Special Article

High-Quality Nursing Home and Palliative Care—One and the Same

Mary Ersek PhD, RN, Kathleen T. Unroe MD, MHA, MS, Joan G. Carpenter PhD, CRNP, John G. Cagle PhD, MSW, Caroline E. Stephens PhD, RN, GNP-BC, David G. Stevenson PhD

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Abstract

Many individuals receiving post-acute and long-term care services in nursing homes have unmet palliative and end-of-life care needs. Hospice has been the predominant approach to meeting these needs, although hospice services generally are available only to long-term care residents with a limited prognosis who choose to forego disease-modifying or curative therapies. Two additional approaches to meeting these needs are the provision of palliative care consultation through community- or hospital-based programs and facility-based palliative care services. However, access to this specialized care is limited, services are not clearly defined, and the empirical evidence of these approaches’ effectiveness is inadequate. In this article, we review the existing evidence and challenges with each of these 3 approaches. We then describe a model for effective delivery of palliative and end-of-life care in nursing homes, one in which palliative and end-of-life care are seen as integral to high-quality nursing home care. To achieve this vision, we make 4 recommendations: (1) promote internal palliative and end-of-life care capacity through comprehensive training and support; (2) ensure that state and federal payment policies and regulations do not create barriers to delivering high-quality, person-centered palliative and end-of-life care; (3) align nursing home quality measures to include palliative and end-of-life care-sensitive indicators; and (4) support access to and integration of external palliative care services. These recommendations will require changes in the organization, delivery, and reimbursement of care. All nursing homes should provide high-quality palliative and end-of-life care, and this article describes some key strategies to make this goal a reality.

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The Centers for Medicare & Medicaid Services (CMS) defines palliative care as follows:

Patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice.12

Palliative care, including hospice, is characterized by open discussion about prognosis and illness trajectories; interdisciplinary care; facilitation of life closure; and grief and bereavement support. This approach to care is appropriate for persons with serious, potentially life-limiting illnesses at any stage, from diagnosis to death. Hospice care, which is largely funded by the Medicare Hospice Benefit, is designed for people in the final 6 months of life.

Currently, hospice is the most common mechanism for delivering palliative care in NHs. Among the 1.1 million Medicare beneficiaries who died in 2018 while receiving hospice services, 17% were residing in an NH at the time of death.13 From 2005 to 2015, an average of 41% of NH residents received hospice services each year.14 Early observational studies comparing NH-based hospice care vs traditional NH care at end-of-life found several benefits to decedents receiving hospice care, including fewer hospitalizations and potentially burdensome treatments (eg, feeding tubes, intravenous fluids), better pain assessment and management, and more positive bereaved family evaluations of care.15–17 Despite these benefits, however, there are challenges to this approach. First, hospice serves only residents who have a prognosis of 6 months or less and choose to forego curative therapies. Importantly, these restrictions limit access for most patients receiving post-acute NH care under the Medicare SNF benefit who cannot concurrently access the Medicare Hospice Benefit. Similarly, focusing on hospice as the major delivery model does not address the palliative care needs of NH residents who are not at the end of life or who do not elect the benefit. Second, there are growing concerns that some hospice agencies target NH residents to maximize length of stay while providing fewer interdisciplinary team visits compared with patients living in private homes.20 Finally, and most importantly, is the recognition that using hospice to deliver palliative care places the expertise and authority outside the NH itself, despite the fact that the NH is ultimately responsible and held accountable for residents’ quality of care.21

A second approach to delivering palliative care in NHs is through external specialty palliative care consultation, often provided by clinicians working for a community hospital- or hospice-based palliative care program.22 Consultations typically focus on conducting goals of care conversations and advance care planning, complex symptom assessment and management, psychosocial care, care coordination, and referrals to home-based palliative and hospice care.23–26 These services are reimbursable under Medicare Part B, therefore allowing clinicians to bill for face-to-face visits and advance care planning discussions.27 Key advantages of this approach are improving palliative care access for patients who are not hospice-eligible and allowing patients to access services while receiving care under the SNF benefit. Studies have shown that specialty palliative care in NHs enhances symptom management,28 increases referrals to hospice,29 decreases emergency department visits and hospitalizations at the end of life,30,31 and may reduce health care costs.32 Despite these potential benefits, external palliative care consultation is not widely available or used.32–34 A recent survey of 890 community palliative care programs found that only 28% of community palliative care programs serve long-term care facilities.22 Lima and colleagues examined the consultation rates among 54 NHs in 2 states that had established relationships with specialty palliative care providers and found only 4% of residents had received a palliative care consult prior to death.33 These low rates reflect the challenges of this approach, which include limited financing for, supply of, and access to palliative care specialists, inadequate knowledge about palliative care by NHs as well as poor collaboration and communication, resulting in a lack of NH staff and leadership trust in palliative care providers.35–37 The study also underscores the difficulties in ascertaining palliative care consultation rates from Medicare claims data, which can lead to an underestimation of the number of consults.33

A third approach for delivering palliative care is to build internal capacity within the NH. Recent surveys of US NHs suggest that 38% to 40% of NHs have a palliative care program; however, these surveys included small numbers of NHs and low response rates and thus may overestimate their prevalence.22,32 Furthermore, little is known about the clinicians’ expertise and scope of these programs. For example, they may include policies to identify short-stay patients and long-term care residents needing palliative care or advance care planning, staff training, and/or specialized palliative care units.34,38 Importantly, there currently are no widely agreed upon standards and quality measures for NH-based palliative care services despite some small-scale efforts to identify appropriate guidelines.23 Finally, evidence for the effectiveness of these programs is largely anecdotal, although there is some evidence that facility-based palliative care can increase appropriate deprescribing at the end of life,39 decrease rehospitalizations and emergency department visits in SNF patients,28,40 and reduce agitation and pain.41 Lack of training and limited financial and human resources are major barriers to establishing and maintaining internal capacity for palliative care.38 Current Medicare and Medicaid reimbursement rates, which provide incentives for rehabilitation, further erode the ability of NHs to develop internal capacity to deliver high-quality palliative care.

Given the current state of palliative and end-of-life care in NHs, we propose a set of recommendations to improve NH care by integrating palliative care into regular, ongoing practice and, when needed, accessing outside services to provide palliative and hospice care to seriously ill residents and their families. This will require changes in the organization, delivery, and reimbursement of care. We must expect all NHs to provide high-quality palliative and end-of-life care.

A Framework for Integrated Palliative and Nursing Home Care

In the vision of NH care that we propose, palliative care is woven into the fabric of NH practice, reflecting our perspective that palliative care is an inseparable component of high-quality NH care. Figure 1 depicts a framework for achieving such an integrated model. The base of the pyramid depicts the component that we believe is most important to improve palliative and end-of-life care in nursing homes, that is, enhancing the expertise and skills of nursing home staff and providers. Building on a strengthened internal capacity, we propose 3 additional core components to this model: eliminating regulatory, payment, and policy barriers to providing high-quality care; ensuring that quality measures reflect palliative care indicators; and supporting access to external palliative and end-of-life resources as appropriate. Although all components are important, each should rest on a foundation of strong internal palliative care capacity. Three interwoven themes supporting these components are resources, accountability, and expertise.

Our framework reflects several important principles. First, palliative and end-of-life care is aligned with the basic tenets of high-quality person-centered care, such as those embodied in the NH culture change movement.42 Second, palliative care should be available for all people with serious illness, including those who are newly diagnosed and those at the end of life. Short-stay post-acute care patients as well as long-term residents should receive excellent palliative and end-of-life care, with service delivery guided by their diverse, individual needs. Third, hospice and external specialty
Palliative care should augment rather than replace NH expertise and accountability. The extent to which these services are used will be based on the resources available in each facility and community. Nonetheless, we believe the responsibility for palliative care must rest within the NH. Fourth, development of palliative care programs must involve all stakeholders, including residents, families, community partners, and policy makers. Finally, policies, reimbursement and regulations should be developed and evaluated for their ability to ensure equitable access to high-quality palliative care in NHs, particularly for those with lower socioeconomic status and racial and ethnic minorities.

**Recommendations to Enhance Palliative and End-of-Life Care in Nursing Homes: Implications for Practice, Policy and Research**

**Recommendation 1: Promote Internal Capacity Through Comprehensive Training and Support**

Research has demonstrated serious gaps in palliative care knowledge and skills among NH staff and providers. Deficits in knowledge and skills are associated with resident outcomes such as suboptimal symptom control. Training is required to enable frontline staff to recognize palliative care needs of residents and to provide symptom management, including use of pain medications or non-pharmacologic interventions. Palliative care education is associated with improved symptom assessment and management, higher rates of end-of-life discussions, and receipt of care that is consistent with residents’ preferences, and better caregiver satisfaction. Further, enhancing the ability of NHs to deliver palliative care can mitigate some of the challenges associated with the shortage of palliative care specialists and limited access to these services.

Palliative care training should be integrated into CMS and state-required staff competencies. In addition, palliative care knowledge and skills should be built into licensure and certification for NH staff, clinicians, and leadership such as the state certification process for nursing assistants, Certified Director of Nursing Exam (CDONA), Gerontological Nursing Certification (RN-BC), Certified Medical Director (CMD), and the National Association of Long-Term Care Administrator Boards (NAB) national licensing examination. Trainings and certifications in palliative care practice are available through organizations such as the End-of-Life Nursing Education Consortium, Hospice and Palliative Nurses Association, National Association for Social Workers, and the Center to Advance Palliative Care, for multiple professionals including social workers, nurses, and physicians.

**Recommendation 2: Ensure That State and Federal NH Payment Policies and Regulations Do Not Create Barriers to Delivering High-Quality, Person-Centered Palliative and End-of-Life Care**

There are several regulatory and policy barriers to overcome in delivering high-quality palliative care in NHs. One major barrier is the lack of palliative care focus for patients with life-limiting illness who are receiving post-acute SNF care. NHs are incentivized to deliver rehabilitative post-acute care because reimbursement rates are...
substantially higher compared to custodial care. Patients and families are reluctant to eschew SNF care even when they prefer a palliative approach because doing so means that they must assume the cost for room and board (an estimated $255–$290 per day), unless it would be covered by Medicaid. To the extent that payment and coverage policies—and not patient preferences—drive treatment decisions, patients’ goals of care may be misaligned with the orientation of services under the SNF benefit. To address this misalignment, we propose incorporating greater flexibility into the skilled needs of the SNF benefit to encompass palliative care services (including end-of-life care), similar to a proposal outlined by James Fausto. Under such an approach, a need for skilled palliative care services would be sufficient to establish eligibility for patients with a qualifying hospital stay. In the context of receiving SNF services, clinicians could engage individuals in goals of care discussions and, where appropriate and consistent with patient preferences, transition individuals from the SNF benefit to receive hospice or supportive services. A single SNF payment for palliative care services could be established, a shift that would likely require some modifications to the current Patient Driven Payment Model (PDPM).

Another challenge is the misalignment of the state and federal survey standards and processes with EOL care. For example, state surveyors cite NHs for residents’ weight loss, which could reflect inattention to nutritional needs in some residents. In many instances, however, weight loss is an expected result of the dying process and life-sustaining treatments such as medically administered nutrition are ineffective, inappropriate, or not in alignment with care goals. To overcome this challenge, policy makers and stakeholders (eg, residents, family members, ombudsman, administrators) should develop recommendations for interpreting regulations in a manner consistent with high-quality palliative and EOL care.

**Recommendation 3: Align NH Quality Measures to Include Palliative Care—Sensitive Indicators**

Quality measurement in health care is critical to ensuring accountability, helping consumers make decisions about where to get health care and from whom, guiding reimbursement, and driving quality improvement activities. Several general palliative care quality measures are endorsed by the National Quality Forum and have been adopted by CMS. However, to date, there are no widely accepted valid and reliable measures of the quality of palliative care delivered in NHs, despite calls to develop such measures and include them in national quality reports. The CMS-mandated Minimum Data Set 3.0 includes only a few items that are germane to palliative care, most notably, assessment and management of depression and pain, feeding tube use (a potentially burdensome treatment), hospice care, and resident overall goal for end-of-life care. However, there are no benchmarks that define high-quality palliative care.

There have been some efforts to develop NH-specific palliative care quality measures. Candidate indicators include process measures such as symptom assessment and management, addressing emotional and spiritual needs, advance care planning, care coordination, and communication among residents, families, and providers/staff. Other proposed process measures include evidence of policies and procedures for symptom management and quality improvement projects focused on palliative care issues. Outcome measures include the percentage of eligible residents enrolled in hospice and proportion of residents who are hospitalized at the end of life. None of these quality measures have been extensively examined for feasibility, validity, reliability, or usability in monitoring and improving quality. Given the dearth of palliative care—sensitive quality measures, we recommend that CMS commission a group of experts to guide the development and testing of palliative care measures that are tailored to the NH environment.

One particularly important area for quality measurement is patient and family experiences of care. Currently, only a handful of states use patient/family experience surveys as part of their NH quality metrics. The Consumer Assessment of Healthcare Providers and Systems program includes 3 NH-specific experience of care measures but none is required by CMS. The Medicare Payment Advisory Commission (MedPAC) recently recommended that CMS add a patient experience measure to a suite of quality measures that would be publicly reported and used for a revised value-based purchasing program. We agree with adding patient/family experience surveys into the national Nursing Home Compare quality measures; however, any measure adopted by CMS must include items that are relevant to palliative and end-of-life care (emotional and spiritual support for the patient and family, bereavement outreach, providing care that is consistent with the patient’s goals, and symptom management).

Once these palliative care quality measures, including a patient/family experience of end-of-life care survey, are developed and shown to be psychometrically sound and able to distinguish between high- and low-performing NHs, they should be incorporated into publicly reported CMS metrics for NHs and included as a component of the 5-star rating system. In addition to these steps, we also recommend that CMS support NHs in quality improvement efforts to enhance access to and quality of palliative care. Support can take many forms including directing quality improvement organizations (QIOs) to prioritize palliative care processes and outcomes in their QI campaigns, providing funding to support palliative care quality improvement (eg, by designating Civil Monetary Penalty funds for these efforts), or expanding facility-directed palliative care QI projects using programs that are similar to the Minnesota Performance-Based Incentive Payment Program.

**Recommendation 4: Support Access to and Integration of External Palliative Care Services**

We propose 2 policy changes to overcome the current limited access to external palliative care consultation. The first is to strengthen collaborations between external palliative care consulting groups and NHs. One way to scale up these collaborations is to enlist palliative care and hospice agencies that have established, effective relationships with NHs to serve as models of excellence for other palliative care agencies and NHs. These agencies could provide individualized clinical and administrative mentoring and guidance to increase access to and integration of external palliative care services for persons who are cared for in NHs. NH staff also need guidance on when to request a palliative care consultation, including tools for identifying palliative needs. We endorse Oregon’s approach, which requires NHs and other health care facilities to establish procedures to identify patients who could benefit from palliative care, provide patient and family education, and refer to palliative care services, as needed.

The second strategy to expand external palliative care services in NHs involves the use of telehealth. The COVID-19 pandemic accelerated the use and acceptance of telehealth in NHs, including the use of telehealth for advance care planning, counseling, and access to specialists. Especially where supported by broadened capacity and attention to palliative and end-of-life care by NHs, offering palliative care visits from a distance may improve health equity—specifically specialist access for vulnerable people living in NHs who otherwise would be denied services owing to their geographic location. CMS recently made permanent coverage of some telehealth services, but palliative care was not included in the list. We call on CMS to include palliative care in their permanent telehealth coverage.
Summary

Substantial changes are needed to address the palliative and end-of-life care needs of people living with life-limiting illnesses in NHs and their families. We propose a concerted, coordinated framework for achieving an integrated model of palliative care in NHs. Although our recommendations are based on current empirical evidence, there are substantial gaps in understanding the most effective models and strategies for improving palliative and end-of-life care in NHs. Thus, we propose that funding agencies (eg, National Institutes of Health, Patient-Centered Outcomes Research Institute, Center for Medicare & Medicaid Services Innovation Center) develop tailored programs to address the gaps in knowledge.

Our approach underscores the centrality of enhanced NH-based expertise, resources, and accountability. Further, palliative and end-of-life care should be part of high-quality NH care—with a focus on person-centered care and management of complex geriatric syndromes. At the same time, we recognize that most NHs currently are unable to deliver comprehensive, expert palliative and end-of-life care due to one or more of the following reasons: (1) limited expertise, resources, and accountability; (2) palliative and end-of-life care are not a central focus of training and education; (3) palliative care workforce: preview to an impending crisis. J Gerontol A Biol Sci Med Sci 2017;72(suppl 1):S38–S48. Elsevier, 2017.

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