

NHPCO *Review Article*

Hospice Care in the Nursing Home Setting: A Review of the Literature

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*Department of Health Care Policy, Harvard Medical School, Boston, Massachusetts, USA***Abstract**

The U.S. Medicare hospice benefit has expanded considerably into the nursing home (NH) setting in recent years. This literature review focuses on the provision of NH hospice, exploring its growth and the impact of such care on NH residents, cost and efficiency implications for NHs and government, and policy challenges and important areas for future research. Although hospice utilization is relatively modest among NH residents, its increased availability holds great promise. As an alternative to traditional NH care, hospice has been shown to provide high-quality end-of-life care and offer benefits, such as reduced hospitalizations and improved pain management. The provision of NH hospice also has been shown to have positive effects on nonhospice residents, suggesting indirect benefits on NH clinical practices. Importantly, the expansion of hospice in NHs brings challenges, on both clinical and policy dimensions. Research has shown that NH-hospice collaborations require effective communication around residents' changing care needs and that a range of barriers can impede the integration of hospice and NH care. Moreover, the changing case mix of hospice patients, including increased hospice use by individuals with conditions such as dementia, presents challenges to Medicare's hospice payment and eligibility policies. To date, there has been little research comparing hospice costs, service intensity, and quality of care across settings, reflecting the fact that few comparative data have been available to researchers. The Centers for Medicare & Medicaid Services have taken steps toward collecting these data, and further research is needed to shed light on what refinements, if any, are necessary for the Medicare hospice program. J Pain Symptom Manage 2009;38:440–451. © 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Introduction

Elderly individuals at the ends of their lives can access health care through a number of options in the United States. The most common among these is traditional curative care, through which patients receive care in accordance with their Medicare, Medicaid, or private insurance benefits. Unfortunately, for some individuals, disease-modifying therapy may involve painful, invasive, and expensive

procedures that do little to extend life or improve the end-of-life (EOL) experience. In these instances, a primary alternative is hospice care, which became available for public funding through the Medicare Hospice Benefit in 1983. While enrolled in hospice, a patient essentially waives his or her right to receive curative care. In return, Medicare provides extensive palliative and EOL care, including bereavement and spiritual services for the patient and his or her family.

Although the Medicare hospice benefit is most frequently provided in the patient's own residence by a hospice agency, there has been recent movement toward increased provision of hospice care in nursing homes (NHs), with hospice services wrapping around services provided by the facility as the "primary caregiver." The expansion of hospice into the NH setting raises a number of issues for researchers and policymakers, given the characteristics of the NH population and the manner in which the benefit is provided and paid for. This literature review will focus on the provision of NH hospice, exploring the growth of hospice care in the NH, the impact of such care on the patients, cost and efficiency implications for NHs and the government, policy challenges, and some suggestions for further research.

Background and Trends

The Hospice Benefit

Medicare (the U.S. health care reimbursement program primarily for patients above 65 years of age) added the hospice benefit in 1983 as an alternative to curative care, both to reduce costs and to improve the EOL experience. Hospice includes a broad array of palliative and supportive services aimed at improving symptom management and quality of life for patients with a terminal illness. On implementation, the Medicare hospice benefit was intended to allow terminally ill beneficiaries (primarily cancer patients at that time) to die at home with improved quality of life; it was expected that patients using hospice would have fewer hospitalizations at the EOL, and thus, that the cost of the benefit would be offset by reduced Part A (including Medicare reimbursement to hospitals) costs.

Hospice services in the United States are provided by a variety of agency types, including freestanding agencies and those based in home health agencies, hospitals and skilled nursing facilities. Most of the hospice care is provided by freestanding agencies, with these providers serving individuals across settings of care (e.g., contracting with NHs and hospitals).

A Medicare beneficiary is eligible for the Medicare hospice benefit if his physician certifies that his prognosis is a life expectancy of six months or less if the terminal illness runs its natural course, and if he agrees to forgo treatment intended to cure the terminal illness. Guided by a physician's certification, Medicare hospice is administered in periods of care: for two initial 90-day periods and then an unlimited number of 60-day periods. It is important to note that the benefit has no capped duration, as long as the patient continues to meet eligibility requirements, including the six-month life expectancy. Medicare hospice defines four levels of care: routine home care (which can be received in personal residences, assisted living facilities, or in an NH setting), 24-hour continuous home care, inpatient hospice care, and inpatient respite care. The vast majority of Medicare hospice days are paid at the routine home care rate.¹

In the initial years of the benefit, most Medicare beneficiaries electing hospice care did so within their own homes. With the Omnibus Budget Reconciliation Act (OBRA) of 1989, Medicare extended the availability of the hospice benefit, easing restrictions on NHs that sought to integrate hospice care into their EOL regimens and seeking to ensure access to hospice care for Medicare beneficiaries in NHs. Now, any NH that desires such care can freely contract with hospice agencies, although there is no requirement to do so.²

Hospice Payment

The Medicare hospice benefit is paid directly to the hospice agency, regardless of the setting in which the enrollee receives care. Assuming that hospice services fall under the routine home care category, the per diem rate, adjusted annually by the Centers for Medicare & Medicaid Services (CMS), is approximately \$140. Payment is capped based on an aggregate rate of \$22,386.15, corresponding to the average for

all enrollees in the agency over the 12-month cap period.³ For individuals dually eligible for Medicare and Medicaid (the U.S. health care reimbursement program for the indigent) and residing in NHs, state Medicaid programs also pay the hospice agency for the NH stay at 95% of the facility's Medicaid room and board rate, whereas private paying residents' obligations are determined by contract. Room and board payments are redirected to the hospice because of their responsibility to professionally manage the care of the patient. The hospice agency subsequently pays NHs a negotiated rate, typically passing the NH payment to the facility in full.⁴ Under most contracts, a hospice agency is responsible for providing all palliative care related to an individual's terminal illness, including nursing, added personal care, counseling and social work services, medications, supplies, and so on. The NH, meanwhile, provides room and board and the usual compensatory long-term care services.

Growth and the Changing Nature of Hospice Use

Utilization of the Medicare hospice benefit has grown substantially in recent years. By 2000, hospice enrollment among Medicare decedents had increased to 27.3%, and it reached 40% five years later. Spending for hospice care has grown at an even faster rate: between 2004 and 2005, spending rose by almost 20%, attributable both to an increase in the number of beneficiaries (10%) and to rising payments per user (8%). Medicare hospice expenditures per year now exceed \$10 billion, and they are expected to double in the next decade.⁵

In recent years, NHs have expanded their hospice programs considerably, with the number of NH-hospice residents more than tripling between 1996 and 2004, from 13,000 to 41,000.⁶ At the same time, though, the expansion of NH hospice could be considered modest. Although 17% of hospice patients lived in NHs by 1995, 34% of these individuals were served by the 4.5% of homes that enroll 5% or more of their EOL patients in hospice. Similarly, even though a large majority (87%) of NHs holds nominal contracts with hospice agencies, only 30% of them actually have any hospice enrollees—and most of these have only one or two at a time.² NH-hospice care,

in short, is not yet widely used among dying NH residents.

The types of beneficiaries receiving hospice services in NHs and at home differ considerably. Compared with home hospice, NH hospice patients are more likely to be older (76.6 vs. 70.3 years), female (55.3% vs. 47.4%), unmarried (68.5% vs. 44.6%), and dually eligible for Medicare and Medicaid (13.9% vs. 4.2%).⁶ These are not surprising characteristics considering the general population of NH residents, many of whom transition directly from long-stay status to hospice as their condition deteriorates. Diagnoses also differ by care site: NH hospice patients have higher rates of dementia and other noncancer diseases as the primary diagnosis, whereas home hospice enrollees have more cancer and other terminal diseases.⁷ These differences affect treatment options and profitability, both of which are addressed later.

The growth in NH hospice has coincided with a shift in the use of hospice care more generally. Perhaps most visibly, growing numbers of patients with dementia and related conditions have enrolled in the Medicare hospice benefit; compared with cancer, these conditions have a much wider range in life expectancy.⁸ Hospice agencies increasingly have also enrolled patients with longer episodes of care, even within diagnosis groups. The mechanics of hospice payment could be partially to blame for these shifts.⁵ With payments made on a per diem basis, it can be financially advantageous for agencies to enroll longer-stay residents, within limits (e.g., at any given point in time, the average enrollee should continue to have an expected prognosis of six months or less).

A related point is that the role of for-profit hospice agencies has been important in the expansion of hospice care into the NH setting. Between 2000 and 2007, the number of hospice agencies participating in the Medicare program increased by more than 1000 providers, almost all of which were for-profit agencies. More specific to NH hospice use, a recent report from the Medicare Payment Advisory Commission (MedPAC) found that 72% of hospice agencies predominantly focusing on institutionalized patients (i.e., for 40% or more of their business) were for-profit agencies. In the context of these findings,

and given that hospice payment incentives reward longer patient stays, MedPAC expressed concern that NHs were an attractive referral source for hospice agencies and that higher profit margins for long-stay residents could potentially result in inappropriate use. As such, MedPAC directed the Office of the Inspector General to perform a comprehensive review of hospice-NH arrangements to inform future policy.⁵

Provision of Nursing Home Hospice

Residents who enroll in hospice continue to receive supportive services from the NH, much like the supportive services provided by family and friends that the patient might receive if he or she were at home; at the same time, they receive supplemental support and care for their terminal condition from the hospice agency. There are benefits to this arrangement for both the hospice and NH provider, such as economies of scale and assistance in providing supportive services to patients for the hospice, improved resident access to specialized EOL care, and assistance in providing supportive end-of-life care for NHs. However, there are also important regulatory and administrative hurdles that need to be addressed for such agreements to work. In particular, NHs and hospice agencies must communicate sufficiently to ensure that care plans of both entities are mutually compatible and compliant with regulatory guidelines, that each entity is clear about its clinical responsibilities, and that mechanisms are in place to ensure that changes in the residents' status are communicated effectively.⁹

Clinical and Quality Impact of the Hospice Benefit in the Nursing Home Setting

The numerous benefits of hospice care over conventional care have been documented elsewhere.^{5,10-14} Among these are reduced hospitalizations, more comfortable conditions for both the patient and family, attention to emotional and spiritual needs, and better pain management. The literature on the quality of NH hospice care is less extensive and is focused primarily on relative service use (e.g.,

hospitalization), though common themes have emerged.

Nursing Home Hospice vs. Nursing Home Traditional

Some studies suggest that EOL care is quite poor in NH settings and that the provision of hospice may be a mechanism to improve it.^{13,15} The comparison of NH hospice care to nonhospice care at EOL in the NH has found similar quality improvements to those listed earlier, with some additional benefits worth noting. Some of the most detailed analyses on this topic were conducted by researchers at Medstat and Brown University for the U.S. Department of Health and Human Services (HHS).¹⁶ These analyses merged data from NH Minimum Data Set with Medicare claims data across five states for the 1992-1996 period. The analyses found that residents enrolled in hospice were less likely to be hospitalized in the final 30 days of life (24% vs. 44%),¹⁷ were more likely to be assessed for pain, were twice as likely to receive daily treatment for pain (given its presence), and were more likely to receive pain management in accordance with clinical guidelines.^{18,19} In addition, compared with similar residents not enrolled in hospice, residents in hospice were less likely to have physical restraints, receive parenteral/intravenous feeding, receive medications by means of intravenous or intramuscular injections, or have feeding tubes in place.²⁰

The detection and treatment of pain is especially important given that freedom from pain and symptom management are among several consensus measures consistently rated as important at the EOL by patients, families, physicians, and other care providers.²¹

In contrast to the findings detailed earlier, one exploratory study of residents in two NHs detected no statistically significant difference in the quality of pain management between hospice and nonhospice residents.²² Similarly, another study based on qualitative interviews of family and staff involved in EOL care for NH and assisted living residents did not find differences in unmet need or family satisfaction between hospice and nonhospice users at EOL.²³ These studies were much smaller in scope than the HHS studies but point to the need for more investigation of

these differences. Finally, one cross-sectional study of a nationally representative sample of NH residents found that hospice residents in NHs have a significantly greater completion of advance directives (93.6% vs. 69.9%), such as living wills and do-not-resuscitate orders; these results potentially indicate better preparedness for death as a result of hospice enrollment, but they could also simply reflect characteristics of the population that elects hospice.²⁴

Outside of the NH, one concern with hospice is that it could shorten patients' lives by denying them useful curative care. There has been limited study of this issue for NH hospice recipients, perhaps, in part, because shortened life expectancy is not a primary concern given the distinct age and diagnostic profile of NH residents relative to more traditional hospice recipients. One study comparing hospice and nonhospice residents at EOL found that life expectancy does not differ after controlling for disease category, suggesting that hospice care does not necessarily come at the cost of earlier death.²⁵ Surprisingly, another study that included both home and NH patients found somewhat *increased* survival for hospice users across four of the six diagnostic categories it reviewed.²⁶

Nursing Home Hospice vs. Home Hospice

Research studies comparing NH with home hospice users have focused primarily on differences in service use across these two settings as opposed to quality per se. For instance, one study found that hospice recipients in NHs were more likely to receive physician services (odds ratio: 2.55), prescription medicines (odds ratio: 1.60), diet and nutritional services (odds ratio: 2.33), and intravenous therapy (odds ratio: 2.33), whereas home hospice enrollees were not significantly more likely to receive services in any of the measured categories.⁶ Another study found that NH-hospice enrollees received fewer nurse visits than home users (odds ratio: 0.59), but more visits from social workers (odds ratio: 2.46), aides (odds ratio: 1.97), and clergy (odds ratio: 3.23).²⁷ It is difficult to draw definitive conclusions about quality of care from these findings, primarily because much of the variation likely reflects differences in patient characteristics, which remain even after controlling for

diagnosis.²⁸ Moreover, in the absence of data about service intensity, assessing the relative degree of care across settings cannot be determined with any specificity.

Few articles have attempted to overcome these obstacles to measure the quality differential between NH and home hospice. One notable exception is the study by Casarett et al.,²⁹ which examined the records of 167 NH hospice and 975 home hospice enrollees. According to this study, NH-hospice enrollees were more likely to have no care need (58% vs. 36%), and less likely to experience constipation (1% vs. 5%) and pain (25% vs. 41%). At the same time, however, NH enrollees were twice as likely to need feeding tubes (8% vs. 4%) and had a significantly shorter median time until death (11 vs. 17 days).²⁹

Hospice Impact on Nursing Home Practices

One analysis of NHs in five states identified a 47% hospitalization rate in the last 30 days of life in facilities that did not offer hospice care, compared with 39% in those with moderate hospice and 41% in those with low hospice use.¹⁷ Similar results were also found around pain assessment in NHs offering hospice care relative to those that did not. Interestingly, these results might denote that the important factor is the existence of hospice use at an NH rather than its degree. Similarly, a pre/post study based on residents in one NH found that an intervention to improve EOL care at one NH decreased overall terminal hospitalizations (48.2%–8.9%) and increased completion of advance care planning (88%–100%) and treatment for pain (7.4%–31.1%).³⁰ In light of these results, future research should consider both the direct and indirect effects of NH hospice to evaluate its full impact.³¹

Spending, Payment, and Efficiency—Government

The incentive of the federal government in providing hospice care is to provide high-quality EOL care for Medicare beneficiaries at the lowest cost possible. Despite this clear goal, comparing the cost of care across settings and diagnoses is complex. Detailing the results of previous studies that generally compare the cost of hospice to nonhospice care at the

EOL across settings is not the goal of our review; however, it is important to note that these studies have reached somewhat conflicting conclusions. They have also taken different methodological approaches to dealing with selection bias and choosing the time period to base the cost comparison on. These studies generally have found that Medicare spending for hospice enrollees across settings is less than that for nonenrollees in the last few months before death, but that these savings diminish as hospice stays increase in length.⁵

Importantly, most previous studies examining the cost of hospice care have not focused on the NH setting specifically; yet, some of these analyses provide important insights in the context of NH hospice recipients and their use of services. For instance, an important context for assessing the cost of NH hospice is that previous cost analyses of hospice care generally have identified large variance in costs across hospice recipients by diagnosis and length of stay. One retrospective analysis of Medicare claims data that found slightly higher costs overall for hospice compared with curative care identified substantial heterogeneity in costs across diagnoses.³² In particular, the analysis found that Medicare costs for younger cancer patients were significantly lower (and more predictable) compared with those of older patients with dementia. The former group posted cost decreases of up to 17% compared with nonhospice residents, whereas the latter group had increases of up to 44%.

In addition, other generally focused (i.e., non-NH-focused) analyses have found substantial variation across length of stay: although short- (8–30 days) to medium-length (30–90 days) stays were found to be cost-effective, very short (one week or less) and very long (>90 days) stays were found to be very expensive. The latter are costly because payments are per diem and they often do not end in death, whereas the former do not allow facilities sufficient time to assess and stabilize patients clinically and to make them comfortable³³ or to use some of the cost-saving strategies that require weeks to implement.³⁴ One recent analysis that more precisely accounted for the time of hospice use in determining its impact on Medicare expenditures found cost savings of around \$2300 per beneficiary overall and found that the optimal hospice length of service—in terms of savings to the

Medicare program relative to usual care—was approximately seven weeks.³⁵ The study also found that hospice achieved savings for up to an average of 139 days of care for patients with noncancer diagnoses and up to 154 days of care for patients with cancer diagnoses.

In light of the general findings described earlier, one would expect hospice care to be relatively expensive for the typical hospice recipient in the NH. As discussed earlier, NH hospice has a higher proportion of noncancer diagnoses than does home hospice, suggesting a higher likelihood of residents having long hospice stays and being discharged without death.³⁴ In addition, at the other end of the length-of-stay distribution, analyses have shown that there is a greater likelihood of NH hospice patients having short hospice stays, with 22% having enrollments of zero to three days (vs. 12% at home) and 20% with four to seven days (vs. 10% at home).⁶ Given these descriptive traits, the initial aggregate results of costs for NH hospice care are somewhat promising. One analysis of NH residents in Florida found that mean government expenditures in the last month of life were around 10% less for hospice compared with nonhospice residents (\$7365 vs. \$8134).³⁶ These aggregate results were largely confirmed in subsequent analyses of the same data;³⁷ yet, both analyses also identified differences in savings across resident diagnoses and overall length of NH stay. In particular, results showing cost savings were more robust for short-stay NH residents relative to long-stay residents.

Cost, Payment, and Profit—Nursing Homes and Hospices

Although MedPAC recently expressed concerns that profit incentives could inappropriately drive NH hospice referrals,⁵ there are few systematic analyses of the costs of NH hospice or of the profitability for providing these services. One recent analysis of cost data from a single hospice agency serving residents at home and in NHs found that costs tend to be higher for noncancer patients and that average daily expenditures decrease with episode length.³⁸ Unadjusted results imply that NH hospice care is relatively expensive, given

its higher proportion of noncancer diagnoses and short-stay residents; yet, within given diagnoses, NH hospice was found to be less costly than home hospice, perhaps because the NH staff provides some basic care. More generally, previous analyses of hospice cost data have found that costs are relatively high during the initial and final days of the hospice stay and that they are somewhat lower in the interim.⁸ However, it is unclear whether and how these trends apply to the NH setting, both because of the distinct diagnostic profile of NH hospice recipients and because of the potential for overlap between NH services and hospice care services (e.g., individuals are typically receiving supportive services in the days leading up to hospice election).

Overall, hospice agencies' Medicare profit margins appear to be positive, with MedPAC estimating aggregate margins of 3.4% in 2005.⁵ Still, margins vary depending on agency type, profit status, geographic region, patient-case mix, and average length of hospice stay. In particular, agencies serving patients with longer lengths of stay generally had higher profit margins, a factor indicative of the financial incentive of Medicare's per diem payment for longer hospice stays. An important caveat to this general point is that profit margins erode considerably in agencies that hit the per-beneficiary cap, as they must absorb 100% of subsequent costs.⁵ At the same time as hospice use is trending toward longer enrollment periods, the number of individuals with short enrollment periods also seems to be on the rise, perhaps because of people enrolling later in their illnesses. As described earlier, NH hospice has a disproportionately high number of very short lengths of enrollment. Thus, in the context of uniform payment, late enrollments could threaten profitability by limiting service provision to the highest-cost days of treatment.³⁴

Finally, assessing the financial benefit of hospice care for NHs is difficult, given that NHs do not receive hospice payments directly from Medicare; furthermore, residents may have their care financed in different ways if they choose not to opt for hospice care. Relative to having residents receive EOL care in the context of a Medicaid-financed stay (i.e., typical long-stay NH residents), the NH has little to lose financially in the hospice-NH

arrangement. In particular, the NH typically receives the full NH per diem payment while also receiving additional supports from the hospice agency for the residents who have enrolled in the hospice benefit. Relative to having residents receive posthospital care in the context of a Medicare-financed short stay, the Medicare hospice benefit reimburses facilities at a much lower rate, a financial disincentive of hospice to which we return later.

Barriers to Growth and Challenges for Public Policy

If current trends are a reliable predictor, the NH hospice market is likely to see steady growth in the future. The structural mechanism for such an expansion exists, with 87% of all NHs holding at least nominal contracts with hospice agencies. In addition, 80% of NH hospice enrollees enter hospice from the facility instead of entering from the community, implying that a push for greater enrollment could be made from within the NH setting itself.³⁹

Nonetheless, other indicators suggest that NH-hospice expansion might remain fairly limited and that there are important barriers to its expansion. Hospice has certainly grown rapidly in the past 25 years, and NH hospice's share of total hospice has risen from one-tenth to one-third.⁶ Yet, only 6% of NH residents currently elect the hospice benefit,³⁹ even though nearly one in four deaths in U.S. residents occurs in an NH.⁴⁰ Moreover, even if this gap is overcome, the government may face challenging public-policy issues resulting from current rules and care practices. These limiting factors include interaction between hospice and the Medicare skilled nursing facility (SNF) benefit, facility reluctance to embrace hospice, and shifting hospice demographics in the context of eligibility and payment policy.

The Medicare Skilled Nursing Facility Benefit

As mentioned earlier, NHs face financial disincentives to promote the Medicare hospice benefit over Medicare SNF care for individuals eligible for either benefit. In particular, for individuals being discharged from the hospital and who are eligible for either the Medicare hospice or SNF benefit, the facility receives

much lower reimbursement for hospice stays relative to SNF stays; moreover, residents who are not Medicaid eligible are liable for paying room and board costs if they choose hospice care instead of Medicare postacute care (financial implications for dual-eligible residents are neutral across benefits).^{41,42} Calculating precise numbers of residents enrolled in SNF care who could benefit from earlier admission to hospice is difficult; however, previous research has identified a sizeable minority of individuals who transition from SNF care to hospice within one day of SNF discharge, possibly suggesting that financial factors influence the timing of referral.²⁰ The clinical implications of these incentives for residents and the nature of the transition from skilled-rehabilitative care to hospice care are unclear.

Facility Reluctance

Even though it might be financially advantageous for NHs to enroll their residents in hospice care, some facilities have shown resistance to the transition. The lack of enthusiasm could come from the NH administrator, especially if promotion of the Medicare hospice benefit is perceived to be an admission that the home's EOL care is insufficient. Research has shown that hospice enrollment within the NH tends to rise as administrators' general opinions of hospice improve.⁴³ A reluctance to expand hospice also may come from the doctors and nursing staff, who are more typically oriented toward rehabilitative services in the NH setting, a feature reinforced by NH regulatory standards themselves.⁴⁴ Indeed, the literature has acknowledged a tricky balance in NHs between maximizing health and facilitating a comfortable death. Until this trade-off is addressed by the homes and policy makers, facility resistance could remain a serious barrier to growth.⁴⁵ Underscoring the importance of facility and staff attitudes regarding hospice care, one study of nurses and aides in NHs showed that enhanced training about terminal decline, coupled with an improved understanding of the role of hospice care, can significantly increase hospice referrals.⁴⁶ Likewise, an experimental intervention that gave physicians information on the appropriateness of hospice care for 205 residents in three NHs increased hospice enrollment from 1% to 20% after 30 days, and from 6% to 25% after 90

days.⁴⁷ An important caveat to emphasize in using NH provider education in expanding appropriate use of hospice among eligible NH residents is the high turnover of direct care staff at NHs.

Shifting Hospice Demographics in the Context of Hospice Eligibility and Payment

With growing rates of hospice use across settings among individuals with noncancer diagnoses and increasing enrollment lengths in every diagnosis category, hospice care is becoming more expensive for Medicare. Longer lengths of stay are partly a result of the difficulty of prognosis for patients with advanced dementia, which, even if a consensus diagnosis is reached, have variable symptoms and times until death.⁴⁸ Many of these patient-referrals die in a short period of time, but a large portion survives well past six months. Although less than 10% of patients with cancer, genitourinary diseases, and digestive diseases survive longer than six months, this rate is 25% or higher for hospice enrollees with Alzheimer's, dementia, or other nervous system disorders.⁵

Even in the context of the changing patient mix across the hospice benefit, the typical NH hospice user is different from home hospice users, with a much greater likelihood of having noncancer diagnoses, such as dementia, and of being eligible for Medicaid. These differences have important clinical and financial implications for providers and the Medicare program as a whole. For instance, longer lengths of stay for diagnoses common to NH residents operate in the context of Medicare's aggregate payment cap, where agencies are responsible for all costs of care if payments received exceed the limit. The vast majority of hospice agencies were not subject to the payment cap in 2005;⁵ however, those that did reach the limit disproportionately served individuals with noncancer diagnoses. Thus, even though there is no maximum length of time any individual is eligible to receive hospice care, there is an incentive for hospice providers to approach but not exceed the aggregate payment cap for its beneficiaries. As agencies serve larger proportions of individuals with noncancer diagnoses, access to hospice and the issue of hospice disenrollment and its effects should be monitored.

Another feature of Medicare hospice payment that can present access barriers for some potential recipients is the uniformity of payment. Outside of the geographically adjusted wage component of provider payments, Medicare hospice per diem rates are independent of all cofactors, including site of care, patient characteristics, diagnosis, and service provision. Of course, care intensity and service costs do not display such consistency, creating differential profit margins for different diagnoses. This gap could influence referrals and it may similarly have negative consequences for access to care. Certain individuals may be systematically screened out of a system that regards them as unprofitable—hospice patients with genitourinary diseases, for instance, are expensive to treat and have a very low (median: six days) expected time until death (at the same time, of course, the uniformity of hospice payment could also make some individuals particularly profitable).⁵ MedPAC recently made recommendations to implement hospice payment reforms to make payments relatively larger during the first and last periods of a hospice stay and smaller during the middle ones; however, MedPAC did not recommend any modifications based on setting or patient case mix.

Data Needs and Areas for Future Research

Little information about the direct costs of hospice care is available to date, with hospice agencies being required, until recently, to report only the number of enrollees and their durations of stay. The cost of hospice care per patient, as well as the service intensity and the breakdown of costs across service types, remains largely unknown in the NH setting. More specifically, the inability to obtain service use and cost data from most data sources on hospice care, including Medicare administrative data, has been a substantial impediment to understanding service provision in this area. Medicare is moving to lessen this barrier. New rules implemented in 2007 require hospices to report on the location of care for all Medicare patients, and analyses will begin soon to determine an accurate distribution of care settings. Other new rules will gradually increase data availability, with

compulsory reporting of agency visits for hospice enrollees beginning in July 2008.⁵ For the provision of NH hospice in particular, assessments of cost and service use should include the cost of hospice and NH care.

A lack of quality data also hampers research on hospice care, and NH hospice in particular. Although a growing number of agencies voluntarily submit data on selected structure, process, and outcome measures to the National Hospice and Palliative Care Organization, CMS has not mandated submission of any such data.¹⁴ In addition, the current set of publicly reported NH quality measures do little to assess the quality of EOL care. Various quality indicators have been suggested, including family experience and satisfaction with care, freedom from pain, advance directive completion, and reduced hospitalizations. Important domains of care that have been identified include attending to family needs for support and information, coordination of care, the provision of desired physical comfort and emotional support, and overall satisfaction.⁴⁹ In combination with greater cost information from the NHs, data on quality of care will allow for more reliable evaluations and comparisons of hospice care. As described earlier, analyses should also consider the potential indirect effects of hospice care on overall NH practices (e.g., through diffusion of knowledge).

Future research must seek greater specificity in its evaluation of the Medicare hospice benefit with respect to potential differences across settings. As with analyses of Medicare beneficiaries' experience with hospice more generally, endogenous selection of facilities and individuals into the hospice program can threaten the validity of comparative analyses. Several questions important to future hospice policy remain unanswered, including whether agency costs are generally lower in NHs compared with home settings and whether different diagnoses affect the timing of hospice use and service costs among NH residents. If spending for hospice care continues to rise at its current pace, there will likely be increased pressure on U.S. policy makers to assess the quality and appropriateness of hospice utilization and the methods used for its payment. This cannot be accomplished without further empirical insights, including how the growing use of hospice outside the home affects options for reform.

Conclusion

The Medicare hospice benefit has expanded considerably into the NH setting in recent years. Although utilization of hospice is still relatively modest among NH residents at the end of their lives, the greater availability of hospice holds promise. As an alternative to traditional NH care at EOL, hospice can provide quality EOL care and offer benefits, such as reduced hospitalizations and better assessment and management of pain. The provision of hospice care in NHs also has been shown to have positive secondary effects on nonhospice residents in the homes, suggesting benefits for clinical practices.

The provision of hospice in the NH setting also brings challenges on both clinical and policy dimensions. Collaboration between NHs and hospice agencies requires alignment of clinical goals and effective communication around residents' changing care needs. As the Medicare hospice benefit expands further into the NH setting, policy challenges also arise, particularly with respect to payment policy and even the conceptualization of the benefit itself. In particular, the changing case mix of hospice patients, including the increased use of hospice by individuals with conditions such as Alzheimer's disease and dementia, has resulted in greater variance and uncertainty around the predicted and observed life expectancy for enrollees. To address these and other changes in the provision of hospice across settings, there must be greater availability of comparable data on cost, service intensity, and quality of care. CMS has taken steps toward collecting these data; however, further efforts are needed to bolster the information base for future reform and to shed light on what refinements, if any, are necessary for the Medicare hospice program. By streamlining and modernizing hospice care, particularly in the NH, Medicare can minimize costs and ensure access to high-quality EOL care for the nation's elderly.

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