the four types of Medicare-certified hospice providers, not to the level of hospice care. Medicare-certified hospice providers that are not an organizational entity of a hospital, SNF, or home health agency are classified as free-standing hospice providers. Other Medicare-certified hospices are classified as either hospital-, SNF-, or home-health-agency-based providers. All Medicare certified hospice providers deliver the four different levels of hospice care.

home health agencies (Table 5). Nearly half (47 percent) were female, 90 percent were white, and 16 percent had non-cancer diagnoses. The average age at hospice enrollment was 75.6 years.

Across hospice provider types, SNF-based hospices enrolled the highest percentage of females (53 percent), whereas free-standing facilities had the fewest (45 percent). Hospital-based and SNF-based hospices had the largest share of non-whites (13 percent), and free-standing facilities the least (9 percent). Hospital- and SNF- based hospices had fewer enrollees with non-cancer diagnoses (15 percent and 13 percent respectively). Of enrollees in home-health-agency-based and in free-standing hospices, 16 percent had diagnoses other than cancer. Mean ages did not differ significantly by hospice provider type (Table 6).

As discussed earlier, the National Center for Health Statistics (NCHS) profiles hospice users across all insured populations in its National Home and Hospice Care Survey (NHHCS). These data are useful in comparing hospice patient characteristics across all insured populations with those of Medicare hospice patients. The sample universe for the NHHCS is home care and hospice agencies classified by the (updated) 1991 National Health Provider Inventory (10,900 total home and hospice agencies in 1992 and 13,500 in 1996). For each provider chosen, a random sample of six current and six discharged patients in a randomly selected designated month are chosen. Table 6 shows national estimates from the 1994 and 1996 surveys of characteristics of discharged hospice patients.

Besides providing data for comparisons, the NHHCS highlights the importance of the public payer. In both the 1994 and 1996 surveys, at least 90 percent of the patients received care from a hospice certified by Medicare or Medicaid or both (NCHS, 1996 and 1998). Almost 70 percent of all hospice enrollees were 65 or older in 1996, although this represents a decline from the 1994 survey, when 72.9 percent of discharges were 65 or older.

The survey found that regardless of insurer, hospice patients are less likely to be “White” (80 percent hospice enrollees compared to 85 percent in total Medicare population) and of different ages than Medicare hospice enrollees. Additionally, among survey participants one finds a much higher percentage of hospice discharges with non-cancer diagnoses (32.7 percent in 1994 and 30.3 percent in 1996), compared with Medicare hospice enrollees (16 percent overall in 1987-90) (Banaszak-Holl and Mor). These differences may be due either to changes in diagnosis mix over time, inasmuch as the 1994 and 1996 NHHCS represent four to eight years, respectively, after Banaszak-Holl’s and Mor’s study, or to the different diagnosis mix among younger hospice patients seen across all provider types. That a smaller share of Medicare hospice patients have diagnoses other than cancer may also reflect restricted access (see the section titled “Diagnosis”).

As Banaszak-Holl and Mor suggest, hospice care in nursing facilities is particularly important for females. Because women generally outlive their husbands, or if not married have no children, they are more likely to lack the social support to remain in the community as their health fails. Therefore, females make up a disproportionate share of nursing facility residents. Without the availability of hospice in nursing facilities this benefit would not be available to a significant proportion of older women. When compared to Medicare hospice enrollees (in the 1996 Banaszak-Holl and Mor study), the NHHCS estimates of hospice discharges show that hospice patients across all payer sources seem quite comparable to Medicare hospice patients in terms of the percentage of female hospice patients. However, Medicare SNF-based hospice providers still appear to provide hospice care to the highest percentage of female hospice patients.

MEDICARE HOSPICE BENEFICIARIES IN NURSING FACILITIES

Medicare hospice beneficiaries residing in nursing facilities have been the fastest-growing hospice population since OBRA 89 was passed. Indeed, these residents accounted for up to 35 percent of all hospice beneficiaries in some markets (Petrisek and Mor, 1998). Banaszak-Holl and Mor (1996) examined Medicare claims between 1986 and 1991. They found a statistically significant increase in the proportion of hospice beneficiaries who were receiving nursing facility-based services between 1987 and 1990 (6.6 percent versus 9.9 percent). Furthermore, this increase was concentrated in certain markets and community based hospices. By 1997, an estimated 12 percent of Medicare hospice beneficiaries were living in nursing facilities while receiving hospice care (Gage, 1998). Still, only a fraction (about 1 percent) in each facility were on hospice (Petrisek and Mor, 1998). The percentage of nursing home decedents who received the hospice benefit is unknown, but will be examined in five states in the next phase of the ASPE project.

The growth in the number of nursing facility residents receiving hospice care is changing the profile of the traditional Medicare hospice patient. Unlike hospice patients enrolled from the community, hospice beneficiaries in long-term care settings often include patients with lower functional status, dementia, and chronic illnesses (e.g., congestive heart failure, chronic obstructive lung disease). Also found among this group are patients without available caregivers in the community (Banaszak-Holl & Mor, 1996) a recognized deterrent to hospice admission for African Americans and Hispanics (Gordon, 1995).

Such diversity was seen in a study of hospice patients in a nursing facility served by the Hospice of Washington (a hospice in a long-term care setting). In that study, major changes in patient sociodemographic characteristics, diagnoses, and payer and referral sources were observed over a 10-year period from 1978 to 1988 (Infeld et al., 1990). Specifically, by 1988 a much higher percentage of hospice

patients were unmarried (46.2 percent versus 23.5 percent), non-white (49.5 percent versus 17.6 percent), had non-cancer diagnoses (24.8 percent versus 0 percent), and were enrolled in managed care (36.8 percent versus 0 percent). The investigators saw hospice care in long-term care settings as providing an option for elderly people living alone who have no available caregiver—a growing population among Medicare beneficiaries. And like Infeld, Banaszak-Holl and Mor found that an increasing share of hospice beneficiaries in nursing facilities had diagnoses other than cancer, 12 percent in 1987 versus 17 percent in 1990.

7. HOSPICE PROVIDERS

VOLUME AND GEOGRAPHIC DISTRIBUTION

Even before Medicare's hospice benefit was enacted in 1982, the number of organizations furnishing hospice care had grown substantially. The General Accounting Office (GAO) identified 59 operational hospices in 1978 (GAO, 1979). A National Hospice Organization survey counted 235 hospices by 1980. The Joint Commission on the Accreditation of Hospitals in 1981 received 650 responses to a national survey of hospices; by 1982, the National Hospice Organization had 464 provider program members. By 1984, McCann (1985) estimated there were 1,694 hospices. Yet despite their proliferation, as of January 1986, only 245 hospice programs were Medicare-certified. Since then, however, that number has increased ten-fold (Table 7). The distribution of Medicare-certified hospices by provider type has changed as well, with free-standing and hospital based providers growing most rapidly. In 1996, 38 percent of Medicare-certified hospice programs were based in home health agencies and 37 percent were free-standing, 24 percent were hospital-based, and 1 percent was SNF-based.

Over time, Medicare-certified hospices have increased as a share of all hospice providers and now represent the majority (Figure 2). Of 2,722 hospice programs in the United States in 1996, 79 percent (2,154) were certified by Medicare (NHO, 1998a).

NURSING FACILITIES WITH MEDICARE HOSPICE BENEFICIARIES

Petrisek and Mor (1998) not only documented the distribution of hospice beneficiaries in nursing facilities, but also examined how facility type, market, and environmental factors affected provision of hospice services to residents. They found that 30 percent of nursing facilities had at least one Medicare hospice beneficiary and that the proportion of residents on the Medicare hospice benefit differed substantially within and across states. Only 4.2 percent of the nursing facilities studied had 5 percent or more of their residents on the hospice benefit, but these nursing facilities served approximately 34 percent of all hospice beneficiaries in nursing facilities.

Organization and market-area characteristics also seem to influence whether nursing facilities offer hospice. When comparing nursing facilities with at least a 5 percent concentration of Medicare beneficiaries on hospice to those with less than 5 percent concentration, the researchers found that facilities with a small share were more likely to be hospital-based, to have fewer Medicare and Medicaid residents, and to have lower nurse staffing levels. Additionally, all else equal, nursing facilities in counties with greater hospice penetration (i.e., where there were more total hospices altogether, and where most were for-profit, institutional-based, and larger) were more likely to have at least a 5 percent concentration. The distribution of hospice beneficiaries in nursing facilities follows an economically motivated path, Petrisek and Mor suggest. State Medicaid policies, such as the services that must be included in daily Medicaid rates, may also partly account for variation among states in the use of Medicare's hospice benefit in nursing facilities.

Similarly, Jones and colleagues (1997) found that factors besides patient need or demand influenced whether hospice was available in nursing facilities. In 23 nursing facilities owned by the same company whose hospice use rates ranged from 2 percent to 39 percent, for instance, the administrator's attitude influenced whether the facilities used such services. Usage rates were three times higher in nursing facilities where administrators were "most sympathetic" to hospice than in those where they were "least sympathetic." The administrators' discretionary power thus seemed to influence hospice enrollment options. This finding is consistent with program implementation theory, which describes how the power of local administrators can limit access to new programs they find problematic.

CONTRACTUAL RELATIONSHIPS BETWEEN HOSPICES AND NURSING FACILITIES

The HHS Office of Inspector General, which examined the contractual arrangements between hospices and nursing facilities, identified opportunities for fraud, waste, and potential abuse in implementing the Medicare hospice benefit in nursing facilities. The OIG's study was conducted to determine whether hospice contracts in nursing facilities lead to inappropriate or excessive payments to nursing facilities (HHS, 1997 a). Of the 31 responding hospice programs, 22 had patients residing in nursing facilities and 17 had contracts with information sufficient to determine the payments made to nursing facilities. Medical and financial records of 208 patients residing in the 22 hospices in December 1995 were reviewed, as were the 17 contracts. Nearly all 17 hospices paid the nursing facilities the same or more than the state Medicaid agency would have paid if the resident had not opted for hospice care (10 paid 100 percent, 5 paid 105 percent, 1 paid 120 percent, and 1 paid less than 100 percent).

It was unclear to OIG whether additional services were provided by the nursing facility to warrant the increase in payment over what the State would have provided. The hospices paying over 100 percent

had a high percentage of their patients in nursing facilities (on average, 49 percent with two hospices having close to 100 percent of patients residing in nursing facilities) when compared to the hospices paying 100 percent or less had (on average, 24 percent of patients in nursing facilities). Additionally, three contracts suggested that kickbacks were provided for hospice referrals, leading the OIG to voice concern that some hospices may be violating Medicare-Medicaid anti-kickback laws. The OIG also speculated that financial incentives, rather than patient care, might sometimes have influenced hospice referrals.

Since OIG released its findings and recommendations, HCFA has worked with hospice associations to educate hospices about how to avoid potential fraud and abuse—or the appearance of such in inappropriately worded contracts. The OIG also recommended that HCFA work with states to develop regulations specifying what room and board payments include, but such regulations are yet to be released.

The OIG study noted that hospices and nursing facilities alike can benefit financially by enrolling patients in hospice. Indeed, in some instances they have a strong financial incentive to enroll residents prematurely (that is, when life expectancy is longer than six months). The report spelled out potential financial benefits as follows:

For hospices, these benefits were seen as:

- additional income if Medicaid payment to the hospice exceeds the hospice payment to nursing facility;
- increase in average length of stay of patients resulting in more potential profit per patient; and
- increase in efficient use of staff, since several patients may be at one geographic location.

For nursing facilities, these benefits were seen as:

- increase in reimbursement if the nursing facility receives more than the 100 percent daily rate it would have received from Medicaid;

- additional staff at no extra cost and reductions in supply and medication costs when provided or paid for by the hospice; and
- increase in patient census by admitting hospice patients to the nursing facility.

The OIG based its conclusions on its study, *Hospice Patients in Nursing Homes* (HHS, 1997b).

The study's findings about average length of stay are most likely biased, as will be discussed later. The true average hospice length of stay in a nursing facility is probably much shorter than the OIG observed.

8. UTILIZATION OF THE MEDICARE HOSPICE BENEFIT

HOSPICE LENGTHS OF STAY

Banaszak-Holl and Mor (1996), who studied hospice enrollees between 1987 and 1990, found average stays longest in free-standing hospices and shortest in SNF-based ones (Table 8). In fiscal year 1995, free-standing hospices still had the longest stays on average, at 62.9 days. By comparison, stays averaged 56.7 for hospital-based hospices, 53.8 days for those based in home health agencies, and 49.3 days for those in SNFs. For residents receiving the Medicare hospice benefit, NHO estimated average length of stay at 56.3 days in 1995, in contrast to the OIG, which estimated average stays of 181 days (HHS, 1997b). However, as detailed in the next section, the OIG figure is probably too high.

OFFICE OF INSPECTOR GENERAL RELATED INVESTIGATIONS

In 1995, Operation Restore Trust was established to identify areas in the Medicare program that might be vulnerable to fraud, waste, and abuse. The initiative was a joint project of the OIG, HCFA, and the Administration on Aging. Audits were conducted in five states (California, Florida, Illinois, New York, and Texas) where Medicare spending represents 40 percent of total program expenditures. Hospice care

was one of three areas being investigated. In-depth audits revealed problems related to both the certification of nursing facility residents as hospice patients and the services they received. Certain provisions in the Balanced Budget Act of 1997 partly responded to some of the OIG's concerns. One, for instance, mandated more frequent physician certifications of patient eligibility after 180 days of hospice care.

Hospice Patients in Nursing Homes examined the eligibility, services, and growth in numbers of hospice patients living in nursing facilities (HHS, 1997b). Specifically, hospice and nursing facility records were reviewed to determine: (1) whether patients were eligible for the Medicare hospice benefit at hospice admission, (2) the frequency, type and nature of services hospice provided, and (3) whether services changed after patients elected hospice. Additionally, a medical reviewer was asked if staff members could have furnished the same services hospice did.

Six hospices were selected from each of the five states where Operation Restore Trust was under way. Six others were randomly selected from the nonparticipating states. The sampling frame was patients receiving routine home care during December 1995. A sample of 262 hospice nursing facility beneficiaries was selected from the 22 hospices with patients living in nursing facilities. If a hospice had fewer than 35 patients in a nursing facility, all were included in the study. Otherwise, 35 patients were chosen on a random basis. In the end, 200 Medicare nursing facility beneficiaries remained in the sample.

Two levels of hospice and nursing facility medical record review were conducted, the first by nurse reviewers with experience in hospice or nursing facilities and the second by physician reviewers in specialties related to a patient's diagnosis and who had referred their own patients for hospice care. If the first medical reviewer questioned hospice eligibility, another one responsible for hospice services at a Medicare Regional Home Health Intermediary performed a second review.

The OIG estimated that 16 percent of hospice patients living in nursing facilities did not actually qualify for the Medicare hospice benefit upon enrollment. Some enrollments were considered premature—though patients had a terminal illness, the condition was not deteriorating per NHO’s *Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases* (NHO,1995a). Of the questionable enrollments, many involved dual eligibles, most of whom went on hospice after being admitted to the nursing facility.

As NHO noted in responding to the OIG hospice report, to be eligible for Medicare’s hospice benefit, patients do not have to show signs of decline when they choose the benefit. Nor do they have to be in an unstable condition or on the brink of death. The NHO also criticized the OIG for using NHO’s medical guidelines to determine eligibility since they postdated the OIG’s study and thus probably were unavailable to hospices and physicians in the period being reviewed.

Patients the OIG found ineligible when they chose hospice had much longer average lengths of stay (369 days) than those found to be eligible (145 days). Average length of hospice stay overall was 181 days, which was longer than the 58.8-day average stay found in fiscal year 1995 (HHA, 1997). It also exceeded the average of 56.3 days estimated by NHO for hospice beneficiaries in nursing facilities in 1995 (HHS, 1998).

Although OIG’s estimates are compelling and raise concerns about possible abuse of the benefit, they are based on an extremely small sample and are most likely influenced by incidence-prevalence bias. (Especially in a nursing facility setting, prevalent cases represent more long-stay patients with chronic conditions than do incident cases.) Further, given that OIG sampled active beneficiaries in December 1995, rather than sampling incident admissions or deaths per discharge across a longer time period, the probability of oversampling residents with longer lengths of stays (i.e., prevalent cases) is high. This oversampling of

prevalent cases is especially likely since individual hospices had so few nursing facility residents included in the study (reducing the likelihood of capturing incident cases). (Of the 22 hospices studied, 15 had 9 or fewer nursing facility patients, while 11 had 4 or fewer.) With the probable sampling of beneficiaries with longer lengths of stays, it follows that the estimation of the percentage of questionable admissions would be high. (Beneficiaries with longer lengths of stay are more likely to have conditions more difficult to accurately prognosticate, such as non-cancer diagnoses.)

The incidence-prevalence bias discussed above is documented by results from the National Hospice and Home Care Survey, which samples both hospice discharges (i.e., incident patients) and current patients (i.e., prevalent patients). Three major differences between the current and discharged patient samples in the 1996 NHHCS are noteworthy. First, current patients are likelier than discharged ones to have a diagnosis other than cancer (40.4 percent versus 30.3 percent in 1996). Current patients are also more apt to be 85 or older (21.3 percent versus 16.4 percent) and female (55.1 percent versus 49.7 percent in 1996). In a nursing facility population, these contrasts are probably even sharper. Because current patients in the NHHCS had not been discharged from hospice when the survey was conducted, it is spurious to use NHHCS data to compare current and discharged patients.

Another possible shortcoming of the OIG study is the difficulty of making an accurate six-month prognosis (and agreeing on it) for most nursing facility residents, the majority of whom are dying from chronic conditions like congestive heart failure, Alzheimer's disease, or chronic obstructive pulmonary disease. Further, the OIG hospice audits were performed on hospice admissions that occurred before fiscal intermediaries introduced more stringent requirements for documenting a terminal illness (Texas Association for Home Care, 1997). Thus, although the number of hospice beneficiaries retrospectively deemed ineligible

through the OIG study provides some support that a problem exists, the culprit may be poor documentation practices or actual difficulty in predicting death rather than faulty admission practices.

According to OIG, hospice workers saw beneficiaries living in nursing facilities less frequently than NHO guides recommended (Table 9) (HNO, 1995b). Also, even though hospice patients in nursing facilities received fewer services than those living in the community, hospices were paid at the same level for care in both settings. That finding raised concerns that hospices were being overpaid for services provided in nursing facilities. Consequently, the OIG recommended that HCFA seek legislation to modify Medicare and Medicaid payments for hospice patients living in nursing facilities. The OIG recommended reducing the hospice payments for beneficiaries in nursing facilities or revising the benefit requirements for nursing facility residents.

But before concluding that fewer hospice services actually are provided to hospice beneficiaries in nursing facilities, the validity of OIG's comparisons must be considered. In fact, the data may not be comparable. For example, OIG observed hospice services provided in nursing facilities only during December 1995, not across the entire hospice episode. NHO, on the other hand, derived the average number of visits per week from staffing ratios (ratio of visits per week to patient caseload) based on a survey of providers. NHO's figures thus reflect visits made to patients over time and throughout their hospice episode, including when they were close to death (NHO, 1995b). Since the number of hospice visits increases as death approaches, the OIG average is likely to be too low. This possibility warrants serious attention when considering the validity of the OIG's findings on service use. It also underscores the need for other studies that examine provision of hospice care to nursing facility residents.

OIG also reported that although regulations may have made it hard for nursing facility staff to provide certain hospice services, most hospice patients received only basic nursing and aide visits. Recall,

however, that these findings are based on medical reviewers' opinions rather than on empirical data. No comparable group of dying nursing facility residents was examined to determine if, in fact, similar services were or could be provided by nursing staff. Thus, it seems premature to conclude that they could duplicate all hospice services.

The OIG also addressed hospice eligibility for Medicare hospice beneficiaries in *Medicare Hospice Beneficiaries: Services and Eligibility* (HHS, 1998). Although this study concluded that Medicare's hospice program seemed to be working as intended, it raised questions about possible ineligibility of a large percentage of hospice beneficiaries in nursing facilities.

Besides using methodology similar to that in the Operation Restore Trust study, this analysis also sampled hospice beneficiaries enrolled as of June 14, 1996. Nurses reviewed 236 beneficiary hospice records, 102 of which were referred for physician review. The records were for beneficiaries in nursing facilities (all were referred) or other beneficiaries for whom nurses questioned eligibility. (Documentation in 27 records was not sufficient to determine eligibility.) In the 209 medical records in which documentation allowed for determination of eligibility, 10 of the 19 beneficiaries found ineligible were in nursing facilities. Using weighted averages, the OIG found 7.21 percent of the total sample ineligible for hospice: 29.3 percent of community-dwelling hospice beneficiaries (10 of 39) and 2 percent of nursing facility hospice beneficiaries (9 of 197).

These findings are influenced by the incidence-prevalence bias described earlier. Because of this, the ineligibility percentages may be overestimates. Since there are well-known differences in diagnosis and length of stay among nursing facility residents, depending on whether they are incident cases (admissions or discharges) versus prevalent cases (current residents), this overestimation is likely to be greater for the nursing facility hospice beneficiaries. In addition, *all* nursing facility hospice beneficiary records were

referred for physician review, whereas referrals occurred for other Medicare hospice beneficiaries only when nurses questioned eligibility. For the 10 ineligible nursing facility residents, 7 had non-cancer diagnoses, 1 had prostate cancer, and 2 had lung cancer. Other than the lung cancer, all of these diagnoses represent a significantly reduced risk of death, and thus a longer hospice stay (Christakis and Escarce, 1996).

In relation to the above ineligibility findings, NHO disputed what in its view were differences in medical opinion used to determine ineligibility. The NHO thinks OIG's "intense scrutiny" of hospices has led to underutilization of the benefit. It was disappointed that OIG failed to comment on that possibility (HHS, 1998). The Hospice Association of America (HHA), while not expressing specific concerns about OIG's methodology, thought it would be inhumane to "support a system that focuses on error-free prognoses of six months or less." HHA also said that Medicare's requirement of a prognosis of six months or less to live, "in reality translates to the last few days or weeks of life" (HHS, 1998).

9. MEDICARE EXPENDITURES AND HOSPICE CARE

SPENDING ON HOSPICE

In 1997, Medicare spent \$2.7 billion (1 percent of total program expenditures) on hospice care (Figure 3). Over half of the program's hospice expenditures (53.4 percent) went to free-standing hospices, 27.8 percent to home-health-agency-based hospices, 17.4 percent to hospital-based hospices, and 1.4 percent to SNF-based hospices (HCFA, 1998a).

Medicare hospice payments grew rapidly between fiscal years 1990 and 1996. However, the projected growth per hospice enrollee in fiscal years 1997 to 2002 is less than the average for all other

Medicare benefits (Figure 4). This growth reflects increases in average lengths of stay, and heavier utilization of more costly levels of hospice care. For example, between fiscal years 1994 and 1995 total hospice continuous care hours climbed by 73 percent and inpatient respite days by 60 percent, while total hospice routine care days rose by 36 percent and general inpatient days by 39 percent. Average length of stay actually fell slightly (from 58.9 days to 58.8 days) (Hospice Association of America, 1997).

END-OF-LIFE COSTS AND MEDICARE'S HOSPICE BENEFIT: LESSONS FROM THE LITERATURE

Although this review found few new studies of patient and family outcomes relating to hospice, the debate over whether hospice is more economical than conventional care continues in the literature. This dialog is not surprising, given that the amount of health care resources consumed in the last year of life has become a significant national concern. Lubitz and Riley (1993), who examined Medicare data for 1976, 1980, 1985, and 1988, found that almost a third of program payments (27 percent to 30 percent) each year were for the small percentage (5 percent to 6 percent) of beneficiaries who died in a year.

Studies of Medicare's hospice benefit in the early 1990s showed that expenditures varied by type of hospice – those affiliated with a hospital, SNF, home health agency, or free-standing (Banaszak-Holl and Mor, 1996). They found significant differences in costs, depending on the setting. SNF-based hospice programs were costliest, while those in free-standing facilities were the least expensive. They also found that hospices based in SNFs and hospitals attracted more non-white, female beneficiaries and fewer beneficiaries with non-cancer diagnoses, suggesting that spending differences may be related to what types of patients choose a particular hospice program. In SNF-based hospices, for example, the study data suggested that hospice patients had lower functional status—or at least a more complex cancer diagnosis—than patients who used other types of hospice programs.

The National Hospice Study (NHS) was the first examination of the difference in end of life costs for those dying with or without hospice care (Greer, et al. 1983). The study, which consisted primarily of cancer patients, evaluated hospital-based and home-based hospice care. The latter appeared to save money by substituting home care for inpatient hospital care. Occurring largely in the last months of life, these savings offset higher costs incurred by patients served in hospice for longer than two months (Mor and Kidder, 1985; Birnbaum and Kidder, 1984). Mor and Kidder (1985) comment that the savings estimates may be sensitive to any shifts in time of entry into hospice or to the mix of patients admitted to hospice. Considering this, the NHS findings may not be generalizable to hospice beneficiaries in nursing facilities.

Legislative changes in hospice care financing and their cost effectiveness have also been examined. In 1988, HCFA sponsored what became an influential study of Medicare's hospice benefit during its first three years of the program (Kidder, 1992). Multivariate analyses matched hospice and non-hospice decedents by length of enrollment, controlling for geographic access to certified hospice programs. For hospice users the enrollment period was the length of hospice enrollment. For non-users, it was the time that elapsed between the first claims with a diagnosis of cancer and the date of death. Based on comparisons of Medicare Part A expenditures in the last seven months of life for hospice and non-hospice decedents with at least one diagnosis of malignant cancer (90 percent had cancer as a primary diagnosis), Kidder estimated that Medicare Part A saved 26 cents for every dollar it spent on hospice patients. Much of the savings occurred during the last month of life, largely due to home care being substituted for inpatient care. Importantly, the study also found that savings were associated with length of enrollment in hospice, decreasing the longer a beneficiary is enrolled. An exception was hospice patients with the longest length stays (180-210 days) whose hospice care still resulted in savings, a net of 6 cents on every dollar spent for

hospice care (Table 10). These savings were greatest—\$2.77 for every dollar spent – in the last month of life.

In addition, although Medicare Part A expenditures generally were lowest in free-standing hospice programs, long-stay enrollees in hospices based in home health agencies, hospitals, and nursing facilities also saved Medicare dollars during the last month of life. For example, Medicare Part A saved one dollar for every dollar spent in the last month of life for hospice patients in hospital and skilled nursing facility based hospices with enrollments of at least 150 days. Similar long-enrollment hospice patients (controlling for demographic factors and medical conditions) in free-standing facilities represented dollar losses to Medicare Part A in the last month of life.

Despite cost savings, Kidder concluded that Medicare’s hospice benefit is not likely to be “an important tool for containing costs of terminally ill Medicare beneficiaries.” Hospice reimbursement rate increases and preliminary evidence at the time of the study that lengths of hospice enrollment were increasing influenced Kidder’s thinking. In addition, both Kidder and Scitovsky (1994) thought that estimated savings associated with hospice care might be too high due to selection bias. That is, people who choose hospice probably would have declined expensive, invasive care even if they had not enrolled in the palliative treatment program. Presumably, hospice enrollees differ from patients who choose not to enroll in hospice in the first place (assuming the option is available). (Because of data limitations, Kidder’s analysis could not optimally control for selection bias. Thus, some of his estimated savings could be too high.)

In 1994, HCFA submitted to Congress a report, *High Cost Hospice Care*, in response to OBRA 89, which mandated an examination of costly hospice care provided to Medicare beneficiaries and an evaluation of the adequacy of payment to cover these cases (HCFA, 1993). HCFA found that high-cost cases were more likely to be associated with unusually long lengths of stay in hospice care rather than

expensive medical intervention. Since Medicare pays for hospice on a per diem basis and since per diem rates vary for each level of care, the study concluded that hospices were already receiving appropriately higher payment for these long-stay patients and recommended continuing the current payment system.

In 1995, the National Hospice Organization (Lewin-VHI, INC., 1995) sponsored a study to determine if the cost savings Kidder (1992) had observed earlier had persisted, given the health care environment of the 1990s. The research design was similar to Kidder's: All Medicare enrollees who had died between July 1 and December 31, 1992, and who had a primary diagnosis of cancer on at least one claim were studied. (By contrast, only 90 percent of Kidder's sample had cancer as a primary diagnosis.) While Kidder examined Medicare Part A expenditures only, the Lewin study compared Medicare Part A and B spending. Decedents with one or more hospice claims were classified as hospice users; those with no such claims were designated as non-users.

A variable called "length of illness" was created and used for matching. This variable represented the time between the first claim with the primary diagnosis of cancer and the date of death. (The comparable variable in the Kidder study represented time between the first claim with any diagnosis of cancer and the date of death.) For hospice users the enrollment period was the length of hospice enrollment; for non-users, it was the length of illness. As in Kidder's study, multivariate regression analyses were performed separately for seven groups of decedents who were matched by length of enrollment. Also, as in Kidder's study, variables reflecting geographic access to Medicare-certified hospices were included in multivariate models. Analyses by Medicare-certified hospice provider type (i.e., free-standing or home-health-agency, hospital or SNF-based hospice organization) were not performed.

Overall, whether examining Medicare Part A expenditures alone or combined with B spending, hospice beneficiaries cost Medicare less in the last month of life (Tables 11 and 12). Like Kidder's study,

Lewin's found that Medicare Part A savings fell the longer patients were enrolled in hospice before dying (with no savings for patients in hospice 120 days or longer) (Table 11). Unlike patients in the Kidder study, hospice patients with the longest stays (180 to 209 days) did not save Medicare Part A dollars. However, Lewin's study did not calculate Medicare Part A savings for long-stay patients by hospice provider type, in contrast to the Kidder study. Because of that, it is possible that Medicare Part A savings accrue for long-stay patients enrolled by a certain type of hospice provider, such as a SNF.

Looking at Medicare Part A and B spending by length of hospice enrollment, on average, hospice saved Medicare dollars, regardless of length of stay (Table 12). These savings accrued in the last two months of life, regardless of category. The authors concluded that despite longer stays, a shift to unlimited days of coverage under, and the rapid growth in hospice enrollment for beneficiaries with cancer, hospice would still save Medicare money.

Like the Kidder study, Lewin's work may be affected by inadequate control for selection bias. However, as the Lewin investigators argued, even if selection bias were better controlled, one still would find Medicare savings associated with hospice enrollment because of the size and significance of the hospice effect. (This observation is likely applicable to the Kidder study as well.) Both studies thus provide some evidence that Medicare's hospice benefit saves the program money. However, since both included primarily hospice patients with cancer diagnoses, such savings for Medicare hospice patients with other diagnoses cannot be inferred.

Although the literature suggests that, for dying patients, hospice care is a cost-effective alternative to conventional care, some have challenged these findings. Emanuel and Emanuel (1994), for instance, called the cost savings associated with advance directives and hospice care at the end of life an illusion. The researchers point to the fact that savings cannot be generalized beyond cancer patients because data are

limited and there are too few randomized studies. They also cite the higher socioeconomic status of hospice patients as enabling them to get additional services not included in cost estimates, and point out the fact that if overall rates of hospitalization at the end of life decline, so will the savings seen from hospice.

Emanuel's meta-analysis of cost savings from hospice care (1996) concluded they were far lower than most people had anticipated. In the last year of life, for example, he found very little savings (zero to 10 percent of costs). In the last six months, savings rose to 10 percent to 17 percent, reaching 25 percent to 40 percent for care in the last month of life. This review also outlined methodological difficulties that make it hard to assess some of the existing studies of cost savings related to hospice. These problems include selection bias, time frame of assessment, types of medical costs assessed, reporting of savings, and generalizability.

On the basis of current evidence, hospice seems to provide cost savings over conventional care for at least the last one to two months of life. However, controversy persists. The literature continues to call for a large-scale, randomized study of costs lasting longer than six months. Emanuel (1994) has argued that a prospective cohort study of terminally ill patients that assesses preferences for life-sustaining treatments and social support and follows the patients until death is a more feasible undertaking. Using these data, patient preferences and other factors can be controlled for and information about cost, choice of hospice and other factors can be examined.

10. ISSUES REGARDING ACCESS TO THE MEDICARE HOSPICE BENEFIT

GEOGRAPHIC ACCESS

As Petrisek and Mor (1998) documented, the percentage of nursing facility residents enrolled in Medicare's hospice benefit varies substantially by state and by regions within states. The extent to which the geographic availability of Medicare-certified hospice providers versus the individual characteristics of nursing facilities and their case-mix affects the individual nursing facility's choice to offer hospice care to its residents has not been documented. The researchers found that in counties with greater hospice penetration, nursing facilities were more likely to have at least 5 percent of their residents on the hospice benefit. Furthermore, both Petrisek and Mor (1998) and Jones and colleagues (1997) showed that a nursing facility's characteristics and its staff influence its decision to offer Medicare hospice care.

Brown University's Center for Gerontology and Health Care Research is currently conducting research to measure the importance of geographic availability relative to facility factors in a nursing facility's decision to offer hospice care. Research to date clearly shows that availability varies substantially geographically, for reasons besides beneficiary demand.

The influence of factors other than patient need in determining whether certain services are provided is not unique to hospice. For example, the Dartmouth Atlas of Health Care (1998), shows Medicare beneficiaries' utilization of health care resources at the end of life and site of death vary considerably depending on where they live. In the Dartmouth study, a community's supply of hospital resources (i.e., beds), rather than patient demand, was the strongest predictor of dying in a hospital. In other words, the more inpatient beds in a community, the more likely was death to occur in a hospital. Petrisek and Mor's work (1998) suggests that the same type of relationship exists between a community's hospice

penetration and the proportion of nursing facilities in the community with at least 5 percent concentration of hospice beneficiaries. The greater a community's total number of hospices and the greater the percentages of for-profit, institution based and larger hospices, the more likely a nursing facility resident will enroll in Medicare's hospice benefit. The question raised in the Dartmouth study and relevant for hospice care in nursing facilities is which rate is the right one?

Using NHO's 1997 National Hospice Census and the 1989 Area Resource File, Hamilton (1993) examined the sensitivity of hospice certification to changes in fixed-price reimbursement. After simulating certification decisions, outcomes of alternative reimbursement methodologies were assessed. Of primary interest was whether the Medicare hospice benefit increased access to hospice care by enabling a hospice to serve more patients than it would if it were not certified.

Hamilton found that the Medicare hospice and home care reimbursement rates played a significant role in a hospice's decision on whether to become Medicare-certified. A one dollar increase in the hospice payment rate resulted in a 1.7 percent increase in the probability of certification, while a one dollar increase in the home health agency payment rate resulted in a 1.9 percent decrease in the probability of certification. Also, the Medicare hospice benefit was found to increase access to hospice care by enabling Medicare-certified hospices to serve more patients. In her work, Hamilton noted that the wage indices HCFA uses to adjust hospice reimbursement rates did not fully reflect actual variations in labor costs across regions and thus failed to adjust reimbursement rates correctly for the real cost of certification across region. Hamilton speculated that these disparities resulted in differential access to hospice care for Medicare beneficiaries.

To our knowledge, whether such disparities are associated with the current geographic availability of Medicare certified hospices has not been studied. Nor have researchers looked at whether reimbursement mechanisms compensate hospice providers equally across geographic regions for the

differential costs of providing Medicare hospice care in a nursing facility. However, Hamilton's work suggests that differences in geographic access to Medicare hospice in nursing facilities (not associated with Medicare beneficiary demand or facility factors) can be modified by adjusting the reimbursement structure and rates. These questions may be addressed better in the future as hospices begin submitting cost reports to the Medicare program.

MINORITY ACCESS

There is some evidence that minorities experienced differences in access to Medicare hospice depending on provider type and payer. As discussed previously, hospital-based and SNF-based Medicare-certified hospices enrolled higher percentages of non-whites (13 percent) than did free-standing facilities and hospices based in home health agencies based facilities (9 percent and 10 percent) (Banaszak-Holl and Mor, 1996). Access to Medicare hospice by Latinos and African Americans may be limited by the need for continuity of care and the resulting (implicit) requirement for a primary caregiver (Gordon, 1995).

The higher percentages of minorities cared for in institution-based hospice programs may reflect the lower need for a primary caregiver in these settings. Indeed, hospice patients are more apt to be non-white than their non-hospice Medicare counterparts (9 to 13 percent versus 21 percent) (NCHS, 1996 and 1998; Petrisek and Mor, 1998). Whether this difference is due to greater variation in age and casemix for hospice patients across all payer types, to time period differences, or to the design of the Medicare hospice benefit itself is unknown.

In its resolution on access to hospice care, the National Hospice Organization states its "support [of] the principle of access to hospice care for all terminally ill individuals regardless of age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, availability of primary caregiver, or ability to

pay” (Harper, 1995). A national task force on minorities’ access to hospice care, convened by NHO in 1987, concluded that data were inadequate and outlined actions plans. Since then, awareness about access problems for minorities has grown. The *Hospice Journal*, for example, devoted an entire issue to this subject, most of which consisted of editorials and descriptive research reports (NHO, 1995c).

ACCESS FOR PERSONS WITHOUT CAREGIVERS OR ELIGIBLE FOR MEDICARE SKILLED NURSING FACILITY CARE

Primary caregivers provide direct patient care and support, or, alternatively, assume responsibility for arranging whatever care hospice does not provide directly. (NHO, 1997b). Although Medicare does not require a primary caregiver to ensure continuity of care, beneficiaries who want to be cared for at home need such a person (or a group of committed caregivers). In nursing facilities, staff members act as surrogates. That setting, then, may be the only feasible hospice option for beneficiaries who lack other caregivers. Banaszak-Holl’s and Mor’s (1996) observation that beneficiaries enrolled in Medicare-certified, SNF-based hospice programs are less likely to have caregivers in the community supports this notion.

Second, beneficiaries discharged from the hospital to a nursing facility may have problems accessing the hospice benefit. According to anecdotal reports, nursing facility administrators “discourage” Medicare hospice enrollment for dual-eligible beneficiaries who qualify for Medicare’s SNF coverage because Medicare’s SNF benefit has a higher room and board payment rate than does the typical Medicaid nursing facility benefit. Since Medicare’s hospice benefit does not include room and board coverage, dual-eligible enrollees on hospice would have their NF costs paid by Medicaid. If a beneficiary enrolls in hospice, the NF would receive only the Medicaid residential rate while the hospice would be paid for the hospice care. Similarly, Medicare-only beneficiaries who have just been discharged from a hospital also have a disincentive to enroll in hospice rather than be admitted to a SNF because the latter covers room and board

while hospice does not provide that type of coverage. Although there are no hard data, anecdotal reports suggest that beneficiaries have less access to hospice care if no caregiver is available at home. The implication for quality of care for these beneficiaries is unknown.

ACCESS TO HOSPICE FOR AIDS PATIENTS

This literature review also found many articles on access to hospice care among persons with AIDS. Although in principle hospice programs accept these patients, in practice that is problematic. The key issues for AIDS patients relate to difficulties in prognostication about their illness, rapid development of new treatments, the view of HIV as a chronic condition, and questions about reimbursement for hospice care (von Gunten, et al., 1991; Tehan, 1991). Buchanon's research (1995-96) on Medicaid recipients with AIDS indicated that the range of services, including hospice care, differed among states. (Medicaid's hospice benefit to persons with AIDS is optional.) Buchanon speculated AIDS patients might be more expensive to treat than other hospice patients. Of the six states with a high incidence of AIDS (all of which offered Medicaid hospice), only New Jersey and New York made allowances for Medicaid payment rates for AIDS patients in hospice.

Nonetheless, persons with AIDS seem to have more access to hospice than do patients with other non-cancer diagnoses (NHO, 1996). Data from the NHO showed that one in three persons who died of AIDS in 1995 was in hospice. That figure is comparable to people who died of cancer, but is a much higher share than for those succumbing to chronic heart disease (one in 10 of whom die in hospice). New treatments, however, have changed the disease trajectory for AIDS; it has now become a chronic illness with a mortality that is hard to predict. This changed disease trajectory is thought to have resulted in a smaller hospice enrollment of AIDS patients and in much shorter hospice lengths of stay for AIDS patients.

Both of these effects presumably are related to the difficulty in predicting mortality for AIDS patients (NHO, 1998b). Considering this, the following discussion may be appropriate for the diagnosis of AIDS as well.

ACCESS BY DIAGNOSIS - PROGNOSIS IN NON-ONCOLOGIC DISEASE MODELS

A final issue related to access is whether Medicare's hospice benefit is as available to beneficiaries with terminal diagnoses other than cancer. An issue is that accessibility is driven by a physician's ability to make a definitive, six-month terminal prognosis (if the illness runs its normal course), rather than by the beneficiary's needs. The imprecision of survival prognoses for people with chronic illnesses like dementia, congestive heart failure, and chronic lung disease may limit accessibility to this benefit for most nursing facility residents (Christakis and Escarce, 1996; Luchins et al., 1997; Lynn et al., 1997). The ability of doctors to predict the course of a patient's terminal illness accurately became an important consideration when Medicare's hospice benefit was established. The inherent difficulties in making such predictions have caused confusion about timing patient referrals to hospice as well as the appropriateness of patients for the Medicare hospice benefit.

Early literature suggested that prognostication for terminally ill cancer patients was an inexact science and that performance scales (e.g., the Karnofsky scale) might be helpful in making these assessments (e.g., Yates et al., 1980; Forster and Lynn, 1988; Reuben et al., 1988). Indeed, the Institute of Medicine's book, *Approaching Death: Improving Care at the End of Life*, reaffirmed difficulties in making prognoses for patients with cancer and non-cancer diagnoses (IOM, 1997).

In a pilot project, Christakis (1994) examined the timing of referral to an outpatient hospice and possible predictors of that referral. The researcher found that 15 percent of patients died "early" (within seven days) and 12 percent died "late" (after 180 days). Although many of the variables Christakis studied

were not related to length of hospice stay, clinical factors like depression and whether the patient was mentally oriented were related to lower death rates. So, too, were prostate cancer and cardiovascular disease. The author concluded that making accurate prognoses for different types of terminal illnesses called for more study and that results might lead to more timely referral to hospice programs.

On examining length of survival in 1990 among Medicare hospice patients in California, Florida, New York, Pennsylvania and Texas, Christakis and Escarce (1996) found the median survival time was 36 days. The researchers considered 15 percent of the referrals to be early and 14.9 percent to be late. Additionally, survival time varied markedly, depending on diagnosis (i.e., survival was longer in people with more chronic terminal illnesses) and by type of hospice provider. For instance, patients being cared for by newer, for-profit, larger, hospices that were not based in hospitals lived longer than their counterparts in other types of facilities. As for survival times, patients with renal failure, leukemia or lymphoma, and liver or biliary cancer did not live as long as those with dementia, chronic lung disease and breast cancer. Looking at gender, men on hospice died before women (10 percent increased risk of death) while non-Latino whites died before non-whites (11 percent increased risk of death).

Christakis and Escarce speculate that given the short lengths of many hospice stays, the high up-front costs associated with evaluating newly admitted hospice patients, and the hospice per diem payment system, some hospices may “encourage the early enrollment of patients as a way to recoup the high up-front costs associated with admission.” Even so, they are not certain whether hospices having a higher share of long-stay patients are eliminating barriers or whether patients whose life span is expected to exceed six months are being enrolled inappropriately. As for short lengths of stay, the authors theorize that Medicare’s hospice benefit requirement of a six-month terminal prognosis, together with the imprecision of terminal prognoses for those with chronic terminal illness, may lead to late referral to hospice. However, they also

point out that late referral is a cultural phenomenon not unique to the United States, noting that it may reflect more fundamental factors related to how physicians and patients confront terminal illness.

The researchers maintain that more study is needed on characteristics of physicians, patients, and hospice providers as these relate to timing of enrollment in hospice programs. They conclude that earlier referral to hospice may enhance outcomes for patients and families, as well as reduce the cost of end-of-life care.

The Christakis-Escarce study was limited by its inadequate controls for clinical severity. Because claims data were used for analysis, a Charlson score reflecting diagnosis mix was the only severity measure used. Reuben and others (1988) documented that functional performance (using the Karnofsky Performance Scale) is the most important clinical factor in estimating cancer patients' survival time. They also found, however, that the clinical symptoms of shortness of breath, problems with eating or anorexia, trouble swallowing, dry mouth, and weight loss were independently predictive of survival. When they controlled for patient functioning and symptomatology, neither gender nor site of cancer was associated with length of survival. Although the Christakis and Escarce study observed survival in hospice (and thus also reflects referral patterns), rather than survival overall, the work by Reuben and colleagues suggests that observed differences by gender and diagnosis (especially by site of cancer) may be overestimates.

To help overcome problems with prognostication, NHO published guidelines for identifying patients with non-oncologic terminal illness who are likely to have significantly decreased prognosis if the illness were to follow its normal course (NHO, 1995a and 1996). Besides general non-cancer guidelines, NHO also publishes more specific guidelines and worksheets for heart, pulmonary, liver, renal, and HIV disease, as well as for dementia, stroke and coma, and amyotrophic lateral sclerosis. NHO's most recent general non-cancer and end-stage dementia guidelines are in Appendix C.

One barrier to utilization of the hospice benefit has been difficulty with prognostication, even though early pilot hospice programs for at least dementia patients were both feasible and ethical. For example, Luchins and colleagues (1997) published the first study of the utility of the NHO guidelines in evaluating the prognosis of dementia patients. In that study, the researchers also developed and evaluated eligibility criteria for the Medicare hospice benefit for patients with advanced dementia and related medical complications (see Appendix C for criteria). Their criteria predicted a median survival time of 4 months and a mean survival of 6.9 months. Of the patients in their sample, 38 percent lived more than 6 months. Conversely, NHO guidelines identified patients who had high mortality and a short time to death. The authors caution that using NHO guidelines might decrease access to hospice for many dementia patients.

According to Volicer (1997), the Luchins study suggests that the NHO end-stage dementia guidelines can predict who will not die within six months, but not who will. This poor sensitivity in detecting who will die within a 6 month period results in lack of hospice access for dying patients who do not satisfy the NHO guidelines (see Appendix B). Notably, however, sensitivity vastly improved when the Functional Assessment Staging criteria (FAST) could be applied (which was possible for only about half the patients studied). NHO states that its 1996 guidelines have made changes to the FAST criteria so that they are applicable to many more patients (NHO, 1996).

Commenting further on the Luchins study, Volicer observes that the findings cannot be generalized. Luchins's patient population was limited by enrollment criteria (those persons with current or recent history of serious complications), whereas NHO guidelines only require the presence of a co-morbid condition in the last year. Also, the Luchins study compared its criteria with NHO dementia guidelines using FAST criteria only, whereas NHO's guidelines also contain alternative criteria on medical complications.

Medicare fiscal intermediaries now use adaptations of NHO guidelines to review eligibility for hospice admission. One proposed revision was evaluated to determine whether the criteria could pinpoint patients with fewer than six months to live (Schonwetter et al., 1998). This study applied the criteria to 104 hospice patients who died within six months of being admitted to a Florida hospice. The criteria identified only 35 percent of these patients as meeting hospice eligibility criteria. While 94 percent of the decedents with the diagnosis of stroke and coma were identified as eligible for hospice, only zero to 44 percent of decedents with the diagnoses of dementia, cardiac disease, amyotrophic lateral sclerosis, liver disease, renal disease, pulmonary disease or HIV were identified as eligible for hospice. The average lengths of hospice stay for those decedents determined to be ineligible for hospice ranged from 16 to 48 days.

The researchers noted that the criteria they studied were more restrictive than NHO's guidelines. However, they did not compare eligibility determinations using the NHO guidelines. Although the study population was small and included decedents at just one hospice, the findings raise concerns about how Medicare fiscal intermediaries' use of eligibility criteria affects access to Medicare hospice for beneficiaries with terminal diagnoses other than cancer.

11. RESEARCH ON THE QUALITY OF HOSPICE CARE

Hospice is one of the few innovative health care services introduced in the United States that was evaluated extensively before being adopted as a Medicare benefit. The largest, most comprehensive study of hospice care was the National Hospice Study (NHS), which evaluated the impact of a federally funded hospice demonstration program introduced by the Health Care Financing Administration (Mor et al., 1988). The NHS study included primarily people with a diagnosis of cancer and evaluated two hospice options – hospital-based hospice (i.e., hospice had inpatient beds) and home care based hospice (i.e.,

hospice had no inpatient beds). Patients served by home-based hospice programs received substantially more care at home and were in the hospital for fewer days in the last month of life than hospice patients cared for by hospital-based programs or patients receiving conventional non-hospice care (Greer et al, 1986). Patients served in any type of hospice were significantly less likely than conventional care patients to receive diagnostic testing or intensive therapies such as surgery, chemotherapy, radiation therapy, transfusions, and intravenous lines in the last weeks of life.

Another study, funded by the Department of Veterans Affairs (VA) evaluated an inpatient hospice program in a single VA hospital, using a randomized trial approach (Kane et al., 1984). Both the National Hospice Study and the VA analysis found that in terms of quality, outcomes in good hospice programs were comparable to those with good conventional care. These observations suggest that an individual and his or her family should be able to choose the style of care they prefer.

This section reviews current literature on whether hospice as a model of terminal care maximizes quality of life for patients and families and whether outcomes differ for hospice and non-hospice patients. In examining the effectiveness of hospice, patient outcomes (e.g., pain and symptom control), family member outcomes (e.g., grief), and persistent measurement issues are discussed.

PATIENT OUTCOMES AND FAMILY OUTCOMES

Findings from the National Hospice Study suggested that patients served by home-based hospices received substantially more care at home and were hospitalized for fewer days in their last months than those in hospital-based programs or those receiving conventional non-hospice care (Greer et al., 1986). Patients in any type of hospice were significantly less likely than those getting conventional care to receive

diagnostic testing or intensive therapies like surgery, chemotherapy, radiation, therapy transfusions, and intravenous lines in the last weeks of life.

There were few differences in quality of life or symptom management between hospice and non-hospice patients, a National Hospice Study finding corroborated by Kane and others (1984). However, in the NHS study, patients in hospital-based hospices were significantly less likely to be “in persistent severe pain” than patients who received conventional care at both three weeks (3 percent versus 14 percent) and one week (5 percent versus 22 percent) before death. Non-significant differences were also seen for patients treated in hospital-based hospices rather than home-based hospice programs (Morris et al, 1986). The researchers speculated that these observed differences might result in part from the ability of a hospital-based program to more closely monitor pain and calibrate treatment in a controlled environment.

A related finding was that patients in hospital-based hospices were more likely to have an analgesic prescription and to have consumed analgesics than patients in the conventional or home-based hospice setting (Goldberg et al, 1986). For example, 91.3 percent of the hospital-based patients had an analgesic prescription compared to 66.1 percent of the home-care based and 69.7 percent of the conventional care patients. Additionally, both hospital-based and home-based hospice patients were significantly more likely than conventional care patients to receive medications orally, rather than by more invasive methods such as intramuscularly or parenterally. Hospice patients were also significantly less likely to receive analgesics on a prn (as necessary) basis rather than on a scheduled basis (Goldberg et al, 1986). These findings suggest hospice is superior for managing pain. However, since a randomized control trial by Kane and colleagues (Kane et al, 1984; Kane et al, 1985) failed to replicate these pain management findings their generalizability should be viewed with caution.

The study by Kane and colleagues was funded by the Veteran's Administration and used a randomized trial approach to evaluate the impact of an inpatient hospice program in a single VA hospital. The study sample was predominantly male. The trial showed no difference in pain control, symptoms, or levels of depression or anxiety for hospice and nonhospice patients. However, hospice patients were more satisfied than non-hospice patients. Measurement in the Kane and colleagues study differed from the NHS study in two important ways: 1) Kane only used patient reports while the NHS study used patient and caregiver reports, especially near the end of life when a large proportion of patients were nonresponsive) and 2) it made no attempt to measure pain and symptom levels at comparable time periods prior to death as did the NHS study (Masterson-Allen and Mor, 1988).

In a 1987 review, Mor and Masterson-Allen concluded there was too little evidence to support the claim that hospice care was more effective than conventional care in treating patients' physical or psychological symptoms or in improving overall quality of life. Hospice did, however, seem to facilitate patient choice in location of death. Control over that aspect of dying was related to hospice patients' having greater satisfaction with care than non-hospice patients.

Very little research has been added to the literature regarding the influence of hospice on patient outcomes. One study examined site of death for cancer patients. It confirmed that hospice patients with cancer were more apt to die at home than cancer patients who were not on hospice (McMillen 1996; Moinpour and Polissar, 1989). Two other studies compared outcomes of hospice patients with those of non-hospice patients, while two more looked at quality-of-life issues in hospice patients.

Wallston and his colleagues (1988) used data from the National Hospice Study to examine "quality of death" for hospice and non-hospice cancer patients. They developed this measure for the study and defined it as "experiencing in the last three days of life feelings and events that terminally ill patients reported

they desired.” Patients’ primary care providers perceived quality of death was higher for hospice patients than for those who had received conventional care. Although the components of the researchers’ quality of death scale were not analyzed individually, the largest difference was seen in the reports of “patient able to stay home as long as he/she wanted.” Fully three-quarter (76 percent) of primary care providers for hospice patients agreed, in contrast to 53 percent of those caring for non-hospice patients. The study results appear to be a promising development in measurement, although further research is needed to determine the reliability and validity of the researchers’ scale.

Hendon and Epting (1989) examined depression, hopelessness, and death threat in hospice patients, cancer patients with remission, and patients with a temporary illness. Though hospice patients were more depressed than the patients with a limited illness, they were no more depressed than cancer patients. Hospice patients were as optimistic as those with a limited illness, but less optimistic than cancer patients in remission. As predicted, the hospice patients were the least threatened by their own death in comparison to the other patients. The authors suggest that hospice patients had integrated their death into their daily existence because they were in an environment that facilitates coming to terms with death.

Two studies focused on the quality of life of cancer patients receiving hospice services. The first evaluated patients’ quality of life as perceived by patients and caregivers at admission, and three weeks after hospice services had commenced (McMillan and Mahon, 1994). There was no significant difference in patients’ own ratings on the overall quality of life scale, although some individual items suggested improvement. Caregivers, by contrast, perceived that patients’ quality of life was significantly better. The authors suggested that hospice services may be considered as effective since there was no great decline in quality-of-life scores, an observation supported by other studies of patients near the end of life. However, the sample size here was quite small. Further, although quality-of-life scores improved for half the patients,

they fell for the other half. McMillan (1996) later replicated the stability of quality of life scores in cancer patients receiving hospice services.

Since hospice services focus on the patient and the family as the unit of care and target their services as such, outcomes experienced by family members are equally important in evaluating the effectiveness of hospice. Most research has focused on a family's experiences during bereavement rather than while the patient is still alive. Mor and Masterson-Allen (1987) document only a handful of studies that compared hospice caregivers' anxiety and depression reactions with those of conventional care providers. The results of these studies were mixed. The National Hospice Study, for example, found no differences in anxiety, depression, or an array of other indicators of distress. On the other hand, a few studies found some evidence that hospice caregivers were less anxious than conventional care providers. Much more attention has been given to bereavement outcomes of family members who received hospice care, with no conclusive evidence supporting the superiority of hospice over conventional care.

Since Mor and Masterson-Allen's 1987 review, only a few studies have addressed family outcomes. One looked at family needs during a member's final days and death from cancer. Two others examined the bereavement experience. Dawson (1991) compared how well hospice and conventional care met the emotional needs of families whose loved one was dying from cancer. Although overall satisfaction with hospice care was consistent among the hospice groups, family members of those who had home hospice care reported the highest level of satisfaction with both the nurse and meeting basic needs.

Ransford and Smith (1991) explored the grief experience of surviving spouses of patients who died in a hospice or a hospital acute care oncology ward. At six months after the patient's death, differences were reported between the two groups, with surviving spouses of hospice patients being better adjusted on depression and orderly physical appearance scales but not on a measure of anxiety. At 12 months, the

differences were even greater: Those whose spouse had hospice care scored significantly better on most measures of grief resolution than those whose spouse died in the hospital. Speer and others (1995) reported no differences in the bereavement adjustment of caregivers based on their spouses' length in hospice before death.

It is clear from reviewing the literature that patient and family outcomes have become less of a research focus. The limited number of studies add little to support the contention that hospice care produces better care for patient and family outcomes than conventional care could, although better measurement tools are needed. When examining both quality of life and quality of care while dying, most researchers choose from limited existing measures, each of which seems to capture a different aspect of care. Two conferences have been convened to address the measurement problem for those who study end-of-life care. These meetings will likely change the face of hospice and palliative care research in the coming years. (See www.chcr.brown.edu/ for information on the palliative care outcomes collaborative.)

12. THE DYING EXPERIENCE OF NURSING FACILITY RESIDENTS

No population-based, empirical study has described the dying experience of nursing facility residents. In the SUPPORT study, seriously ill patients who died in hospitals often had severe pain and dyspnea in their final days (The SUPPORT Investigators, 1995). Two out of three dying persons found it difficult to tolerate emotional symptoms in the last days of life, according to family members. Other studies by nursing facilities show that physicians often fail to identify pain as a problem (Ferrell, 1995; Sengstaken, 1993), to reassess pharmacologic interventions (Wagner et al., 1996), or to prescribe adequate pharmacologic treatment for nursing facility residents (Bernabei et al., 1998; Ferrell, 1995; Wagner, 1996). Ferrell and colleagues (1995) found that most nursing facility patients were given only acetaminophen. In five

states, Bernabei and colleagues found that only 26 percent of those nursing facility residents with cancer and daily pain received any analgesic agent, and only 26 percent of those patients with cancer received morphine. Presence of pain was associated with age, gender, race, physical function, depression, and cognitive impairment. It was prominent among older and minority patients.

Hanson and colleagues (1997) studied deaths of 461 older adults across sites of death in North Carolina central and eastern counties having no university medical centers. Bereaved family members were asked about their perceptions and satisfaction with terminal care, as well as for recommendations to improve it. While family perceptions and satisfaction with care were not reported separately for 28 percent of the deaths occurring in nursing facilities, those facilities had the smallest share of positive comments (51 percent) when compared with hospitals, the decedent's home, or other locations.

These findings reconfirm the opinion of an expert panel convened by the Agency for Health Care Research (AHCPR). The panel concluded that the frail elderly—especially those in nursing facilities—need special attention for pain management (AHCPR, 1994). The findings also raise concerns about possible nursing facility shortcomings in all the major health care quality problem areas identified by the Institute of Medicine (IOM) (Lohr, 1990). The IOM's study found that (1) care may be underutilized (i.e., poor symptom assessment and management and inaccessibility to palliative care); (2) care may be overutilized (i.e., unwanted interventions and hospitalizations); (3) technical performance may be poor (i.e., inadequate medical management of symptoms); and (4) interpersonal performance may be inadequate (i.e., failure to fully inform patients and families regarding care and to ascertain and adhere to patient and family preferences). Clearly, study is needed to elucidate the dying experience of nursing facility residents. Also, study is needed to document the “value added” of providing hospice care in these nursing facilities.

13. RECENT END-OF-LIFE INITIATIVES AND DEMONSTRATION PROJECTS

The National Institutes of Health have funded a variety of research projects (related to cancer, Alzheimer's disease, and AIDS), 'educational efforts,' 'demonstration projects,' and clinical trials. One AHCPR-funded dissertation grant (R03HS06619), "The Impact of the Medicare Hospice Benefit on Hospices," which produced the article, "The Impact of Ownership Form and Regulatory Measures on Firm Behavior: A study of Hospices," was applicable to the current review (Hamilton, 1994). In addition, AHCPR has supported work conducted by Christakis and Escarce (Survival of Medicare Patients After Enrolling in Hospice Programs, 1996; NRSA training grant T32 HS00009) and is supporting a new study (HS08691) that is examining the adoption of AHCPR's cancer pain guidelines, a project that will inform the referral and timing of referrals to hospice care.

The Robert Wood Johnson Foundation's Last Act Initiative has funded a variety of grants aimed at improving care at the end of life. It has also supported conferences, educational efforts, and basic research on this topic. One grant partially supported the IOM's (1997) book, *Approaching Death: Improving Care at the End of Life*. A second is examining care of the dying in managed care settings (Fox, 1999). A third is studying the impact of a palliative care team on end of life care in nursing homes (Genesis, 1999).

Another RWJ-funded research effort is the development of a Toolkit of Instruments to Measure End-of-Life care (TIME, see <http://www.chcr.brown.edu>). A central goal of TIME is that measures incorporate perspectives of both patients and their loved ones; are clinically meaningful; and strive for high standards of reliability, validity, and responsiveness.

The National Hospice Organization has received funding through the RWJ's Chronic Care Initiatives for a planning grant to establish the scope of a National Hospice Outcomes Planning Project

(NHOPP). The objective of the planning grant is to determine the scope and design of a NHOPP to assess the impact of various treatment strategies on outcomes of hospice care using the Clinical Practice Improvement study methodology. The project will also create a large, national, integrated database to determine what works best and when for the management of hospice patients.

RWJ and other foundations, such as the Archstone and Andrus Foundations, have also funded demonstration projects examining alternative terminal care models under the “MediCaring” concept (www.Medicaring.org). Demonstration projects under MediCaring combine capitated financing and palliative care models for people with chronic and eventually terminal illness. Participating providers will include various health care systems, including VA, several managed care organizations, and some of the larger hospices. The national project will target alternative service packages for seriously ill populations, particularly COPD and CHF patients. The demonstration differs from Medicare’s hospice benefit because eligibility is not based on a prognosis of six months survival. Outcomes like costs, satisfaction, and symptom management, will be measured. The demonstrations are in the initial development stage.

One project already completed is the development and test marketing of a supportive care benefit for elderly Medicare beneficiaries. Focus groups, expert panels, and telephone surveys were used to assess beneficiaries’ understanding and preferences for an alternative benefit that enhanced the availability of home-based nursing services, maintenance rehabilitation, symptom relief, and terminal care at home without making surgery, intensive care, and hospitalization more difficult to access. Unlike Medicare’s hospice benefit, under this proposed benefit package no specific treatment was made unavailable, and beneficiaries did not have to be certified within six months of death. However, there was a greater focus on pain control and provider continuity of care. This study showed that even though beneficiaries understood the issues, many would prefer staying at home with significant illness and disability (Lynn, 1999).

The Department of Veterans Affairs (VA) also has several important end-of-life initiatives under way. In May 1998, the department sponsored a national strategy summit to discuss ways to improve care for terminally ill veterans. In addition, with RWJ's support VA has incorporated end-of-life care issues into its physician training programs. The VA also developed a Palliative Care Index to measure the proportion of patients with advanced, progressive, incurable illnesses who have discussed options other than aggressive curative treatments and been given psychological, social and spiritual support. Cancer, AIDS, chronic renal failure, congestive heart failure, and chronic obstructive pulmonary disease patients with two or more hospitalizations were randomly sampled to measure the proportion who were receiving individualized plans for comprehensive, coordinated, palliative services.

The VA is also collaborating with the Center to Improve Care for the Dying at George Washington University and the Institute for Healthcare Improvement in a Medicaring project targeting end-of-life care for CHF and COPD patients. About 50 health care providers will participate in this nine-month project to improve care for these patients. In addition, VA recently completed a congressionally mandated study of hospice care that described the numbers and types of veterans using hospice, where they were receiving it, whether patients and families were satisfied with it, estimated costs, and potential barriers and solutions to accessing hospice in the VA system (Hickey et al., 1998).

The Open Society Institute also has funded several major initiatives on end of life issues, including co-supporting the Institute of Medicines's 1997 efforts. OSI's Project on Death in America Campaign has funded projects aimed at understanding and affecting the culture and experience of dying in the United States. One area of attention is financing options and costs of end-of-life care. OSI has sponsored meetings and supported educational materials on this issue. Two other projects are in the early stages. One will focus on educating long-term care providers in the care of the dying, while the second will compare outcomes of

end-of life care (e.g., access to hospice, pain and suffering, satisfaction) in three settings (acute care hospital, nursing facility, and home/hospice) in Oregon.

Other initiatives to improve end of life are described in IOM's *Approaching Death: Improving Care at the End of Life* (1997). More recent initiatives also are summarized in "New Endeavors and Innovative Programs in End of Life Care" in a recent issue of *The Hospice Journal* (Wilkinson, 1998).

14. DISCUSSIONS WITH INDUSTRY AND STATE REPRESENTATIVES

Representatives from the nursing facility and hospice industries, state survey and certification officials, and state Medicaid officials were asked to discuss the different roles of the Medicare and Medicaid programs in covering dual-eligible beneficiaries residing in nursing facilities. Representatives from the provider industries were chosen by staff at the National Hospice Organization, the American Health Care Association, and the American Association of Homes and Services for the Aging. In addition, staff at the Hospice Association of America were included in these discussions. The goals of these discussions were to understand the relative contributions of nursing facilities and hospices in caring for the terminally ill in nursing facilities and the differences in quality of care for residents enrolled in hospice versus those who were not enrolled.

Medicare is the primary payer for hospice services for the dual-eligible because it covers hospice care. States may supplement the Medicare benefit with other medical services not covered by Medicare, such as personal care. In addition, Medicaid may cover room and board costs for dual-eligible hospice enrollees who live in nursing facilities. (States may also provide their own hospice services to Medicaid eligible persons who do not qualify for Medicare.) As noted earlier, the two public programs together, cover the medical and residential costs of dual-eligible beneficiaries living in nursing facilities.

INDUSTRY AND STATE CERTIFICATION REPRESENTATIVES

This section summarizes the issues raised by nursing home and hospice providers, and survey and certification officials. These groups often raised similar issues and shared recommendations as to how the two types of providers could promote better care for the dying, and better integrate and monitor their services. These issues and alternatives for resolving them are discussed here.

Divergent Goals

One problem that underlaid other difficulties in coordinating the care of dual-eligible nursing facility residents on hospice was the divergent goals and perceptions of nursing facilities (either skilled or residential) and hospices. Nursing facility staff and state surveyors view the facility's role as one of restoring health or providing rehabilitation services. This orientation makes it difficult for nursing facility staff to switch between providing restorative/rehabilitative care and palliative care. This issue was mentioned by both the nursing facility and hospice professionals and was complemented by the survey and certification officials' perception that nursing homes are expected to restore function and that death in the nursing homes may often be perceived as a situation requiring greater review. While the state operations manual provides guidance on evaluating whether assessments and care plans are coordinated, the discussants thought this remained a confusing area.

Different "Treatments"

In concert with these viewpoints, respondents also distinguished differences in how dying residents were treated by hospice staff (including physicians and nurses) and nursing facility staff. Hospice professionals specialize in palliative care and are reported to have a particular expertise in caring for dying patients that nursing facility staff do not possess. For example, hospice physicians regard narcotics as pain

management tools. They review care plans to ensure that patients are not being excessively drugged but managed with a level of medication that may be greater than the average resident receives. This is a sensitive issue since NFs can be cited for quality of care issues if a resident is perceived to be overmedicated. Similarly, hospice nurses recognize an unwillingness to eat as a dying patient's right to refuse food rather than a difficulty to be overcome. The NF, on the other hand, is concerned with possibly being cited for substandard care if a resident is malnourished or dehydrated. These citations are less likely since interpretive guidelines were developed for surveyors (Appendix PP in the State Operations Manual) but remain an issue.

Discussants further distinguished the types of services provided by hospice from those provided by nursing home staff. Both agreed that hospice staff spend their time with patients differently than do nursing facility staffs. They may hold a patient's hand or help him or her achieve inner peace prior to death—services that a typical nursing facility staff does not have the resources to provide. In addition, hospices reported regularly providing bereavement counseling for the patient and family (including nursing home staff and residents) in the year following the patient's death. While religious personnel tend to visit in nursing facilities, and some facilities may have a rabbi or pastor on staff, the hospice team consistently includes this type of professional to assist in caring for the dying and their family.

In view of the nursing facility's emphasis on restorative care rather than palliative care, all informants agreed that hospice in the nursing facility improves the quality of care and psychosocial support provided to terminally ill residents and their families or significant others. Participants in these discussions generally indicated that nursing home residents receiving hospice often had more comprehensive assessments and better symptom, pain, and psycho-social management than terminally ill residents not receiving hospice services.

Dying without Hospice in Nursing Facilities

Despite these observations, and perhaps because of them coupled with the recognition that hospice is not available in all communities, most discussants recommended that nursing homes need to recognize that caring for the dying is also an important part of their mission. The State of Colorado has dealt with this issue by developing “comfort measures” that address the quality of care provided to nursing home residents who die without the support of the hospice benefit. These guidelines require that each nursing facility establish policies for caring for terminally ill residents who lack hospice. In addition, this state requires that the facilities supplement the minimum data set with a pain assessment tool to monitor the “comfort” of the dying patient.

Who Is Responsible?

One theme that emerged with most informants (including surveyors) was that nursing facilities are held responsible for their residents’ care, regardless of whether another entity is coming into the facility to treat them. While Medicare rules require both parties to enter into a contract for service delivery and to develop a coordinated plan of care maintained in each patient’s records at the hospice and nursing facility, nursing homes perceive these requirements as inadequate for relieving them from responsibility if problems arise. Some states, including Wisconsin, Colorado, and Kansas, have handled this problem by establishing state guidelines that nursing facilities and hospices must use when treating these patients. (See Appendix D for Wisconsin’s guidelines.) These guidelines require that the contracting providers (i.e., the nursing facility and hospice) clearly spell out each provider’s responsibilities in the contract. Including these guideline requirements in the contract also addresses payers’ concerns that costs (and responsibilities) are being inappropriately shifted between providers for these patients.

Palliative Care Training Needs

All informants, including the state certification officials, agreed that both nursing facility staff and state surveyors would benefit from training regarding hospice and the needs of terminally ill nursing facility residents, in general. Since health care professionals are not routinely trained in providing palliative care, hospices often educate nursing facility staff so they can better respond to dying patients' special needs. Some hospice and survey officials indicated that the role of hospice as educator was one of the most important functions of hospice in nursing homes.

They respondents also suggested that health care providers would benefit from more training in palliative care, and, more specifically, that initial and on-going training in the care of dying residents was needed for professional and paraprofessional nursing home staff. They noted that on-going training was needed because of the high turnover in nursing facility staff, particularly among aides. Also suggested were broader medical educational reforms to teach physicians how to identify dying patients, listen to family members and patients in their choices for care, and train them in appropriate pain and symptom management. All informants recommended training for surveyors in what constitutes proper care (with and without hospice) for the dying nursing home residents and how to monitor this care.

Payment Issues

Because two payers are involved in reimbursing for services to the dually-eligible dying resident, questions about the relative costs and payments for each type of service arise. One question targets the appropriateness of requiring the hospice to manage the residential costs while the other focuses on whether two different payment rates are needed for the institutional and community-based populations.

Room and Board Payments. Both hospice and nursing facility representatives raised questions about the payment procedures for dual-eligible nursing facility residents. Currently, hospices are responsible for all costs of the dying patient. If the patient is dual-eligible, the hospice receives two sets of payments.

First, Medicare pays the capitated per diem for hospice care. Second, Medicaid pays 1) the per diem rates for room and board and 2) personal care costs for non-Medicare services provided by the nursing facility. The hospice, in turn, is responsible for paying all providers, including the nursing facility.

Respondents thought that having the hospices receive the state payment, and in turn, pay the nursing facility creates unnecessary problems. First, it gives the hospice an opportunity to reimburse the nursing facility at some agreed-upon rate which may differ from the state's room and board rate. This issue has been quite controversial, as the OIG study demonstrated (HHS, 1997). In fact, the OIG issued guidelines (FR Oct 5 1999) that room and board payments that exceed what the NF would have received under Medicaid without hospice and hospice payments for "noncore" NF services that are above fair market value would raise anti-kickback concerns. Effectively, this maintains the pass-through nature of the Medicaid room and board payment. Second, having to bill Medicaid for room and board payments adds an administrative burden to hospices' billing and cost management, and is perceived to delay final payments to nursing facilities for occupied beds. Interestingly enough, however, is that anecdotal reports indicate that many hospices reimburse nursing facilities for the per diem within 30 to 60 days (per a negotiated contract). In these cases, it is the hospice that suffers if the Medicaid payments are delayed.

Hospice Payment Levels. A second payment issue is whether Medicare should use different rates for hospice services delivered in nursing facilities than for those delivered in the community. The OIG's report suggests that hospice patients in nursing facilities receive fewer hours care per day than those living in the community. They argue that nursing facility staff, who are considered family according to the rules, provide care that reduces the need for nursing services to be provided by the hospice. The OIG suggested modifying the hospice per diem rates to reflect this perceived difference in resource costs for the two populations. This concern was echoed by state survey officials who expressed concern that the level

of hospice care to nursing home residents was less than the level of care provided to community-based hospice beneficiaries. However, it is difficult to verify this without cost report information.

STATE MEDICAID PROGRAM OFFICIALS

We also contacted Medicaid program officials in the five states (Kansas, Maine, Mississippi, New York, and North Dakota) whose nursing facility data will be used in this project. We reviewed with them the operational issues related to use of Medicare's hospice benefit by dual-eligible nursing facility residents. Kansas, Mississippi, and New York each have a hospice benefit in their Medicaid programs, while Maine was planning to implement one in the fall of 1998.

In terms of administrative processes, officials said that hospices are responsible for obtaining documentation regarding a beneficiary's election of hospice and forwarding it to Medicaid. The methods and time periods for doing so vary by state. In New York, for instance, hospices must inform the local Medicaid Social Services office of the date hospice was chosen. In Mississippi, the appropriate Medicaid Regional office must receive documentation of the nursing facility's discharge of the resident from Medicaid coverage *on the same date* that the hospice admits the patient to its service.

Upon receiving the appropriate notification from the hospice, state Medicaid agencies change their payment databases, and the hospice is designated as the provider-recipient of the Medicaid room and board and personal care service reimbursement for that patient. Because all payment systems are automated, the database must be updated to stop payments to the nursing facility *before the hospice files a claim*. In one state, although the payment system was automated, officials indicated that there was no formal notification process.

“Our system just indicates what nursing facility an elder is in and we automatically pay the nursing facility unless the nursing facility tells us otherwise, which then opens the door for the hospice provider... We simply react when a claim comes in from hospice to pay them when we have already paid the nursing facility. In this case, the nursing facility has not contacted us, so they have to fill out a void for their claim so that Medicaid can then pay hospice only after the void has gone through.”

According to Medicaid officials, timely Medicaid payments to the hospice depend on three steps occurring in the proper sequence. First, the hospice must submit information regarding the date the resident elected hospice care. Second, the Medicaid payment system must be updated. Third, the hospice must file a claim with Medicaid for the patient. Most billing problems reportedly were due to missing steps or performing them out of sequence. For example, a hospice may have submitted a claim along with the notification, or the nursing facility had already been paid for the resident’s “hospice days” when the payment system was updated.

Because of the OIG’s concern that NFs were being paid too much for room and board once a beneficiary enrolled in hospice, we asked Medicaid officials to define room and board as it applied to dual-eligible residents on the hospice benefit. One state referred to the definition contained in its program information for the Medicaid hospice benefit, which was identical to the federal definition, cited the first section of this review (the definition contained in OBRA 85 but deleted by OBRA 90). Other responses were nonspecific, ranging from “everything it takes to care for that resident” to “meals, room, and facility use.”

We also asked officials about their Medicaid payment policies for services not included in the hospice benefit, specifically for beneficiaries or services not covered by Medicare. All states indicated that the hospice would submit a claim for these services. The only exception mentioned was for a physician claim from a non-hospice physician; the physician would bill Medicaid directly if the patient was not dually-

eligible. When we asked about mechanisms to determine whether such claims were allowable or appropriate, Kansas representatives indicated that prior authorization by Medicaid was required for non-terminal care services used by hospice patients. New York officials indicated that the state's payment system would screen out claims for inappropriate (i.e., terminal) services. No states had a schedule of non-terminal reimbursable services and none of the informants had information regarding the rate of denials of such claims.

In the context of the Medicare hospice benefit for dual-eligible beneficiaries, nearly all billing disputes resulted from failing to follow administrative procedures. These disputes were handled quite consistently across states. Medicaid staff members, usually someone with a clinical background, and a fiscal representative, review the claim. Their findings are submitted to the provider who may appeal.

15. A SUMMARY OF ISSUES RELATED TO THE MEDICARE HOSPICE BENEFIT AND ITS USE IN A NURSING FACILITY

Much research is needed to understand the role hospice plays for patients living in nursing facilities. Nursing facilities are increasingly becoming the site of death for the elderly, with one in five dying in this setting (NCHS, 1996). However, the ability of nursing facility staff to manage terminal symptoms and provide adequate levels of psychosocial support to individuals and their families may not be equal to that of the hospice staff. Yet, relatively few residents – less than one percent (0.9 percent) – enroll in hospice (Petrisek and Mor, 1998).

These low enrollment rates may be related to several issues. First, Medicare's enrollment rules require patients to acknowledge they are dying and no longer want curative or heroic efforts but instead are opting for comfort and palliation. Because this is a difficult step, many physicians hesitate to raise the issue of

hospice, or for that matter, the issue of advance directives. In fact, one recent study showed that only 12 percent of the subjects who had advance directives in place had been counseled by a physician about writing the directive (The SUPPORT Investigators, 1995).

Second, physicians must certify patients as having only 6 months or less to live for them to qualify for Medicare's hospice benefit. Because of the intense scrutiny of the OIG's office in recent years, physicians may be hesitant to predict death unless the patient has one of the more predictable diseases, such as cancer. While cancer still dominates the types of patients enrolling in hospice, other chronic terminal conditions, such as congestive heart failure and chronic obstructive pulmonary disease, whose survival rates are more difficult to predict also are occurring more frequently. Questions have been raised about whether better methods for determining hospice eligibility benefit are needed in order for hospice to continue affecting costs and quality of care at the end of life. Analyses in the second part of this project will help clarify whether the eligibility requirements are creating barriers to access.

Terminally ill residents who do not enroll in hospice may be using more hospital and SNF services in place of palliative care. These patients are more likely to be admitted to a hospital and then discharged to a SNF where they may stay until their health improves or they die. Beneficiaries who live in nursing facilities have a financial incentive to choose the more intensive acute care treatments because the more aggressive SNF benefit covers their room and board. Because Medicare's hospice benefit does not cover room and board costs, a beneficiary who lives in a nursing facility and opts for hospice care incurs additional charges for room and board. Medicaid covers these charges for the dual-eligible population, but other patients must pay for them out of pocket or through private insurance coverage. If, instead of hospice, beneficiaries use the skilled nursing facility benefit, Medicare will cover their room and board and treatment costs for a limited

time. But these residents will be given more aggressive care and may not receive comparable symptom management and psychosocial support that would be available through the Medicare hospice benefit.

If, instead, a nursing home resident elects hospice, other problems may occur because of the divergent goals and conditions of participation for the two types of providers. Because the dividing line for services is sometimes unclear, there may be confusion regarding which provider will be held accountable for various services. As a result, even if a beneficiary has elected hospice they may not be allowed to refuse food or have unusually high levels of pain medication. As noted in the discussions, nursing facility staffs view their primary role as being restoration and rehabilitation. By contrast, hospice staff members view themselves as providing palliative and supportive care, as prescribed in their conditions of participation.

Many of these potential problems can be managed through explicit contract provisions between providers and a patient's care plan, as is being done in Wisconsin, Colorado, and Kansas. But, this level of coordination and alternative responses requires clear guidance and staff acceptance, knowledge, and cooperation. Nursing facility staff and survey and certification staff need greater education regarding the needs of the dying patients.

On a related note, some have suggested that hospices provide fewer hours of care to patients in nursing facilities than to those living in the community because the nursing facility staff can supplement their work. Because of this perception, the appropriateness of paying hospices the same per diem rate when care is provided in a nursing facility has been questioned (HHS, 1998). In contrast, others have suggested that hospice staff and volunteers appropriately supplement the number of hours otherwise provided by nurses, social workers, clergy, and aides to meet the more intensive needs of dying patients (and their families or significant others) in nursing facilities. In the past, it has been difficult to measure whether these differences

exist. As mentioned earlier, the newly required hospice cost reports may shed some light on this issue in the future.

Confusion about expectations of hospice and nursing home providers is exacerbated by the lack of federal regulations specifying what services are included in the nursing facility per diem. The current payment system for dual eligibles, which pays hospices directly for both the hospice and nursing facility room and board is problematic. As discussed earlier, the Office of Inspector General found problems in contracts between hospices and nursing facilities, with some hospices paying nursing facilities a per diem amount greater than they would have received from the state, and with no apparent additional services being provided. Also, there have been many anecdotal reports that this payment mechanism has increased the administrative burden for both hospices and nursing facilities. Both industries advocated dropping the hospice from the nursing facility reimbursement process. This would also eliminate any possibility of “kick-back” payments which the OIG had been concerned about.

Some of these issues have been raised by The National Hospice Organization in its reports on the Medicare Hospice Benefit and End-of-Life Care and their Nursing Home Task Force report (NHO, 1998c and 1998d). These reports make recommendations to reduce the barriers to hospice care. Many of the recommendations address issues discussed in this review, some target nonregulatory changes needed in practice and some target program policies. For example, some of the NHO’s recommendations include:

- Addressing the problems created by the six-month prognosis requirement by changing the eligibility requirement from an expected death in 6 months to 12 months
- Improving the quality of life at the end of life by increasing access to hospice and developing outcome measures and criteria to help providers know when to refer a patient to hospice.
- Addressing inadequacies in Medicare payment for hospice services by analyzing the variation in costs for different types of patients and hospice providers.

- Clarifying the role of hospice in NFs and improving the coordination of hospice and nursing facilities.
- Educating the public and professionals on the value of hospice care.

The second NHO report which specifically targeted hospice care in nursing homes (NHO, 1998d) repeated many of these concerns. They further emphasized the problems generated by the difference in terminology, language, regulation and culture between the two industries. They call for better pathway guidelines for treating these populations and better training for staff working in this environment.

Much of the discussion thus far has focused on improving the Medicare hospice benefit to make it more accessible to nursing facility residents since so many are terminally ill. Yet, nursing facilities are required by law to make appropriate services available to their patients (CFR 483.25). Nursing facility staff and state and federal regulators need to recognize that caring for the dying is part of the nursing facility's mission and that these populations require different services than those receiving custodial care. Nursing facility staff, both professional and para-professional, and regulators need to be trained in appropriate means of caring for the dying. Many of the discussants, including representatives of nursing facilities, hospices, and regulators agreed that the training provided by hospice staff when they are in a facility was invaluable both for the hospice patient and others in the facility.

Better clarification of the roles and responsibilities of multiple providers treating the dying patient are needed. While program rules currently require each resident who is enrolled in hospice to have a care plan documenting the respective services provided, all discussants agreed that better definition of these contracts is needed. Specific responsibilities need to be documented and kept in the patients' records.

Better methods for measuring the quality of care provided to the dying NH resident are also needed. Information on the differences in services provided to hospice and nonhospice residents is needed

before we can measure the impact of hospice services for nursing facility residents. Some of this is available in the minimum data sets collected by the nursing facilities and more will be in the future. The second part of this project will provide some information using these data. Additional information will be available as the hospice cost reports become standard submissions. Understanding the differences in resources used for the two types of patients and their respective impact on pain and symptom management will be extremely important for understanding the impact of hospice in treating the terminally ill.

Last, the procedures for Medicaid room and board payments for dual-eligible enrollees need to be reconsidered in order to minimize opportunities for fraud and abuse. New systems are needed to minimize the hospices' involvement in costs not associated with the terminal illness. Both nursing home and hospice informants concurred that having Medicaid pay the hospice, so that it in turn, could pay the nursing facility, was administratively burdensome, costly, and caused delays in the timely payment for room and board. Paying the nursing facility directly would be consistent with the payment methods for other providers involved in treating the patient for conditions that are not associated with the terminal illness. This would also require a new method for notifying state Medicaid agencies that their recipient qualifies for the reduced Medicaid coverage and no longer needs full nursing care coverage.

16. CONCLUSION

Provision of the Medicare hospice benefit in nursing facilities appears to have extended the benefit to a higher percentage of populations than were previously receiving it. However, access to the benefit does not appear to be equitable across geographic settings, nursing facilities, and perhaps across nursing facility residents with diverse terminal illnesses. An optimal model for care of the terminally ill in nursing facilities

would provide quality terminal care and support to residents and their families or significant others needing this level of care on an equitable basis, while not increasing the costs of care.

Information on whether hospice improves outcomes for beneficiaries living in nursing facilities is needed. This project will be analyzing Medicare claims to identify changes in the types of populations enrolling in Medicare, the types of services used under Medicare's hospice benefit, and to the extent possible, the outcomes of hospice enrollees in nursing facilities relative to other residents. This work will provide policymakers with information to address the issues being raised in the field.

In summary, policymakers should consider how high quality of care can be provided to the dying nursing home resident, and whether and at what level hospice services are needed to achieve that outcome. Some refinements to the service delivery system that will promote high quality care to dying nursing home residents and will allow for future analysis of the outcomes of care for dying nursing home residents who receive and do not receive hospice are as follows:

- Educate health care professionals and paraprofessionals, including nursing home staff, about the needs of and care for the dying
- Provide clear guidance and regulation at the federal and state level regarding appropriate care, with and without hospice, for dying nursing home residents. Guidelines clarifying the need for nursing facilities to provide palliative care, the roles and responsibilities of hospices and nursing facilities when treating a hospice patient, and the minimal contract provisions affecting hospices and nursing facilities when treating these patients.
- Define and measure outcomes of care provided to terminally ill nursing home residents, distinguishing between those who are receiving hospice services and those who are not.
- Simplify the room and board payment systems for dually-covered nursing facility residents who choose hospice.

While these refinements will promote the efficient delivery of high quality care to dying nursing home residents, for both those who receive hospice services and those who do not, they will also permit a study

of different models of terminal care delivery in nursing facilities. Measuring outcomes for the two groups will help document the effectiveness of hospice and nursing homes in caring for terminally ill persons. Only then can the public and policymakers have an informed debate about maintaining the hospice benefit as an alternative to traditional care, and effectively managing and monitoring the quality end-of-life care in nursing facilities.

Finally, simplifying the payment system for dually eligible nursing facility residents who enroll in Medicare's hospice benefit will reduce provider burden and minimize opportunities for fraud. This could be an important contribution to improving the administrative systems related to benefits for the terminally ill.

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Table 1. Balanced Budget Act of 1997: Provisions Related to Hospice Services

Section	Provision	Effective Date
4441. Payments for Hospice Services	The hospice prospective payment rates will be updated by the hospital market basket minus 1 percentage point for each of the fiscal years 1998 through 2002. In addition, the hospices will be required to submit such data as the Secretary requires on the costs of the care they provide for each fiscal year beginning with fiscal year 1999.	as stated
4442. Payment for Home Hospice Care Based on Location of Service	Hospice services will be paid based on the location where the service is provided, rather than where the service is billed (typically the urban location of the hospice agency.)	for cost reporting periods beginning on or after 10/1/97
4443. Hospice Care Benefits Period	Restructures the hospice benefit periods to include two 90-day periods, followed by an unlimited number of 60-day periods. The medical director or physician member of the hospice interdisciplinary team would have to re-certify that the beneficiary is terminally ill at the beginning of each benefit period.	upon enactment 8/5/97
4444. Other Items and Services included in Hospice Care	Amends the definition of hospice care to include the existing enumerated services as well as any other item or service which is specified in a patient's plan of care and for which Medicare may pay. (Existing services include nursing care: physical, occupational and speech therapy; medical social services; home health aide and homemaker services; medical supplies and appliances; physician services, short-term patient care; and counseling.)	for items and services furnished on or after April 1, 1998
4445. Contracting with Independent Physicians or Physician Groups for Hospice Services	Deletes physician services from a hospice's core services and allows hospices to upon enactment: employ or contract with physicians for their services. (Currently, hospices are required to provide directly for certain core services, including physician services.)	8/5/97

Table 1. (continued) Balanced Budget Act of 1997: Provisions Related to Hospice Services

Section	Provision	Effective Date
4446. Waiver of Certain Staffing Requirements for Hospice Care Programs in Non-urbanized Areas	The Secretary is allowed to waive requirements with regard to hospices upon enactment: being required to provide certain services, as long as they are not located in urbanized areas and can demonstrate to the satisfaction of the Secretary that they have been unable, despite diligent efforts, to recruit appropriate personnel. For these hospices, the Secretary could waive (1) the requirement that dietary counseling be provided directly by the hospice and (2) the requirement that physical or occupational therapy or speech-language pathology services be made available on a 24-hour basis to the extent necessary to meet the needs of the patient.	upon enactment: 8/5/97
4447. Limitation on Liability of Beneficiaries for Certain Hospice Coverage Denials	Medicare's limitation of liability protection is extended to determinations that an individual is not terminally ill. (Limitation on liability: Medicare provides financial relief to beneficiaries and providers for certain services for which payment would otherwise be denied, if the beneficiary or provider did not know, and could not reasonably have known, that services would not be covered.)	upon enactment: 8/5/97
4448. Extending the Period for Physician Certification of an Individual's Terminal Illness	The specific, statutory time frame for completion of physicians' certification for admission to a hospice are eliminated. Physicians now will be required to certify that a beneficiary is terminally ill at the beginning of the initial 90-day period.	upon enactment: 8/5/97

Table 2. Hospice Reimbursement Rates From 11/01/83 - 9/30/98

Level of Care	Reimbursement Period												
	11/01/83 12/31/84	01/01/85 03/31/86	04/01/86 12/31/89	01/01/90 09/30/90	**10/01/90	10/01/91 09/30/92	10/01/92 09/30/93	10/01/93 09/30/94	10/01/94 09/30/95	10/01/95 09/30/96	10/01/96 09/30/97	10/01/97 09/30/98	10/01/98 09/30/99
Routine	\$ 46.25	53.17	63.17	75.80	79.74	83.25	86.66	88.65	90.51	92.32	94.17	95.77	97.11
Continuous	\$ 358.67	358.67	368.67	442.40	465.40	485.88	505.88	517.43	528.30	538.87	549.65	558.99	566.82
Inpatient Respite	\$ 55.33	55.33	65.33	78.40	82.48	86.11	89.64	91.70	93.63	95.50	97.41	99.07	100.46
General Inpatient	\$ 271.00	271.00	281.00	337.20	354.73	370.34	385.52	394.39	402.67	410.72	418.93	426.05	432.01

**Note: These payment rates were effective for services provided on or after October 1, 1990 through October 20, 1990 and January 1, 1991 through September 1, 1991. Hospice payments for the period beginning on October 21, 1990 through December 31, 1990 are the same as the 1990 rates. The return to the FY 1990 rate for the period October 21 through December 31 is the result of the freeze in Part A payments provided in Section 4007 of the Omnibus Budget Reconciliation Act of 1990.

Table 3. Medicare Hospice Payments and Use by Level of Care, 1997

Medicare Use and Expenditures	<u>Levels of Care</u>				
	Total Use	Routine Home Care	Continuous Home Care	Inpatient Respite	General Inpatient
Use Levels (In 1,000s) ^a	N.A.	18,190	1,191	48	471
Medicare Expenditure					
In Millions	\$2,025	\$1,770	\$29	\$4.8	\$210
(In percent)	100 percent	87 percent	1 percent	>1 percent	11 percent

Source: Unpublished data from HCFA, 1998a

^a All use rates are reported days except for continuous home care which is reported in hours.

Table 4. Medicare Hospice Payments and Use by Type of Hospice Affiliation, 1997

Medicare Use and Expenditures	Type of Hospice Affiliation				
	Total	Free-standing	Hospital Based	SNF Based	HHA Based
Number of Users	374,723	193,765	68,688	2,547	109,723
Medicare Expenditures					
In Millions	\$2,025	\$1,123	\$345	\$13	\$543
(In percent)	100 percent	55 percent	17 percent	1 percent	27 percent
Average Dollars per Beneficiary	\$5,402	\$5,796	\$5,026	\$5,079	\$4,949
Average Days per Beneficiary	50	53	48	40	46

Source: Unpublished data from HCFA, 1998a

Table 5. Demographics of Hospice Beneficiaries by Type of Hospice Affiliation, 1987-1990

Beneficiary Characteristics	Type of Hospice Affiliation									
	All Providers		Hospital		SNF		HHA		Free-standing	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Female	5,545	47 percent	958	47 percent	487	53 percent	2,168	49 percent	2,195	45 percent
Age Entered Hospice										
Mean	75.6 years		75.6 years		75.2 years		75.6 years		75.6 years	
(SD)	(8.5)		(8.6)		(8.4)		(8.6)		(8.6)	
Race										
White	10,553	90	1,751	87	308	87	3,974	90	4,441	91
Black	776	7	169	8	38	11	296	7	269	6
Other	179	1	49	2	3	1	60	1	66	1
Unknown	242	2	50	3	5	1	84	2	102	2
Diagnoses										
Cancer:										
Colon	2,596	24	437	24	100	30	962	24	1,052	23
Lung	2,551	23	437	24	70	21	937	23	1,086	24
Breast	644	6	104	6	27	8	254	6	254	6
Reproductive	1,163	11	207	11	45	13	411	10	491	11
Urinary	420	4	64	3	11	3	147	4	194	4
Leukemia	141	1	23	1	3	1	52	1	62	1
Other	1,643	15	292	16	36	11	641	16	664	15
Non-Cancer	1,699	16	278	15	44	13	663	16	702	16

Source: From Banaszak-Holl & Mor , 1996

Table 6. Characteristics of Discharged Hospice Patients in the 1994 and 1996 National Home and Hospice Care Surveys

Beneficiary Characteristics	<u>1993-1994 Discharges</u>		<u>1995-1996 Discharges</u>	
	(n = 328,000)		(n = 393,200)	
	Number	Percent	Number	Percent
Sex				
Female	156,500	47.7	195,500	49.7
Race				
White	260,400	79.4	310,000	78.9
Black	24,000	7.3	43,900	11.2
Other or unknown	43,600	13.3	39,100	9.9
Age				
Under 45 years	18,600	5.7	31,700	8.1
45-64 years	69,900	21.3	89,400	22.7
65 years and older	239,100	72.9	265,200	67.5
Marital Status				
Married	160,300	48.9	190,300	48.4
Widowed	97,300	29.7	115,600	29.4
Not married	48,300	14.7	62,000	15.8
Unknown	22,200 ²	6.8 ²	25,300	6.4
Diagnoses (at admission)¹				
Neoplasms (malignant)	220,900	67.3	274,000	69.7 ²
Diseases of Circulatory System	36,100	11.0	37,600	9.6
Diseases of Respiratory System	7,300	2.2	20,500	5.2
Diseases of Nervous System & Sense Organs	8,300 ²	2.5 ²	12,500 ²	3.2 ²
Diseases of GU System	10,700 ²	3.3 ²	9,300 ²	2.4 ²
Infectious & Parasitic Diseases	9,500	2.9	15,200 ²	3.9 ²

Source: National Center for Health Statistics, 1996 & 1998

¹ First listed diagnosis.

² Figure does not meet standard of reliability or precision.

Table 7. Number of Medicare -Certified Hospices by Type of Provider Affiliation

Year	HHA	HOSP	SNF	FSTG	TOTAL
1984	n/a	n/a	n/a	n/a	31
1985	n/a	n/a	n/a	n/a	158
1986	113	54	10	68	245
1987	155	101	11	122	389
1988	213	138	11	191	553
1989	286	182	13	220	701
1990	313	221	12	260	806
1991	325	282	10	394	1011
1992	334	291	10	404	1039
1993	438	341	10	499	1288
1994	583	401	12	608	1604
1995	699	460	19	679	1857
1996 ¹	815	526	22	791	2154

Source: Hospice Association of America, 1997 based on HCFA data

¹Data as of December 1996

Table 8. Lengths of Stay by Hospice Provider Affiliation, 1987-1990

Length of Coverage¹	Hospital		SNF		HHA		Free-standing	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
<15 days	821	41.4	163	46.4	1,845	42.3	1,915	39.7
15-29 days	349	17.6	63	17.9	805	18.5	849	17.6
30-89 days	520	26.2	86	24.5	1,060	24.3	1,269	26.3
90-149 days	162	8.2	18	5.1	340	7.8	383	7.9
150-209 days	76	3.8	10	2.8	189	4.3	237	4.9
210+ days	57	2.9	11	3.1	118	2.7	171	3.5
Mean Length of Coverage (in days)	45.1		39.5		45.3		51.5	
(SD)	(73.0)		(68.4)		(75.4)		(90.9)	
Median Length of Coverage (in days)	21.0		17.0		20.0		22.0	

Source: Banaszak-Hall and Mor, 1996
 Statistically significant at $p < .05$

Table 9. Average Number of Visits per Week by Type of Service

Service	NHO Staffing Ratios¹	Nursing Home Patients²	Home Patients³	Percent Difference⁴
Nurse	2.0	1.5	2.7	-.44 percent
Aide	1.5	1.3	2.5	-.48 percent
Social Worker	.8	.42	.53	-.21 percent
Spiritual/ Pastoral	.4	.28	.16	.75 percent

Source: USDHHS, Office of the Inspector General, 1997

¹Derived from NHO staffing ratios. (Example-average caseload per nurse is 10 patients, average number

of visits per week per nurse for all patients is 20- 20 visits/10 patients = 2 visits per week per patient.)

²Based on medical review of nursing home hospice patients.

³OIG national sample of hospice patients

⁴Percent difference between Columns 3 and 4

**Table 10. Adjusted¹ Medicare Reimbursement Saved per Dollar of Hospice Expenditure,
by Length of Enrollment and Month³**

Enrollment Month	Length of Enrollment ²						
	< 1 Month	30-59 Days	60-89 Days	90-119 Days	120-149 Days	150-179 Days	180-209 Days
Last month of life	1.32*	1.49*	1.48*	1.42*	1.50*	0.93	3.77*
Month 2		0.82*	0.91	0.88	0.88	0.67	1.35
Month 3			0.73*	0.72	0.71	0.61	0.86
Month 4				0.84	0.71	0.46	0.73
Month 5					0.83	0.65	0.61
Month 6						0.92	0.56
Month 7							0.75
Total for all months after hospice entry	1.32*	1.14*	1.04	0.99	0.96	0.72*	1.06*

Source: Kidder, 1992; AAI/HCFA Hospice Benefit Monthly File.

*Ratio is significantly different from 1 at p<.10 level of significance.

¹Adjusted for demographic factors and medical condition, through multivariate regression.

²Enrollment for the comparison nonhospice patients cohort is determined by the date of the first cancer diagnosis. For example, if a patient is diagnosed 80 days before death, they would be included in the estimates reported in the first three columns since they could have enrolled for any of those periods. Hospice patients are included only in the column in which their actual enrollment falls. The savings ratio is the ratio of nonhospice to hospice mean reimbursements.

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**Table 11. Adjusted Medicare Part A Reimbursement Saved per Dollar of Hospice Expenditures,
by Length of Enrollment and Month, 1992***

Enrollment Month	<u>Length of Enrollment¹</u>						
	< 1 Month	30-59 Days	60-89 Days	90-119 Days	120-149 Days	150-179 Days	180-209 Days
Last month of life	1.65	2.13	2.08	1.96	1.98	1.89	0.86
Month 2		0.91	1.07	1.00	0.91	0.90	0.95
Month 3			0.88	0.76	0.69	0.68	0.66
Month 4				0.62	0.62	0.55	0.52
Month 5					0.57	0.51	0.47
Month 6						0.48	0.46
Month 7							0.45
Total for all months after hospice entry	1.65	1.48	1.29	1.09	0.98	0.86	0.82

Source: Lewin-VHI Analysis of 1991-1992 Medicare Part A claims from the National Claims History File.

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¹Adjusted for demographic factors and medical condition, through multivariate regression.

Table 12. Adjusted Medicare Part A and Part B Reimbursement Saved per Dollar of Hospice Expenditures, by Length of Enrollment and Month, 1992*

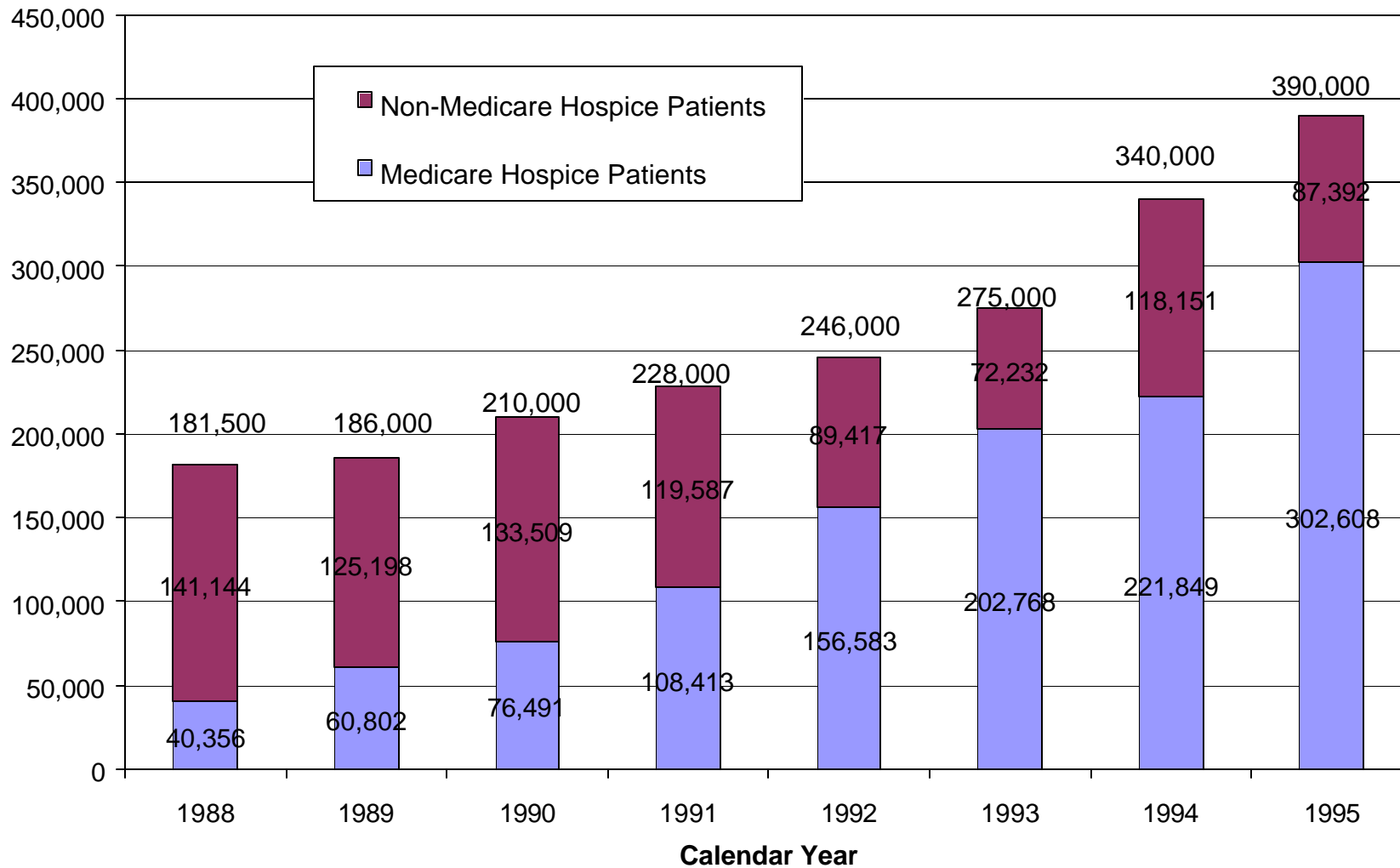
Enrollment Month	Length of Enrollment¹						
	< 1 Month	30-59 Days	60-89 Days	90-119 Days	120-149 Days	150-179 Days	180-209 Days
Last month of life	1.68	2.46	2.39	2.25	2.34	2.17	1.06
Month 2			1.35	1.22	1.17	1.16	1.22
Month 3			0.84	0.99	0.91	0.91	0.89
Month 4				0.72	0.83	0.76	0.72
Month 5					0.67	0.70	0.67
Month 6						0.57	0.65
Month 7							0.56
Total for all months after hospice entry	1.68	1.64	1.49	1.29	1.19	1.06	1.03

Source: Lewin-VHI analysis of 1991-1992 Medicare Part A and Part B claims from the National Claims History File.

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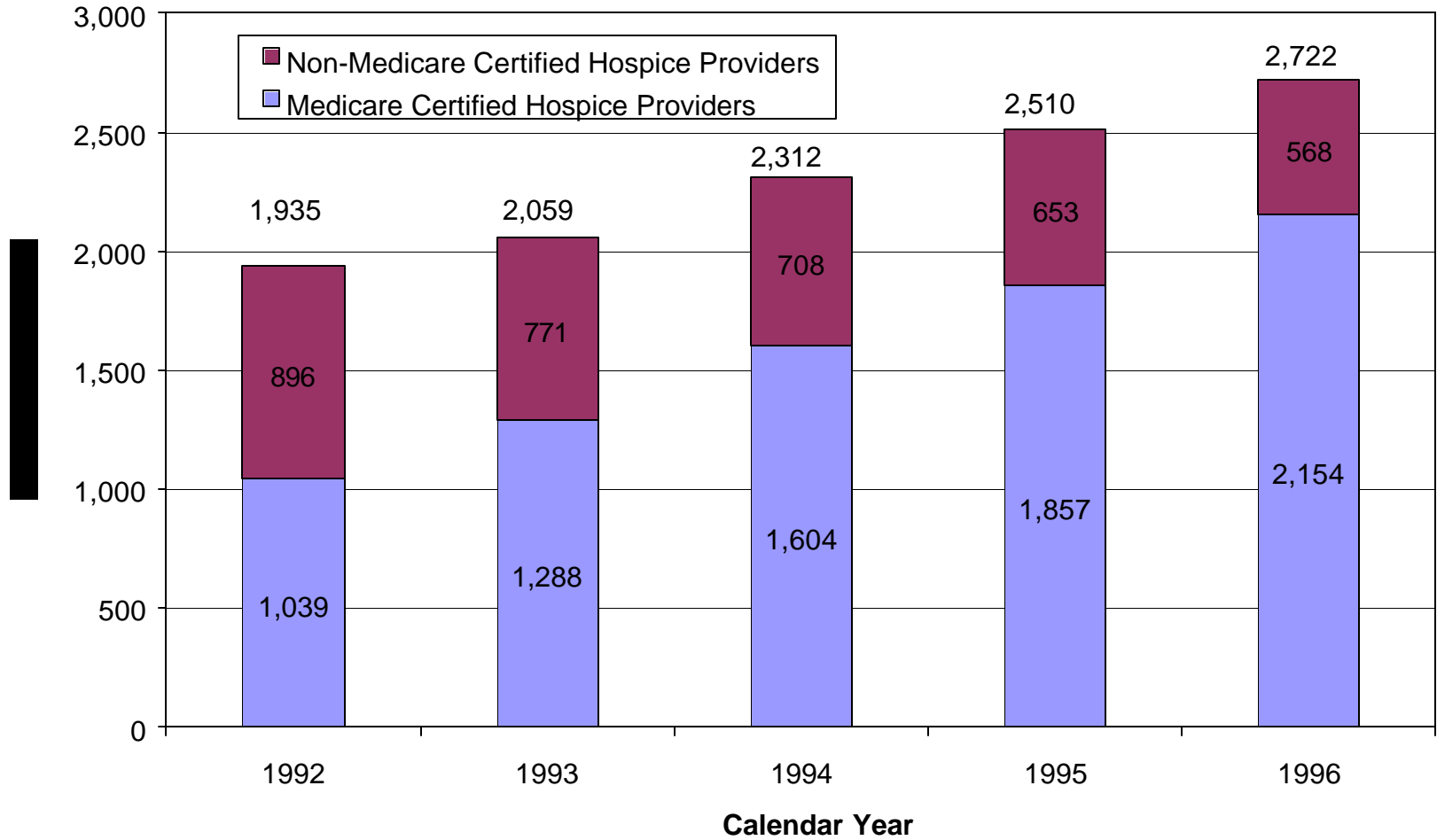
¹Adjusted for demographic factors and medical condition, through multivariate regression.

Figure 1. Number of Medicare and Non-Medicare Hospice Patients



Source for total hospice patients: NHO (1998a), Totals used for 1988 and 1991 represent averages between 2 years.)
 Source for hospice Medicare beneficiaries: HCFA, BPD (10/96) from Hospice Association of America (1997)

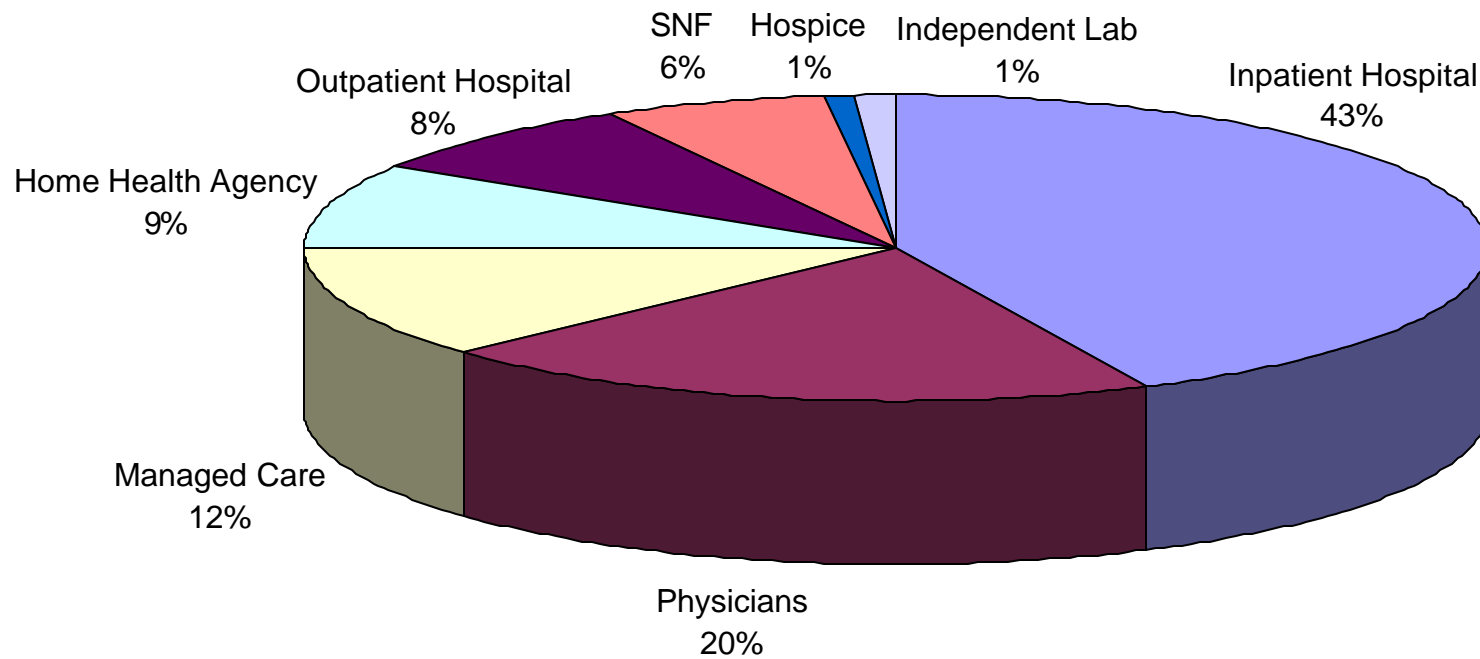
Figure 2. Number of Medicare and Non-Medicare Certified Hospice Providers



Source for Total Hospice Providers in U.S.: National Hospice Organization, (1998a)

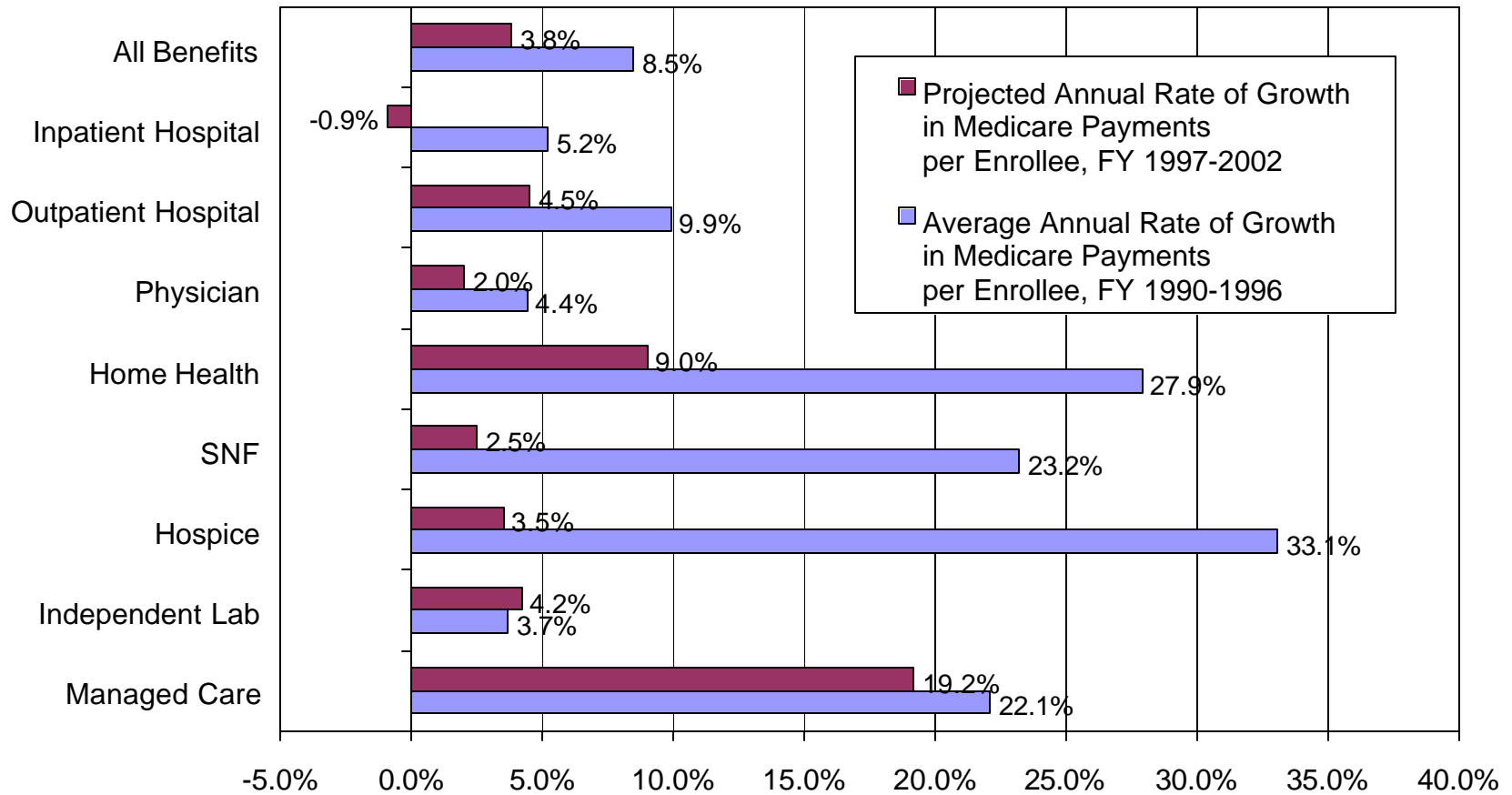
Source for Total Medicare-Certified Hospices: HCFA, HSQB (12/98), from Hospice Association of America

Figure 3. Distribution of Medicare Benefit Payments by Type of Service, FY 1997



Source: HCFA/Office of the Actuary
In: A Profile of Medicare: Chart Book (HCFA, 1998)

Figure 4. Comparison of Rate of Growth to Projected Rate of Growth in Medicare Benefit Payments per Enrollee by Type of Service



Source: A Profile of Medicare: Chart Book (HCFA, 1998). Based on estimates of incurred benefits from the 1998 Annual Report of the Board of Trustees of the Federal Hospital Insurance Trust Fund and Federal Supplementary Medical Insurance Trust Fund.