Strategies and Innovative Models for Delivering Palliative Care in Nursing Homes

Melissa D. A. Carlson, PhD, Betty Lim, MD, and Diane E. Meier, MD

The goals of palliative care address critical issues for individuals with complex and serious illness residing in nursing homes, including pain and symptom management, communication, preparation for death, decisions about treatment preferences, and caregiver support. Because of the uncertain prognosis associated with chronic nonmalignant diseases such as dementia, many nursing home residents are either not referred to hospice or have very short or very long hospice stays. The integration of palliative care into nursing homes offers a potential solution to the challenges relating to hospice eligibility, staffing, training, and obtaining adequate reimbursement for care that aligns with resident and surrogate’s preferences and needs. However, the delivery of palliative care in nursing homes is hindered by both regulatory and staffing barriers and, as a result, is rare. In this article, we draw on interviews with nursing home executives, practitioners, and researchers to describe the barriers to nursing home palliative care. We then describe 3 existing and successful models for providing nonhospice palliative care to nursing home residents and discuss their ongoing strengths and challenges. We conclude with specific policy proposals to expedite the integration of palliative care into the nursing home setting. (J Am Med Dir Assoc 2011; 12: 91–98)

Keywords: Palliative care; models of care

There are approximately 1.5 million individuals residing in nursing homes (NH) in the United States.\(^1\) Individuals with dementia make up the largest single group of NH residents with prevalence estimates ranging from 48% to 66%.\(^2\)-\(^4\) Most NH residents require either extensive assistance or total dependence for bathing, personal hygiene, transferring, and using the toilet.\(^1\) The average and median length of stay for NH residents is 835 and 463 days, respectively,\(^1\) and most residents (66%) die there.\(^5\) NHs are responsible for both the long-term management of individuals with multiple, complex, chronic illnesses, including dementia, and the care of these individuals at the end of life.

Provision of high-quality care in NHs is challenged by limited resources, overwhelmed frontline staff, and beleaguered leadership. Untreated or undertreated pain in NHs is well documented\(^1,6-10\) and roughly 4% of residents experience daily pain that is excruciating.\(^11\) Pressure ulcers (11% of residents),\(^1\) physical restraints (39% of residents),\(^1\) and feeding tubes (53.9 per 1000 persons in a 12-month period)\(^12,13\) are common. Inattention to advance care planning,\(^14-18\) inadequate use of hospice,\(^19\) and recurrent hospitalizations or “churn”\(^20,21\) are widespread, with an estimated 39% of NH residents hospitalized in the last 30 days of life.\(^20\) Hospitalization routinely results in medication errors,\(^22\) functional decline,\(^23\) and poor communication of new care plans.\(^24\) By 2030, it is estimated that more than 3 million individuals will reside in NHs and nearly 50% of adults will die there,\(^25\) yet NHs rank lowest in terms of family perceptions of quality among the last places of care,\(^26\) with families reporting not enough help with pain (32%), dyspnea (24%), and emotional support (50%).\(^26\)

In this article, we describe strategies for improving access to palliative care in NHs. We draw on interviews conducted in the development of the Center to Advance Palliative Care (CAPC) 2008 report, “Improving Palliative Care in Nursing Homes,”\(^25\) as well as additional interviews conducted in 2009. The 2008 CAPC report\(^25\) was an environmental scan of palliative care services in NHs using literature review of research.
published between 2004 and 2007, 3 site visits, and 31 in-depth telephone interviews with NH medical directors and executives, palliative care providers in NH settings, and NH researchers. Individuals and sites were selected to provide a representative sample of NHs, including geographic diversity, rural and urban centers, and large and small NHs. Key topics discussed in these interviews included the needs of NH residents, the perceived challenges to delivering palliative care in NHs, influences on NH practice, and current innovative tools or programs to deliver palliative care in this setting. Based on these interviews, 3 existing, fully implemented models for providing palliative care to NH residents were identified, and here we discuss their strengths and challenges. We also conducted additional interviews with policy experts and executives from 2 of the sites whose models are featured. We conclude with specific policy proposals to expedite the integration of palliative care into the NH setting.

PALLIATIVE CARE OFFERS A SOLUTION

Palliative care is comprehensive interdisciplinary care that aims to relieve suffering and improve quality of life for individuals with advanced illness and their families. The goals of palliative care directly address what has been found to be most important to individuals with advanced illness: pain and symptom management, communication, preparation for death, decisions about treatment preferences, and caregiver support. Palliative care spans the continuum of need for patients who enter, have long stays, and ultimately die in the NH (Figure 1).

Contrary to what is often believed, palliative care is not identical to hospice care, as it differs in terms of both timing and reimbursement. Palliative care is available to patients who continue to benefit from life-prolonging treatments and is not dependent on prognosis (Figure 1). Reimbursement for hospice care under the Medicare Hospice Benefit requires that an individual be certified by 2 physicians as “terminal” (defined as a prognosis of 6 months or less) and agree to give up Medicare coverage for life-prolonging therapies. Palliative care’s independence from prognosis is especially important for NH residents, as most die of chronic, debilitating diseases such as heart disease, stroke, or dementia for which prognostication is particularly difficult. Non-hospice palliative care physicians and advance practice nurses bill fee-for-service under Medicare Part B. Ideally, NH residents could receive palliative care services when needed based on objective measures of functional decline and need, independent of prognosis and in conjunction with all other beneficial therapies. As one interviewee stated,

“In nursing facilities, many residents are not hospice eligible but suffer from chronic pain and other conditions that are not being adequately treated.”

Gretchen M. Broun, MSW, President and CEO, Hospice of the Bluegrass (June 2009)

Recent estimates suggest that up to 80% of NH residents could benefit from palliative care. However, nonhospice palliative care in the NH setting is rare.

Barriers to NH Palliative Care

Significant regulatory and staffing barriers prevent widespread implementation of NH palliative care.

Regulatory Barriers to NH Palliative Care

A major regulatory barrier to delivering palliative care in the NH is the misperception that palliative care is incompatible with the restorative focus of NH reimbursement and regulation. Specifically, the Resident Assessment Instrument (RAI), which consists of the Minimum Data set (MDS) and a set of Resident Assessment protocols, uses expected signs of terminal illness such as functional decline, weight loss, and dehydration as indicators of inadequate care by the NH. The RAI does not include protocols for palliative care outcomes such as symptom control. As one interviewee described:

“Instead of weight loss being recognized as perhaps the start of an expected decline and triggering a palliative care approach and level of care (ie, aggressive symptom control and support), it triggers a cascade of appetite stimulants, dietary supplements, and invasive treatments such as feeding tubes and IV fluids, aimed at reversing the weight loss.”

Howard Tuch, MD, Director of Health Policy, Suncoast Hospice (Florida) (May 2009)

NHs’ fear of being charged with poor quality of care through the MDS assessments reinforces the exclusive emphasis on restorative care as a measure of NH care quality and inhibits delivery of palliative care (Table 1).

Second, the economic incentives in long-term care promote hospitalization because residents who return to the NH from the hospital are covered by the more generous “Skilled” Medicare Benefit, which is applicable for the first 100 days after a hospital discharge. This payment structure creates a strong financial incentive for NHs to rehospitalize their residents to maximize the number of residents with this higher level of coverage. Further, the prospective reimbursement categories, the Resource Utilization Groups (RUGs), do not include palliative care. RUGs for intensive rehabilitation or skilled care (eg, intravenous medications and tube feeding) are far more generously reimbursed than personal care, symptom management, and emotional and spiritual support, creating a direct financial incentive for artificial nutrition and hydration and intravenous therapies even among the very debilitated and dying. As one of our interviewees explained,

“Higher reimbursement for skilled RUGs presents a strong incentive to deliver rehabilitative care to patients who may be more appropriately managed with palliative care approaches.”

Howard Tuch, MD, Health Policy Director, Suncoast Hospice (Florida) (May 2009)
have safely remained in the NH. These hospitalizations are inappropriate and residents could receive standard care. NHs tend to have lower proportions of residents who have Skilled Medicare Benefit days remaining. Medicare policies also serve as a barrier to the receipt of hospice care. An NH resident under the Skilled Medicare Benefit cannot simultaneously receive hospice care under the Medicare Hospice Benefit. It is estimated that more than 40% of these hospitalizations are inappropriate and residents could have safely remained in the NH.

Medicare policies also serve as a barrier to the receipt of hospice care. An NH resident under the Skilled Medicare Benefit cannot simultaneously receive hospice care under the Medicare Hospice Benefit. The forced choice between these Medicare benefits is not financially neutral. The Skilled Medicare Benefit pays for a NH resident’s room and board, whereas the Medicare Hospice Benefit does not. Not surprisingly, residents who are eligible for hospice typically choose to delay enrollment until after the Skilled Medicare Benefit period ends, simply for financial reasons. (For NH residents dually eligible for Medicare and Medicaid, Medicaid generally covers the room and board costs and thus the choice between the Medicare Hospice Benefit and the Skilled Medicare Benefit is approximately financially neutral to the resident.) More worrisome, NHs may not even offer hospice to residents who have Skilled Medicare Benefit days remaining.

Staffing Barriers to NH Palliative Care

Perhaps the most immediate barrier to improving access to palliative care in NHs is inadequate training and numbers of staff. NHs face a significant labor shortage and high turnover because of the difficulty of the work, inadequate pay, low respect, and demanding paperwork and regulatory requirements. Up to 90% of NHs are understaffed, leading to substandard care. NHs tend to have lower proportions of registered nurses (RNs) than other health care settings and the RNs working in NHs often have administrative and supervisory duties rather than direct patient care.

Successful Models of NH Palliative Care

Despite these barriers, there are exemplary programs across the country succeeding in delivering NH palliative care. Using data from our interviews and site visits, we identified 3 different strategies for integrating palliative care into NHs. Although every community is different and the strategies presented here may not be applicable to every NH’s needs, these 3 different approaches provide examples of success in providing NH palliative care. In the following sections, we describe 3 such models and discuss factors considered relevant to their successful implementation, as well as challenges that have accompanied these efforts.

Model 1: Palliative Care Consult Service

The palliative care consult service model uses outside consultants on request of the NH medical director, the patient’s attending physician, or the NH director of nursing. An advantage of the consult model is that palliative care is available to all residents, not just those who are clearly dying and therefore hospice eligible. Further, palliative care expertise is available without additional costs to the NH.

The Palliative Care Center of the Bluegrass (PCCB) in Lexington, Kentucky, is an example of the palliative care consult model. Consultation requests focus on pain and symptom management, advance care planning, family communication, and transition to hospice. In 2008, PCCB consultants visited 325 residents in 11 NHs and each resident received 5 to 6 visits, on average. Forty percent of these residents later transitioned to hospice care with a mean length of hospice stay of 66 days. According to a PCCB executive, “We have no doubt that for most of these patients palliative care consults and subsequent hospice care avoided hospitalization, which is better for the residents and, in terms of costs, better for Medicare.”

Gretchen M. Brown, MSW, President and CEO, Hospice of the Bluegrass (June 2009)

Although the PCCB has successfully implemented the consult service model, replication of this model of NH palliative care requires a number of key success factors and the ability to overcome substantial challenges. First, the model is contingent upon access to palliative care providers in the NH’s service area. Second, from the perspective of the palliative care providers, financial viability depends on the economies of scale in travel and staffing available at larger NHs with greater numbers of residents receiving services.

Table 1. National Nursing Home Quality Measures

<table>
<thead>
<tr>
<th>Chronic Care Quality Measures: Percentage of residents with</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Increased Activities of Daily Living (ADL) dependency</td>
</tr>
<tr>
<td>2. Moderate-severe pain</td>
</tr>
<tr>
<td>3. Pressure sores</td>
</tr>
<tr>
<td>4. Physical restraints</td>
</tr>
<tr>
<td>5. Bowel-bladder incontinence and use of indwelling catheters</td>
</tr>
<tr>
<td>6. Most of time in bed or chair</td>
</tr>
<tr>
<td>7. Decreased ability to move</td>
</tr>
<tr>
<td>8. Urinary tract infection</td>
</tr>
<tr>
<td>9. Increased depression-anxiety</td>
</tr>
<tr>
<td>10. Weight loss</td>
</tr>
</tbody>
</table>

Postacute Care Quality Measures: Percentage of short stay residents with
1. Delirium
2. Moderate-severe pain
3. Pressure sores

Third, palliative care consultants require training specific to the needs of NH residents.32 Fourth, the consultative relationship may inhibit continuity of palliative care, risking lack of necessary expertise during unpredictable illness and a default to hospitalization.25 Finally, for nonhospice palliative care consultants employed by hospice agencies, it is difficult for NH staff to differentiate between palliative and hospice care, in terms of patient eligibility, needs, regulatory requirements, and payer considerations.

**Model 2: NH-Based Palliative Care**

An increasingly prevalent model is NH employment of its own palliative care team. Unlike the outside consultant, the in-house practitioner’s daily interaction with residents may facilitate timely detection of clinical changes.32 Daily contact also promotes understanding of resident/family values, personal goals, and care preferences.32

- **Morningside House**

  An example of NH-based palliative care delivery is Morningside House, a 386-bed nonsectarian NH in the Bronx that established its own palliative care team (MD, nurse practitioner, social worker, and chaplain). Factors considered key to the success of Morningside House’s NH-based palliative care model are shown in Table 4. Morningside’s CEO has a strong commitment to the program, stating “It’s all about leadership,” and ensures that it is attentive to the cultural and religious preferences of the residents. Standardization is strengthened through broad use of The Physician Orders for Life Sustaining Treatment (POLST)41–43 to ascertain specific care goals and translate them into medical orders to ensure that care received is concordant with goals. Palliative care staff receive tuition reimbursement for training, and frequent in-services on palliative care are provided for both staff and families. As described by the CEO, the outcomes of this program include improved staff retention, better resident/family satisfaction, more deaths occurring at “home,” and fewer hospitalizations.25,44,45

  “Pizza at midnight is okay. Recliner next to Mom’s bed is fine. We provide resident-centered care.”

  Morningside’s Vice President for Nutritional Services (January 2007)
Table 3. Key Success Factors for Palliative Care Consultation in the Nursing Home

- Strong committed and consistent leadership
- Palliative care consultants with prior nursing home experience
- Business case for both nursing home and palliative care program
- Clear roles and responsibilities for both nursing home and palliative care staff
- Commitment to bilateral staff training and relationship building
- 24/7 phone availability
- Support from private sector philanthropy


Table 4. Success Factors for Nursing Home–Based Palliative Care

- Strong committed consistent leadership
- Horizontal management
- Investment in career ladder
- Standardization through use of staff and family education, and Medical Orders for Life Sustaining Treatment
- Nursing home size and capacity to scale the innovation


Evercare Hospice and Palliative Care

Alternatively, the NH-based palliative care model may contract with a Medicare managed care organization for palliative care staff. For example, Evercare Hospice and Palliative Care is a Medicare managed care organization that operates as a full-risk capitation model employing nurse practitioners in 35 states to provide on-site medical care, case management, and palliative care to more than 100,000 NH enrollees (Table 5). For NHs using Evercare, the financial risk for a resident’s care, including hospitalizations, shifts from the NH to Evercare. Evercare’s version of palliative care requires neither a terminal prognosis nor a decision to stop life-prolonging treatment. Because of the strong financial incentive to avoid hospitalization, in one study, Evercare reduced hospitalizations by 45%, emergency department visits by 50%, and average length of stay in the hospital by 1 day.46

A challenge to scaling the NH-based palliative care model is the lack of availability of palliative care–trained nurse practitioners and other professionals. Further, financial viability of such models is tenuous because the average 120-bed NH does not have the volume of residents required to support the cost of salary support and benefits for the palliative care staff.

Model 3: NH–Hospice Partnerships

Well-integrated hospice care in a NH has been shown to enhance access to palliative care for all NH residents through knowledge diffusion, availability of palliative care technologies on-site, and heightened awareness of pain and symptom management, psychosocial, and spiritual needs.47 These “spillover effects” in culture and caregiving philosophy are evidenced by substantially lower hospitalization rates20,48 and higher rates of advance care planning and pain treatment48 for NHs offering hospice compared with those that do not, varying by length of hospice stay and hospice diagnosis. NH resident enrollment in hospice in the last month of life is estimated to reduce overall government spending by an average of 6%.49 One researcher we interviewed found that

“…homes with strong hospice collaboration have few resident unmet needs and have greater satisfaction, less invasive treatments, fewer hospitalizations, and provide better care practices.”

Susan C. Miller, PhD, Center for Gerontology and Health Care Research, Brown University53 (November 2006)

As of 2004, 78% US NHs reported a contract with a hospice,50 ranging from 96% in Florida to only 42% in Wyoming. However, the level of penetration, quality, and timeliness of access to hospice care among NHs with hospice contracts is unknown. The proportion of NH decedents using hospice at some point varies from 9% (Vermont) to 42% (Oklahoma),50 suggesting that the existence of a hospice contract may not always translate into access to hospice care.51

POLICY ACTIONS TO FACILITATE AND EXPEDITE IMPLEMENTATION OF NH PALLIATIVE CARE

Implementation of palliative care in NHs will require changes to the current regulatory and reimbursement environment, and investment in the workforce necessary to address the shortage of qualified palliative care practitioners.

Eliminate Economic and Regulatory Disincentives for Palliative Care

The perverse economic and regulatory disincentives for NH palliative care must be addressed to ensure that care decisions are based on resident needs. Specifically, a new RUG should be created for residents assessed on the MDS to have functional decline, weight loss, decreased appetite, breathlessness, frequent hospitalization or acute infections. These indicators are reliable predictors of an increased likelihood of death52 and could be used to identify residents appropriate for a palliative care focus, either in place of or in addition to, a restorative care focus (Table 1). In addition, states should consider ways of reimbursing for palliative care through the Medicaid program. As one interviewee stated:

“Last year during brainstorming sessions orchestrated by the New York State Department of Health regarding alternative forms of reimbursement, one idea that was raised within the context of payments for quality was to provide nursing homes that demonstrate minimum standards and competency...
in palliative care with additional reimbursement for residents who require palliative care services."
Audrey Weiner, DSW, MPH, President and CEO of Jewish Home Lifecare, New York, NY (June 2009)

Second, the financial incentive to hospitalize NH residents should be removed. One option is to eliminate the 3-day hospital stay requirement for the Medicare Skilled Benefit. Many Medicare Advantage plans have eliminated this requirement, suggesting that the approach may have favorable consequences for both residents and Medicare spending. 25

Third, the prohibition of hospice care while on the Medicare Skilled Benefit immediately following hospitalization should be removed so that residents eligible for hospice care or nonhospice palliative care could access it when needed. As one interviewee explained,

“Some amount of rehabilitation is often required to improve the quality of life of a resident transitioning from the hospital to the NH, even when hospice is involved.”
Judi Lund Person, MPH, Vice President of Regulatory and State Leadership for the National Hospice and Palliative Care Organization (May 2009)

Similar to hospice care among specific subgroups of Medicare beneficiaries, 49 nonhospice palliative care has the potential to provide overall cost savings through clarification of care goals and reduced hospitalization. For example, hospital palliative care programs result in cost savings because of better care coordination, clarified treatment goals, and the avoidance of expensive, nonbeneficial treatments covered by Medicare Part A. 53–55

Establish a Licensure Program for Palliative Care Units in NHs

In conjunction with removing regulatory and financial disincentives for palliative care, a licensure program for NHs to train and “specialize” some of their own staff in palliative care could reduce the shortage of palliative care NH staff. As one interviewee stated,

“NHs can be incentivized to have palliative care expertise improved within their own staff. This allows NHs to stay in control, while improving the quality delivered to a specific NH population.”
Laura C. Hanson, MD, Co-Director, University of North Carolina Palliative Care Program (May 2009)

The licensure program could help ensure the quality and content of palliative care training and delivery. As one interviewee explained,

“We are starting to see an increase in the number of home-grown palliative care programs in NHs. These programs try to mimic palliative care principles but often without the palliative care expertise to back it up. Essentially these programs are plagiarized hospice programs. They are offering staff training in palliative care but the training is not coming from anyone certified in palliative care or hospice.”
Todd Cote, MD, Chief Medical Officer, Palliative Care Center of the Bluegrass (June 2009)

Require NHs to Provide Access to Hospice

Access to hospice care should be a requirement for NH reimbursement from Medicare and Medicaid. In addition to demonstration of one or more hospice contracts, NHs could be required to report the percentage of resident deaths in the NH who accessed hospice in the prior year. These conditions would give a reasonable assessment of both the existence and penetration of hospice care within the NH.

The most recent Conditions of Participation for hospices defines the responsibilities, documentation, communication, and training required of hospices serving skilled nursing facilities. A parallel regulation for NHs that have residents receiving hospice is currently under review. These regulations clarify the responsibilities of each provider and the right of patients to access hospice while residing in a long-term care facility.

Invest in a Palliative Care Workforce

Improved access to palliative care in NHs cannot be achieved without efforts to address the shortage of qualified palliative care practitioners. Such investments include loan forgiveness programs for nurses, social workers, and physicians who agree to work in NH palliative care for a specified period of time, graduate and midcareer training programs, and recruitment strategies. A multipronged approach is needed to attract, train, and retain the workforce necessary to serve the growing NH population in need of palliative care.
CONCLUSION

There is broad consensus that a solution to some of the pressing problems of quality and cost in NHs is greater penetration of palliative care into the long-term care setting. We describe 3 operating models for delivering NH palliative care: outside nonhospice palliative care consultants, development of NH staff expertise in palliative care, and greater penetration of hospice services through NH–hospice partnerships. However, as this is a descriptive report based on a convenience sample, there may be additional effective models that have not been included here. The generalizability and applicability of these models depends on the NH setting, capacity, leadership, and community environment. Broad implementation of these models is dependent upon addressing the formidable barriers to NH palliative care including regulation, payment, and staffing. Our interviews with leaders in the field identified policy initiatives that could facilitate NH palliative care.

There is no patient population more vulnerable or more in need of care focused on achieving the best possible quality of life in the context of advanced and progressive illness than persons living in NHs. The near absence of such care matched to the needs of the most vulnerable is a soluble problem, as demonstrated by the examples described here. Policy change and investment are needed to make access to quality palliative care a reality for all requiring, and all who will require, long-term care.

REFERENCES