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The Role of Hospice Care in the Nursing Home Setting

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Abstract

The last days of life for a substantial proportion of dying older adults are spent in nursing homes. Considering this, the provision of Medicare hospice care in nursing homes would appear to be an equitable use of Medicare expenditures as well as a valid investment in improving the quality of life for dying nursing home residents. However, government concerns regarding possible abuse of the hospice benefit in nursing homes, as well as suggestion that the payment for the benefit in nursing homes may be excessive, has perhaps slowed the adoption of hospice services into the nursing home setting. Currently, access to hospice care in nursing homes is inequitable across facilities, and across geographic areas. In nursing homes where hospice is available and present, however, recent research documents superior outcomes for residents enrolled in hospice, and perhaps for nonhospice residents. Still, more research is needed, particularly research focusing on the government costs associated with the provision of hospice care in nursing homes. If subsequent research continues to support the "added value" of hospice care in nursing homes and at the same or less total costs, the issue of foremost concern becomes how equitable access to Medicare hospice care in nursing homes can be achieved. Access may be increased to some extent by changing government policies, and conflicting regulations and interpretive guidelines, so they support and encourage the nursing home/hospice collaboration.

Introduction

Nearly one in five older adults dies in a nursing home[1] with many more dying in a hospital after becoming institutionalized.[2] According to the National Center for Health Statistics, in 1997 more than 20% of the aged died in nursing homes. Nursing home residents in the final phase of their lives have different clinical care and psychosocial needs than other nursing home residents.[3,4] Rather than a focus on restoration or on prevention of decline/symptoms, care of terminally ill nursing home residents requires a focus on palliation—on the management of the terminal decline and its accompanying symptoms.

With the passage of the Omnibus Budget Reconciliation Act of 1989,[5] the availability of the Medicare hospice benefit to dual-eligible nursing home residents (i.e., those eligible for Medicare benefits and receiving Medicaid reimbursed nursing home care) was ensured. In this paper we review what is known about the role of hospice care in nursing homes and reference several recently completed studies that are beginning to shed light on this topic.

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The Dying Experience of Nursing Home Residents

In the SUPPORT study,[6] seriously ill persons who died in hospitals often had severe pain and dyspnea in the last days of life, and according to family, two of three dying persons found it difficult to tolerate emotional symptoms in the last days of life. Research documenting poor management of pain in nursing homes[7–9] increases the probability that the care of dying persons in nursing homes may be similar to that observed in hospitals in SUPPORT.[6] Nursing home studies show that physicians often fail to identify pain as a problem,[8,10] to reassess pharmacologic interventions,[9] or to prescribe adequate pharmacologic treatment for nursing home residents.[7–9] Ferrell and colleagues[8] found that the majority of persons with painful conditions in nursing homes were only prescribed acetaminophen. Among nursing home residents with cancer in five states, Bernabei and colleagues[7] found that 26% of those residents documented to have daily pain did not receive any analgesic agent, and only 26% of those patients with a known diagnosis of cancer received morphine. Presence of pain was associated with age, gender, race, physical function, depression, and cognitive impairment, and under-treatment was prominent among older and minority patients.[7] Hanson and colleagues[11] studied deaths of older adults (n = 461) in central and eastern counties in North Carolina. Although family perceptions and satisfaction with care were not reported separately for deaths occurring in nursing homes (28% of deaths), nursing homes did receive the lowest proportion of positive comments (51%) when compared to deaths occurring in hospitals, in the decedent's home, or in another location.[11]

The above findings reconfirm an Agency for Health Care Policy and Research expert panel's opinion that frail, elderly persons, especially those in nursing homes, need special attention regarding their pain management.[12] There is documented evidence of possible nursing home shortcomings in all the major healthcare quality problem areas identified by the Institute of Medicine (IOM)[13]: (1) that care may be underutilized (i.e., poor symptom assessment and management and inaccessibility to palliative care), (2) that care may be overutilized (i.e., unwanted interventions and hospitalizations), (3) that technical performance will be poor (i.e., inadequate medical management of symptoms), and (4) that interpersonal performance will be inadequate (i.e., failure to inform patients and families fully regarding care and to ascertain and adhere to patient and family preferences). The extent to which hospice can have a positive effect on the dying process of nursing home residents, the “value added” of hospice care in the nursing homes, if, indeed, there is any added benefit, must be documented. Recent studies have begun to document this added benefit. Recent research suggests that hospice enrollment is associated with higher quality symptom assessment and management and with lower rates of hospitalizations.[14–16]

The Medicare Hospice Benefit in Nursing Homes and its Utilization

The Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985 allowed for receipt of Medicare hospice care in nursing homes, but as discussed, OBRA '89 made the benefit more widely available. To receive Medicare hospice benefits, nursing home residents must be eligible for Medicare, and be certified by their attending physician and a hospice medical director as terminally ill, which is defined as having a life expectancy of 6 months or less under normal disease progression. Similar to all hospice beneficiaries, by electing the Medicare hospice benefit, residents agree that the hospice has full responsibility for managing their plan of care. By enrolling in the Medicare hospice program patients also waive their right to receive standard Medicare benefits, including all curative treatment, at least until they “disenroll,” something that they can do up to three different times. The nursing home continues to provide “room and board” for residents enrolled on the hospice benefit. When the resident is a private pay resident, the nursing home “room and board” fee

is paid directly by the individual or the family. However, for the dually eligible (Medicare and Medicaid) resident, Medicaid pays the nursing home "room and board."

Since the enactment of OBRA '89, Medicare hospice beneficiaries residing in nursing homes represent the most rapidly growing segment of hospice beneficiaries. Indeed, nursing home residents constitute up to 46% of all hospice beneficiaries in some markets.[17] In 1996, Banaszak-Holl and Mor[18] found a highly significant increase in the proportion of hospice beneficiaries who were receiving nursing home based services between 1987 and 1990 (6.6% vs. 9.9%). Furthermore, this increase was concentrated in certain markets and among community-based hospices. By 1995, according to estimates by The Office of Inspector General (OIG), 17% of Medicare hospice beneficiaries lived in nursing homes while receiving hospice care.[18] Of those nursing home beneficiaries studied by OIG, almost half (45%) were both Medicare and Medicaid eligible.[18]

Using data from the On-Line Survey and Certification Automated Record (OSCAR) maintained by Centers for Medicare & Medicaid Services (CMS) on all nursing facilities in the country, Petrisek and Mor[19] found that in 1995 less than 1% (0.9% ± 2.7%) of residents per facility were hospice beneficiaries. Whether these low percentages reflect preference and/or need for hospice care, or restricted access to Medicare hospice care in nursing homes is unknown.

More recently, a study conducted for the Assistant Secretary for Planning and Evaluation matched Medicare claims with computerized nursing home Minimum Data Set (MDS) data to determine which residents of nursing homes were concurrently recipients of the Medicare hospice benefit.* In the five states studied, the authors' estimate that 24% of all 1996 hospice enrollees resided in nursing facilities while receiving Medicare hospice care.[17] Nationally, the concentration of hospice in nursing facilities is substantially higher in several other states such as Florida and California.[19] Even in the five states studied, the range of 1996 Medicare hospice beneficiaries residing in nursing facilities was found to be between 11% and 48%. Whether this range and the overall rate of 24% reflect current national proportional is unknown.[17]

Access to the Medicare Hospice Benefit in Nursing Homes

Petrisek and Mor[19] found that the proportion of nursing home residents on the Medicare hospice benefit differed substantially within and across states. They found that 30% of nursing homes had at least one Medicare hospice beneficiary but that the 4.2% of nursing homes having 5% or more (5%+) of their residents on the hospice benefit served approximately 34% of all hospice beneficiaries in nursing homes.[19] They showed that considerable state variation exists. A number of states, such as North Dakota, South Dakota, and Iowa have few nursing homes with 5%+ hospice Medicare beneficiaries. On the other hand, other states such as Texas and Florida have large numbers of facilities with 5+% concentrations of beneficiaries.

Jones et al.[20] also found that factors other than patient need and demand influence the availability of hospice care in nursing homes. In studying administrators in 23 nursing homes owned by the same company and having rates of hospice use ranging from 2% to 39%, they found that the administrator's attitude toward hospice influenced the nursing home's use of hospice services. Rates of hospice use were three times higher in nursing

*The report to the Assistant Secretary for Planning and Evaluation (ASPE) is available on the government web site along with a larger report summarizing the state of the Hospice in the U.S. http://aspe.os.dhhs.gov/daltcp/reports/samhbes.htm

homes where administrators were “most sympathetic” to hospice than in the nursing homes where administrators were “least sympathetic” to hospice.

The influence of factors other than patient need/demand on the provision of services is not a phenomenon unique to hospice. As shown in the Dartmouth Atlas of Health Care,[21] Medicare enrollees' site of death and the utilization of health care resources at the end of life varies remarkably by hospital bed supply.[21] In other words, the more inpatient beds in a community, the more likely death is to occur in a hospital. The question raised in the Dartmouth work and relevant for hospice care in nursing homes is which rate is the right one? For hospice care in nursing homes, the question is what is the best rate of hospice concentration in a community's nursing homes considering the documented needs and preferences of nursing home residents in that community?

To address this question, several basic issues, both conceptual and empirical, need to be addressed. Empirically, we now have some evidence of the “value added” of hospice care in the nursing home. We do not, as yet, have good comparative data on the dollars spent by Medicare and Medicaid to care for dying nursing home residents who do and do not enroll in hospice. From a policy perspective, introducing a second agency into the facility to deliver some “specialized” care raises issues of efficiency, equity, and most importantly whether daily expenditures should be increased by one third to one half because patients have elected “hospice care.” A study conducted by the OIG seriously questioned the appropriateness of the perceived extra spending, noting that the current structure resembles “double dipping”—being paid twice for the same service. On the other hand, hospice and nursing home advocates counter that this is specialized care for which special skills and training are needed and that this care represents the core competence of hospice and not of nursing homes. Furthermore, advocates counter, the added funds are necessary in light of inadequate funding of nursing home care.

The U.S. Office of Inspector General Hospice Studies

With little other information available regarding the implementation of the Medicare hospice benefit in nursing homes, controversial findings from hospice studies by OIG[22] have received much attention. The OIG findings raised concerns regarding possible abuse of the hospice benefit in nursing homes and suggested that payment for the benefit may be excessive. OIG conducted targeted audits in five states (California, Florida, Illinois, New York, and Texas). Medicare expenditures in these states represent 40% of total Medicare expenditures. The purpose of Hospice Patients in Nursing Homes[22] was to examine the eligibility, services, and growth of hospice patients living in nursing homes. Based on studying 200 beneficiaries served by 22 hospices predominantly located in 5 states, the OIG estimated that 16% of hospice patients living in the nursing home did not actually qualify for the Medicare hospice benefit at the time of enrollment because their terminal condition was not deteriorating. Patients whom the reviewers deemed ineligible had a much longer average length of stay than those not deemed ineligible, 369 days versus 145 days. The overall average length of stay was 181 days; much longer than the average of 56.3 days estimated by the National Hospice and Palliative Care Organization (NHO) for nursing home beneficiaries in 1995 and the recent estimate of 91 days using nursing home population-based data in 5 states.[17]

The OIG also reported that nursing home residents received fewer hospice visits than did hospice patients who resided in the community. Careful examination of the OIG study suggests that the figures may not, in fact, be comparable. Based on data from the original evaluation of the impact of hospice on the medical costs and quality of care experienced by dying patients, it has been shown that the intensity and frequency of service visits to patients

increase as death approaches.[23] The OIG sample contained predominantly long stay patients who would, therefore, appear to have a less "intensive" service use profile than would have been the case were many more short stay patients included in the study.

Subsequent to release of the OIG findings, and as recommended by the OIG, the CMS has worked with hospice associations to educate hospices regarding avoidance of potential fraud and abuse, or appearance of such by inappropriately worded contracts. The OIG also recommended that CMS work with states to develop regulations specifying what is included in nursing home room and board payments but such regulations are yet to be released. These OIG findings, although not based on a representative sample of hospice nursing home providers, remind policymakers of the careful regulatory balance needed to ensure access to a benefit while limiting the risk of abuse.

Future Research Needs

At a time when more elderly than ever are dying in nursing homes from chronic illnesses common in old age,[24,25] there is continued concern about the quality of care provided to all nursing home residents, particularly to the most frail and vulnerable.[26] Whether the hospice approach in the nursing home setting is both beneficial and cost effective is not really known at this time. Nonetheless, the consequences of the Inspector General's reports have increased scrutiny of hospices collaborating with nursing homes across the country. Empirical data on the Medicare hospice program suggest that the average length of stay in the program has been dropping as programs worry about admitting patients who might not die within the time frame of the 6-month prognosis. Anecdotal evidence suggests that nursing homes and hospices are entering into contractual relationships much more carefully, perhaps slowing the adoption of hospice services into the nursing home setting, thereby "denying" those with chronic, terminal conditions access to hospice service if their impending death is not imminent.

There are several fundamental questions that have emerged in considering the appropriateness as well as the possible effectiveness of hospice services in the nursing home context. First, how well can nursing homes and hospices "share" the clinical and legal responsibility for the patient and who is ultimately responsible? Second, are the types of financial and contractual arrangements between nursing home and hospice necessarily conflicted? Finally, if hospice adds value to the clinical treatment of the patients it specifically serves, is there any diffusion, or spill-over, effect that might improve the quality of nursing home care, even for nonhospice patients.

Nursing homes have always implemented interorganizational relationships to serve the needs of their patients. Unlike hospitals, most U.S. nursing homes establish relationships with vendors to deliver therapy services, consultant pharmacy and drug delivery services, and of course, medical care. In spite of the fact that nursing homes do not directly provide these services, over the last several decades they have gradually acquired the responsibility for coordinating and monitoring the delivery of such services. The introduction of hospice services into the mix of services provided to terminally ill nursing home residents is not necessarily different from these other arrangements in which responsibility for the clinical care of the patient is "shared." For example, more than 80% of all U.S. nursing homes contract for the physical, occupational, and other specialty therapy services their residents require.* Most often these independent clinicians are autonomous and have little established relationship with the nursing staff at the facility. In other instances, however, these relationships become more generalized and include advising on treatment for other patients

*Per analysis of 1998 OSCAR data.

and giving tips to, or even training, facility nursing staff in certain therapy related tasks. While contracts between hospices and nursing homes are a newer phenomenon and have been stymied by real contradictions in the regulations covering hospices and those covering nursing homes, in principle they are not more complex than those between nursing homes and therapy companies. Thus, it is interesting that this interorganizational relationship has been singled out as being rife with conflicts of interest.

In light of what could be a highly beneficial and close clinical working relationship between hospice and nursing homes, it is not clear that it is advantageous for a nursing home to establish a contract with multiple hospices for the same reason it is desirable to have only one contract with a therapy company—continuity and time to establish patterns of communication to insure that standard clinical care operating procedures are compatible and optimal for the patient. Each such contract requires time, established interorganizational linkages, and a history of trust. Having multiple contracts may not be efficient. However, focusing on a single agency raises the specter of collusion. The point of establishing ongoing, particular interorganizational relationships between a nursing home and a hospice is that the coordination of care, the communication across the clinical staff, and the blending of operational care protocols can be enhanced. Ideally, the skills and core competence of the hospice staff can be disseminated to the nursing home staff who will be exposed to palliative care processes and approaches to care and the subsequent outcomes terminally ill patients experience. Such “diffusion” of knowledge, skills and attitudes can only occur when two organizations are compatibly working together at all levels of the respective organizations, administrative, support and clinical staff. Presently, the level of knowledge about the types of contracts and interorganizational relationships between hospices and nursing homes is very rudimentary.

An adjunct question regarding the “value added” of Medicare hospice care in nursing homes concerns the influence its presence has on nursing home residents who are not hospice beneficiaries. In addition to education provided to nursing home staff that may improve the management of nonhospice terminal residents, the care practices directed toward individual residents by hospice providers may “spill over” to the overall nursing home organization.[16,27] Consequently, whether the presence of hospice in a nursing home improves the dying experience of hospice and of nonhospice decedents is a question worthy of study. Study does suggest that hospice presence is associated with less hospitalization at the end-of-life for nonhospice residents and with superior management of pain,[28] but much additional study is needed to know how generalizable this phenomenon is to other care processes and outcomes.

Conclusion

Provision of the Medicare hospice benefit in nursing homes appears to have extended the benefit to a higher percentage of previously under-served populations. However, access to the benefit in nursing homes is not equally available to all nursing home residents. An optimal model for care of the terminally ill in nursing homes would equitably provide high-quality terminal care and support to nursing home residents and their families/significant others while not increasing the costs of care. The provision of such high-quality care for dying nursing home residents should be a priority in the United States where the population is aging and one in five older persons dies in a nursing home.[1]

Recent research supports the notion that Medicare hospice care in nursing homes results in superior outcomes to residents enrolled in hospice,[14–16] and perhaps to nonhospice residents.[16] If subsequent research continues to support the “added value” of hospice care in nursing homes and at the same or less total costs, the issue of foremost concern becomes

how equitable access to hospice in nursing homes can be achieved. This dilemma will provide a significant challenge to policy makers, but can be addressed to some extent by changes in government policies, and conflicting regulations and interpretive guidelines, so they support and encourage the nursing home/hospice collaboration.

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