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Hospice care in US nursing homes: benefits and barriers

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About a quarter of adult deaths in the USA occur in nursing homes.[1,2] Previous research has concluded that the residents of these homes do not receive adequate pain management or high-quality palliative care at the end of life.[1,3,4] Dementia can make the provision of adequate pain management difficult, in that residents with dementia may have difficulty in reporting their pain. Magaziner *etal* found that almost 50% of all nursing home residents had dementia.[5] Another study found that 83% of nursing home residents with dementia had painful conditions.[6]

One way to improve pain management for nursing home residents with dementia would be to use hospice services in the nursing home. Yet, hospices services are not widely used in nursing homes, even for those residents who qualify for it. Currendy, 24% of nursing home residents who die in nursing homes qualify for hospice services, but only 6% are enrolled.[7] Pain management at the end of life for nursing home residents could be improved by greater use of hospice seivices.

US Medicare hospice services

In 1996, Medicare, the US government-administered programme that provides health insurance for people aged 65-plus, extended its hospice services to cover terminally ill older adults with severe cognitive impairment.[8] Under the new rules, many nursing home residents who were not previously eligible for hospice care became eligible. Severe cognitive impairment, including that caused by Alzheimer's disease, is the fifth leading cause of death among the over-65s in the USA.[9] Hospice seivices can provide support to older adults with cognitive impairment, by helping to manage pain, providing comfort and easing the transition to death.

Since the approval, in 1982, of Medicare hospice benefits, nursing homes have been able to offer a wide range of hospice services to dying residents (see Box 1).[10,11] However, according to Munn *et al,* fewer than half of the residents who are eligible actually receive the benefits.[11] Miller *etal* found that 24% of nursing home residents qualified for hospice

Todd B Monroe and **Michael A Carter** review the literature on the use of hospice services in US nursing homes. They find there are many benefits, both to the residents and the healthcare system, but also that many people, especially those with dementia, are missing out

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services, but that only 6% used them.[7] Evans reported that only 1% of nursing home residents were using the benefits,[12] and Petrisek and Mor showed that only 30% of nursing homes had residents enrolled for hospice care.[13]

Benefits of the use of hospice care in nursing homes

Better pain and symptom management

The management of pain experienced by nursing home residents has been a concern for nearly 30 years.[14] Reynolds *etal* reported that 86% of dying nursing home residents experienced pain, and that more than half of those experienced moderate-to-severe pain.[15]

Hospice care improves pain management. One study showed that nursing home residents enrolled in a hospice for seven days or more had a greater chance than those not enrolled of receiving opioid treatment and were more likely to be given an opioid dose twice a day.[16] Wu *et al* found that residents receiving hospice care were generally more likely to be given opioids for pain management than residents not receiving hospice care.[17] Miller *etal* reported that the use of analgesic medication was 50% greater in nursing home residents receiving hospice care than in those who were not.[7] Munn *et al* found that 85% of nursing home residents who did not receive hospice care experienced moderate-to-severe pain, compared with 52% of those receiving hospice care; and that 82% of hospice-enrolled residents received pain medications, compared with 50% of non-enrolled residents.[11] Nursing home residents receiving hospice care are also 93% more likely to have their pain management documented.[18]

Munn *et al* found that alternative pain management strategies, such as ice packs and massage, were more often used among nursing home residents receiving hospice care, who were also more likely to receive assistance with eating and oral hygiene, than those not receiving hospice care.[11] A meta-analysis of 19 hospice and palliative care studies concluded that hospice and palliative care teams managed pain better, and all other symptoms moderately better, than nursing home teams.[19]

Better management of pain and of medication is a recognised benefit for nursing home residents using hospice services. Miller *et al* reported that nursing home residents receiving hospice care received fewer inappropriate medications than those not enrolled in hospice care, as recommended by the American Medical Directors Association.[7]

Pain management may be better for all nursing home residents when hospice care is provided in the facility - a phenomenon identified as the ‘hospice effect’. Patients who did not receive hospice care, but who resided in a nursing home where hospice care was offered, were more likely to have their pain assessed.[17]

On behalf of the US Department of Health and Human Services (DHHS), Gage *et al* compared nursing home residents who were receiving hospice care (n=l,982) with nursing home residents who were not (n=6,392).[20] They found that the detection of daily pain was different between the two groups. Daily pain was detected in 28.1% of residents with cancer and no dementia receiving hospice care (n=430), and in 16.8% of residents with cancer

and no dementia not receiving hospice care (n=l,529). Daily pain was detected in 16% of residents with cancer and dementia receiving hospice care (n=717), and in 8.9% of residents with cancer and dementia not receiving hospice care (n=2,293). This would seem to show that pain in individuals with dementia may be underdetected, but that enrolment in hospice care results in increased pain detection among these patients.

Financial benefits for the healthcare system

Greater hospice enrolment may help to reduce costs in the US healthcare system by reducing the use nursing home residents make of acute care services.

According to the DHHS, nursing home residents who use hospice services are significantly less likely to be hospitalised at the end of life than those residents who do not. Gage *et al* found that the number of hospitalisations of nursing home residents not enrolled for hospice care decreased as hospice enrolment increased. They also found that the reduction in hospitalisations in the last 30 days of life translated into acute medical care savings of $2,909 for every nursing home resident.[20]

A study of people aged 65-plus with advanced dementia found that 43.7% of nursing home residents were hospitalised at least once during the last 90 days of life, compared with 31.5% of those receiving home-care services.[21] Nursing home residents with cognitive impairments are taken to hospital more frequently than those without cognitive impairments, when available hospice care could help to relieve pain and provide support to the resident and their family.[22,23] According to Kronman, decreasing just one hospital day per beneficiary of Medicare hospice benefit could save millions of dollars.[22]

Among nursing home residents receiving hospice care, 25% had been enrolled for less than one week[20,24] and 50% for less than 30 days before dying.[20] By using hospice services, individuals with cancer save Medicare $7,000 over the course of the illness, while those with other primary conditions help save $3,500.[24] Nursing home residents enrolling in hospice care who received information about palliative care, and subsequent assistance, had fewer acute care admissions and spent fewer days in hospital.[25] Thus, efforts to increase short-term hospice care offer a greater opportunity to save Medicare money than attempts to reduce long-term hospice care.[20,24] However, increasing the length of hospice enrolment of seven out of ten nursing home residents would also greatly increase savings.[24]

Barriers to the use of hospice care in nursing homes

Patient and family attitudes

The family’s culture and religion may influence the decision about hospice enrolment. According to Jablonski and Wyatt, Hispanic and African-American families generally favour life-sustaining measures over palliative care, which may conflict with professional carers’ attempts to offer pain relief.[26]

Another barrier to hospice enrolment is the patient’s own preference for life-sustaining treatment, which may indicate a lack of understanding, by the patient and/or the family, of the terminal nature of the diagnosis[27] (or possibly a desire not to surrender to the disease).

Casarett *et al* found that 56% of patients and families were reluctant to accept a terminal diagnosis, and that 91% of hospice-eligible older adults did not enrol until late in the course of a six-month illness.[28] Among nursing home residents enrolled for hospice care, one-third had been receiving it for less than two weeks and one-fifth for less than one week before dying.[16,29] These figures suggest that patients may not be benefiting fully from hospice care because of late enrolment.

There may be barriers to hospice enrolment that are specific to nursing home residents with dementia. One study found that only one in every ten nursing home residents dying with dementia was enrolled in hospice care.[30] This could be the result of communication problems between residents and staff.

According to one survey, 17% of nursing home nurses believe that hospice staff do not have the skills to care for residents with dementia.[31] This finding is interesting, given that 59% of nursing home residents receiving hospice care have some cognitive impairment.[15] Mitchell *et al* reported that nursing home residents with cognitive impairment had more functional disability, behaviour problems and tube feedings than those who were mentally sound. They also found that this population is often not recognised as terminally ill and infrequently (5.4%) referred for hospice care.[32]

The majority of hospice nurses (88%) and 45% of nursing home nurses believe that the lack of knowledge about hospice care on the part of residents and families is a barrier to its use.[31] In a randomised, controlled trial, hospice enrolment increased after a brief structured interview between a clinician and nursing home residents and their families.[25] Another study reported that 85% of patients and families decided to enrol for hospice care after one conversation with a professional carer such as a doctor or nurse with specialised training in palliative care.[28]

Lack of knowledge and education of nursing home staff

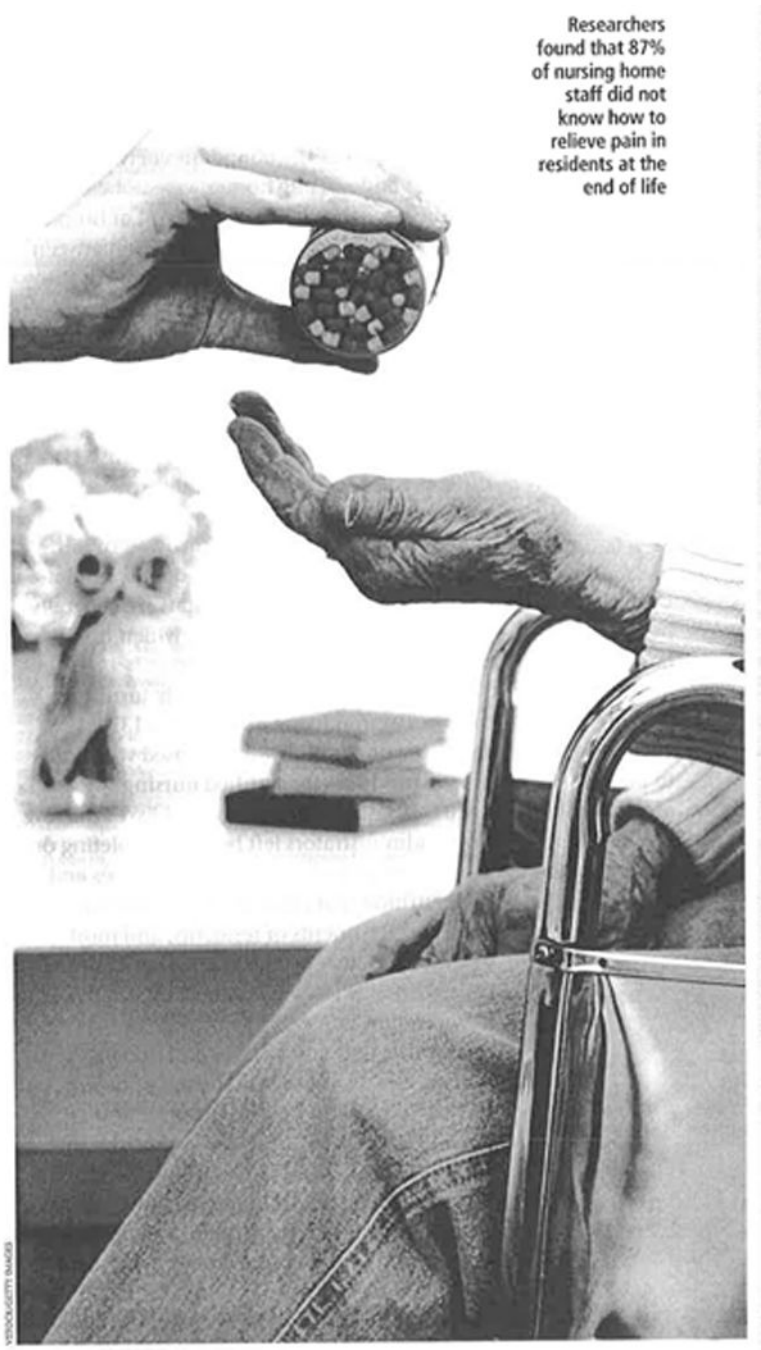
Lack of knowledge about, and unfamiliarity with, hospice and palliative care prevents nursing home staff from using it fully. One survey found that 92% of hospice nurses and 26% of nursing home nurses believed that a lack of knowledge about hospice care on the part of nursing home staff was a barrier to hospice enrolment.[31]

Symptom relief is a major tenet of palliative care, and the overall symptom burden is higher in nursing homes than in residential care or assisted-living facilities.[33] Jablonski and Wyatt explained that the problem of symptom relief in nursing homes may be exacerbated by the large numbers of unlicensed personnel, who lack palliative care education but provide the majority of the care.[26] One survey revealed that nearly 20% of nursing homes did not provide formal training in end-of-life pain and symptom management, and that more than 50% of nursing home administrators believed that lack of education was the single greatest obstacle to providing quality end-of-life care.[34] Hanson *et al* found that 87% of nursing home staff did not know how to relieve pain, and that 89% did not know how to relieve dyspnoea, in residents at the end of life.[33]

Organisational and system issues

Another barrier to hospice enrolment is rooted in the core philosophical differences between traditional nursing home care, which concentrates on maintaining health, and established hospice practice, which is palliative.

These differences are heightened by the requirements of the Minimum Data Set (MDS), the documentation system used in US nursing homes that must be completed on each admission and quarterly thereafter. The MDS focuses on restorative rather than palliative care.[12,31] It centres on health and functional indicators,[35] not on symptom management (such as control of pain, dyspnoea or fatigue) or on end-of-life issues and spiritual needs.[12] For example, the MDS requires that, if there is any evidence that a resident is malnourished, this should be addressed; however, a decreased food intake may be part of the dying process and the prolongation of life through forceful feeding may increase the person's suffering.[12,31,35] Clearly, palliative care is not supported by the current MDS, and changes to this documentation system are needed.



Confusion about, and lack of understanding of, who is ultimately responsible for the residents' care potentially create another significant barrier to hospice enrolment. Parker-Oliver and Bickel found that there was confusion, among the 60 administrators and directors of nursing homes that they surveyed, about who had the ultimate responsibility for the patients' palliative care plan; 40% believed it was the responsibility of the nursing home; 36% believed it was both the nursing home and the hospice, 18% thought it was the hospice; and 6% did not know. Only 38% thought they understood how hospice care was reimbursed and 15% felt that the boundaries between hospices and nursing homes were not clear.[36]

Another study found that one-third of hospice nurses identified miscommunication between nursing home and hospice staff as one of the biggest problems when working with hospice patients in nursing homes.[37] Lack of understanding about hospice and nursing home care plans may lead to gaps or overlaps in care or reimbursements. For example, the nursing home and hospice may establish two different and competing wound-care plans for the same patient.

Staff shortages and a high turnover of staff contribute significantly to low-quality end-of-life care.[1,2,12,34] Nursing home staff are generally the lowest paid in the industry, which makes recruitment and retention difficult.[4]

One study found that the yearly turnover rates in Texan nursing homes were 133% for registered nurses, 108% for licensed vocational nurses and 160% for certified nursing assistants.[38] Clarkin reports that 43% of nursing home administrators left before completing one year of employment.[39] Staffing shortages and high attrition make it difficult to carry out detailed assessments of residents, and most of the care is provided by licensed practical nurses who are less well trained, especially in end-of-life care.

Conflicts between hospice and nursing home staff are another barrier to the use of hospice services in nursing homes. Hospices and nursing homes are both regulated by the state (and to a lesser degree the federal government through federal reimbursement), but each has a different organisational structure and culture. Hospices provide ’relational care’, whereas nursing homes provide ’routinised care’.[40] Relational care is more democratic, giving residents and their families more choice, while routinised care is very structured and bureaucracy-driven.[40] As a result, relationships between hospice and nursing home staff can become strained.

Tarzian and Hoffmann found that many nursing home staff believed that hospice staff were not familiar with nursing home policies and that most hospice staff rarely did anything that they did not do. Nursing home nurses felt that hospice nurses think they ’know everything’ and tend to ’take over’ rather than work in a collaborative effort.[31] Parker-Oliver found that nursing home nurses had the following perceptions about hospice nurses: 70% believed that ’hospice staff come and tell us what to do, yet we are here 24 hours a day’, 54% that ’hospice puts everyone on morphine’ and 53% that ‘hospice just lets residents die’.[37]

Financial problems

Financial problems are another potential barrier to hospice enrolment, particularly with regard to reimbursement and billing for specific services.[29, 31] Medicare Skilled Nursing Facilities pay for room and board, but these items are not covered by Medicare hospice benefits. This means that residents using the latter must find other resources to pay for room and board, resulting in a complicated (and potentially lower) reimbursement to the nursing home.[26]

Reimbursement methods are also an issue. Where nursing homes are reimbursed by hospice agencies, the money takes longer to reach the nursing homes than when it comes directly from government healthcare agencies, such as Medicare and Medicaid.[12] For example, if a

resident is eligible for Medicaid, Medicaid will pay the hospice 95% or more of the state's daily nursing home rate, and then the hospice will reimburse the nursing home for room and board, which complicates and delays the payment to the nursing home.[40] Another concern is that nursing homes receive more money for rehabilitative care than for palliative care, so the revenues will be higher in nursing homes not using hospice services.[26]

Disease progression and prognosis

The US federal reimbursement system requires that a six-month prognosis is made before a patient is deemed eligible for Medicare hospice benefits (see Box 1). Difficulty in determining this six-month 'window to death' may also be a barrier to hospice enrolment.[41] Many doctors are uncomfortable estimating when residents will die, especially residents with dementia,[9,12] congestive heart failure or chronic obstructive pulmonary disease (as opposed to residents with cancer, who typically follow a more predictable trajectory).[41]

One instrument used to establish the eligibility for hospice care of individuals with dementia is the Functional Assessment Staging (FAST) scale.[42] The scale has a number of stages of severity, ranging from stage 1 ('No objective or subjective difficulties') to stage 7f ('Cannot hold head up independently'). In the USA, stage 7a ('Speech limited to fewer than six intelligible words during an average day') and stage 7c ('Unable to ambulate independently') are considered points of hospice eligibility. However, in one study, 40% of residents could not be evaluated using this method because their disease progression did not match that of the FAST scale.[43]

Alternating episodes of deterioration and recovery are common in nursing home residents, making it difficult to ascertain when they are in their final six months of life, which in turn makes it difficult to determine their eligibility for hospice care. Although, in theory, the entitlement can be renewed if the resident does not die within the six-month period, meeting the conditions for enrolment over and over again can be a problem.

Conclusion

In the USA, hospices have been helping people in the transition from life to death, with as little pain and discomfort as possible, for nearly 30 years. However, more nursing home residents could be receiving the benefits of hospice care. Nurses and healthcare professionals working in nursing homes should be encouraged to overcome the barriers to the hospice enrolment of their residents, so that these are given the best possible care at the end of life.

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Box 1.

Who is eligible for US Medicare hospice benefits? What are these benefits?*

To be eligible for Medicare hospice benefits, it is necessary to meet all of tde following conditions:

- The patient must be eligible for Medicare Part A (hospital insurance)
- The doctor and the hospice medical director must certify that the patient has a terminal illness with a life expectancy of six months or less
- The patient must sign a written statement saying that they choose hospice care to treat their terminal illness
- Care must come from a Medicare-approved hospice programme

The Medicare hospice benefits include:

- Doctor and advanced-practice nursing services (on call 24 hours a day)
- Medical care provided by the hospice medical director
- Nursing care (on call 24 hours a day)
- Case management
- Medical equipment and supplies
- Medications for terminal illness and palliative care (small patient co-payment may be required)
- Speech and language therapists
- Short-term inpatient and respite care (small patient co-payment may be required)
- Physical and occupational therapy
- Dietary counselling
- Home health aide services
- Continuous care
- Counselling and social work services
- Spiritual care
- Help from volunteers
- Grief and loss counselling

* Adapted from Medicare Hospice Benefits[10]

Key points

- In the USA, many nursing home residents do not receive adequate palliative care.
- The Medicare hospice benefits scheme allows US nursing homes to offer a wide range of hospice services to their dying residents; however, many eligible residents are not enrolled for hospice care.
- Hospice care has proven benefits for nursing home residents, who get better pain and symptom management, and for the US healthcare system as a whole, in the form of savings on acute care costs.
- Many barriers prevent more US nursing home residents from receiving hospice care, incuding a lack of knowledge about hospice care among nursing home staff.
- Another barrier to the use of hospice care in US nursing homes is a bias, in the nursing home documentation, towards restorative rather than palliative care.