

Geriatric Palliative Care in Long-Term Care Settings with a Focus on Nursing Homes

Mary Ersek, PhD, RN, FAAN^{1,2} and Joan G. Carpenter, CRNP, NP-C, GNP-BC, ACHPN^{3,4}

Abstract

Almost 1.7 million older Americans live in nursing homes, representing a large proportion of the frailest, most vulnerable elders needing long-term care. In the future, increasing numbers of older adults are expected to spend time and to die in nursing homes. Thus, understanding and addressing the palliative care needs of this population are critical. The goals of this paper are to describe briefly the current state of knowledge about palliative care needs, processes, and outcomes for nursing home residents; identify gaps in this knowledge; and propose priorities for future research in this area.

Introduction

LONG-TERM CARE (LTC) is defined as the health and supportive services provided to people unable to practice self-care, usually over months or years. It includes personal care, social services, room and board, transportation, medical and rehabilitative care.¹ LTC is provided in many settings, including nursing homes (NHs), assisted living facilities, group homes, and personal residences. For older adults, especially the cognitively impaired and frail, NHs are an increasingly common setting for LTC. Currently, about 1.8 million Americans live in NHs.² Over half are totally dependent or need extensive assistance with bathing, dressing, toileting, and transferring.³ Despite efforts to minimize institutionalized care, the NH population is expected to grow to more than three million people by 2050.⁴ As more people live in NHs, so too will they die there. In 2007, 28% of adults ≥ 65 years died in a NH,⁵ and nearly 70% of persons with advanced dementia die in this setting.⁶

Compared to other settings for LTC, per person and national expenditures for NH care are notably high. NHs cost between \$114–\$136 billion annually,² and these costs are highest in the last months of life, often for care that is unhelpful and unwanted.^{3,7} Moreover, there is substantial evidence that palliative and end-of-life (EOL) care in NHs often is inadequate. For example, underassessed and undertreated pain and symptoms are major problems,^{8–11} bereaved family satisfaction with care is lower for NH decedents compared with those who receive hospice care,¹² and NH residents are subject to many unnecessary and burdensome transitions in the final months of life.^{11,13}

The purpose of this paper is to review the existing research literature on palliative care delivered in long-term care settings, identify gaps, and propose priorities for future research. Of all LTC settings for older adults, NHs have been the subject of most of the research about palliative and EOL care. While there is interest in applying palliative care principles in LTC community settings such as Programs for All-inclusive Care of the Elderly (PACE)^{14–16} and assisted living facilities (ALFs),^{17–22} to date there is relatively little published palliative care research in these settings. Thus, this paper focuses on palliative care research conducted in NHs.

Summary of the Evidence about Palliative Care in NHs

One could argue that most NH care *is* palliative in nature; this broad interpretation yields an immense body of research. To narrow the scope of this topic, this review targets the following areas: (1) symptom burden among NH residents; (2) EOL transitions among NH residents; (3) goals of care discussions and advance directives (ADs); (4) NH-specific palliative care measures; and (5) tests of palliative care interventions in NHs. We excluded studies that focused exclusively on care for persons with dementia.

Symptom Burden

Several studies have reported general symptom burden of NH residents at the EOL^{23–27} using several methodologies, including Minimum Data Set (MDS) documentation,²⁵ chart audit,²⁷ staff report,^{23,24} family report,^{23,24} resident interviews,²⁸

¹Center for Health Equity Research and Promotion, Philadelphia VA Medical Center, Philadelphia, Pennsylvania.

²University of Pennsylvania School of Nursing, Philadelphia, Pennsylvania.

³University of Utah College of Nursing, Hartford Center of Geriatric Nursing Excellence, Salt Lake City, Utah.

⁴Coastal Hospice and Palliative Care, Salisbury, Maryland.

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and physician opinion.²⁶ Many others have focused exclusively on pain.^{9,29–33} Taken together, these studies show that common EOL symptoms include pain (40%–86%),^{23,24,27,29–31,34} dyspnea (11%–75%),^{23,24,26,27} feeding problems (28%–70%),^{23,27} delirium (29%–47%),^{25,27} incontinence (59%),²⁴ and noisy breathing (39%–59%).^{24,27} Several studies provide evidence that these symptoms often are inadequately managed.^{23,24,27,33} Researchers have investigated the barriers to effective pain and symptom management and palliative care in NHs. These barriers include lack of knowledge and access to pain management therapies,^{35,36} and limited policies and procedures to guide palliative care practices.³⁷

Burdensome Treatments and Transitions at the End of Life

Palliative care is focused on providing treatments and care that are aligned with patients' and families' preferences, values, and goals.³⁸ When asked, the majority of NH residents and their families choose to limit aggressive, life-prolonging therapies.^{39,40} Despite these preferences, several large studies have documented that many NH residents are hospitalized in the final weeks of life^{13,41,42} and receive burdensome treatments with little benefit; these treatments include tube feeding^{43–45} and post-acute, rehabilitative care.^{11,46,47}

Some EOL hospitalizations are both appropriate and reflect residents' preferences. However, transitions between health care settings are fraught with problems, often causing residents and families unnecessary distress.^{48–51} Although transitional care goes beyond palliative care, ensuring that residents and their families discuss with clinicians their goals of care and complete ADs can minimize unnecessary, unwanted transitions and provide continuity of care when transitions do occur.⁵²

Goals of Care Discussions and Advance Directives

The proportion of NH residents with completed ADs increased dramatically over the past 15 years. Jones and colleagues⁵³ reported that 65% of NH residents had an AD in 2004 (the most recent year for which there are national data). As in community samples, having an AD in the NH was associated with older age, white race, and receipt of hospice care. The most common types of ADs were living wills and Do Not Resuscitate orders. The majority of ADs for older NH residents reflect preferences for less-aggressive EOL care.^{40,53}

Although documented preferences about resuscitation are common, decisions about other interventions, such as artificial nutrition and hydration, hospitalization, antibiotics, and comfort measures, are not.⁵⁴ The use of the Physician's Orders for Life-Sustaining Treatment (POLST) is one effective way of encouraging discussion about and documentation of residents' and families' decisions about specific therapeutic approaches.^{40,55} Moreover, the POLST paradigm increases concordance between residents'/families' preferences and care received.³⁹

Measures

Choosing valid and reliable tools to measure palliative care quality in NHs must address specific questions such as, What components of quality need to be measured, i.e., structure, processes of care, and/or outcomes of care?⁵⁶ Will resident

outcomes include self-report, and if so, how should one measure these outcomes in residents with marked cognitive impairment?^{57–59} Was the measure developed for or validated in NHs? Several published reviews have focused on dementia-specific^{60–63} and nursing home specific palliative care measures.⁶⁴ Other authors review general palliative care tools that may be valid for use in NHs.^{65,66} Because the course of dying for NH residents often is prolonged and unpredictable, general quality of life and quality of care measures may also be appropriate evaluation tools.^{57,67,68} Thompson and colleagues⁶⁹ tested a two-pronged measurement model comprised of quality of care (i.e., systems/facility-level factors that influence the dying experience) and quality of dying (i.e., resident and family outcomes). Table 1 provides examples of validated measures that reflect these two factors.

In addition to these measures, many studies rely on the MDS, a federally mandated assessment tool used in the vast majority of NHs in the United States and several other countries. The MDS version 3.0, which has been collected since October 2010, is a better measure for palliative care processes and outcomes than the earlier version, because it requires staff to solicit and document resident input when possible. Interreliability of MDS 3.0 is very good to excellent, and the updated MDS demonstrates improved validity compared to version 2.0.⁷⁰ In addition, it has new and expanded clinically relevant variables related to pain and other symptoms, decision making, and goals of care.⁷¹ Despite improvement to the MDS, there remain serious gaps in collecting and reporting palliative care specific processes and outcomes. To address this gap, the interRAI collaborative developed the interRAI palliative care assessment tool to augment relevant palliative care information that was already included in the MDS 2.0.⁷² To date, however, psychometric testing in NHs has been limited and the tool does not appear to be widely used.

Intervention Studies

Of all the different types of studies, randomized controlled trials (RCTs), comparative effectiveness studies, and implementation research represent the natural endpoint for all clinically based research, seeking to improve health care and patient outcomes. It is typically in this arena that there is a paucity of evidence, and NH-based palliative care research is no exception. For this review, these studies are categorized as follows: (1) interventions focused on enhancing pain and symptom management; (2) interventions aimed at improving resident/family decision making and completion of ADs; (3) interventions to reduce burdensome transitions; and (4) strategies to incorporate hospice and palliative care into NHs.

Although several studies reported the results from NH-based quality improvement interventions for pain,^{73–76} only two RCTs aimed at enhancing pain management were identified.^{77,78} Both studies test multimodal interventions embedded with a program of diffusion strategies to facilitate the adoption of evidence-based practices into daily care. While there were some modest changes in practice, there were no significant differences between intervention and control sites and residents' pain and outcomes in either trial. Moreover, there are no published RCTs of NH interventions to ameliorate symptoms other than pain that were identified by this review.

TABLE 1. SELECTED PALLIATIVE CARE MEASURES DESIGNED FOR OR VALIDATED IN LONG-TERM CARE SETTINGS

<i>Tool</i>	<i>Data source(s)</i>	<i>Description</i>
<i>Quality of care</i> Palliative care survey (PCS) ^{69,105}	NH staff, NH administration	51 items measuring the extent to which NH staff engage in palliative care practices and are knowledgeable about best practices in EOL care Two constructs: (1) palliative care practice (subconstructs: bereavement, planning/intervention, family communication, & provider coordination); (2) palliative care knowledge (subconstructs: psychological, physical, and EOL factors)
Facility level measures ⁶⁹	Resident and administrative records	Percentage of residents with documented ADs Percentage of residents with feeding tubes Percentage of residents with ER visits and/or hospitalizations Percentage of residents receiving hospice
<i>Quality of dying</i> Quality of dying in long-term care (QOD-LTC) ^{106,107}	Staff and/or family caregiver interview Administered postdeath	11 items 1–5 Likert scale, total score derived by averaging the scores of each item Higher scores indicate higher quality Three factors: (1) personhood: cleanliness, compassionate physical touch, dignity, holistic knowledge of resident; presence of nurse/aide with whom the resident was comfortable; (2) life closure: sense of humor, preparedness for death, peaceful appearance; (3) preparatory tasks: ADs, funeral arrangements
After-death bereaved family member interview ^{69,108,109}	Family member interview Administered postdeath	36 items, varying response levels Overall satisfaction with care item Domains: (1) provide desired level of physical comfort and emotional support; (2) promote shared decision making; (3) individualized, respectful care—treated with kindness, able to maintain control over daily decisions, facilitates closure; (4) meets family's needs; (5) coordinated care
Family perceptions of care ^{110,111}	Family members	25 items 1–7 Likert scale, higher scores indicate more positive ratings Four subscales: resident care, family support, communication, rooming

There has been great interest in enhancing goal setting and completion of comprehensive ADs (that is, those that go beyond preferences for cardiopulmonary resuscitation) in NHs. Two interesting studies to increase AD completion are noteworthy, even though they did not test interventions using RCTs. First is Lindner and colleagues⁷⁹ VA-based trial of an addition to the electronic medical record admission order that reminds clinicians to document the therapies to be delivered in the event of a cardiopulmonary arrest. Also included was an electronic alert for the primary clinician to complete an AD discussion note about goals of care and life-sustaining treatments. They reported that this simple intervention dramatically increased discussions about ADs (odds ratio: 42, 95% CI: 15–120). Several linked studies^{39,40,55,80} about the effect of Physician Orders for Life-Sustaining Treatment (POLST) are

also notable. Together, these POLST studies provide evidence that open conversations between residents, family members, and medical providers can increase comfort at the end of life, reduce hospitalizations, and increase the likelihood that residents' and families' preferences be solicited, documented, and honored.

Two RCTs used different approaches to identify and document residents' and families' preferences for EOL treatment.^{81,82} Morrison and colleagues⁸² tested an intervention that targeted social workers who received education and support in conducting advance care planning discussions with residents and families. Also included were organizational changes such as incorporating a review of goals of care at regularly scheduled meetings and communicating with providers about the congruence of residents' preferences with

the care the resident received. Compared to the usual care control group, residents in the intervention were significantly more likely to have their preferences for various EOL therapies documented in the medical record and to receive care that was concordant with their preferences. Molloy and colleagues⁸¹ conducted a large multisite trial involving six NHs and 1292 NH residents/proxies to test an AD program called Let Me Decide. The outcomes included satisfaction with health care and health care utilization. Intervention sites reported fewer hospitalizations per resident and lower health care costs compared to control sites. Resident/family satisfaction was not significantly different in the two groups.

As noted in the Molloy and colleagues⁸¹ study, advance care planning interventions are often aimed at reducing hospitalizations and health care costs. Lack of advance care planning often leads to hospitalization and aggressive life sustaining interventions that are the default mode of care. Another reason for EOL hospitalizations is the real or perceived inability of NH staff to manage acute conditions in seriously ill LTC residents. Ouslander and colleagues^{83,84} used a pre-post intervention design to examine the effectiveness of several treatment algorithms and other tools designed to reduce hospitalizations. These quality improvement initiatives suggested that these Interventions to Reduce Acute Care Transfers (INTERACT) tools could decrease hospitalization rates and health care costs. Packaged into a program, the INTERACT tools are now being examined in several ongoing NH demonstration projects funded by the Center for Medicare and Medicaid Innovations (CMMI) and aimed at reducing avoidable hospitalizations.

Although the INTERACT program is being widely embraced, less attention has been given to the positive results of a cluster RCT conducted by Loeb and colleagues.⁴¹ This study, involving 22 NHs and 680 residents, compared the effects of an NH-based clinical pathway for pneumonia treatment with usual care on hospitalizations, length of hospital stay, mortality, health-related QOL, functional status, and cost. Results showed that the pneumonia clinical pathway was associated with significantly fewer hospitalizations, shorter lengths of hospital stay, and lower costs compared with usual care. There were no significant differences between groups in mortality, health-related QOL, or functional status.

All the preceding studies describe more or less focused palliative care interventions. Palliative care writ large, however, should be viewed as a system or philosophy of care that could conceivably incorporate all the previously described interventions into one model. Carlson and colleagues⁸⁵ described three distinct models for providing comprehensive palliative care services in NHs: hospice partnerships, external palliative care teams, and facility-based teams and hospice units. Of these models, hospice care is the most extensively studied, although no RCT has demonstrated the superiority of hospice over usual care.⁸⁶ Several observational studies have demonstrated that hospice enhances EOL care in NHs.^{46,87–92} These results may be one of many reasons that the number of hospice beneficiaries residing in NHs increased by 40% from 2005–2011.⁹³

The other two models of palliative care—that is, the provision of palliative care using external (i.e., outside the NH) consulting practitioners or teams and facility-based palliative care teams and units—have been evaluated anecdotally, usually by the organization or agency that provides the

care.^{4,85} Thus there have been no rigorous evaluations of these models. Despite the lack of evidence supporting these models, Miller and colleagues⁹⁴ found that 27% of U.S. nursing homes reported having a special program or specially trained staff for hospice or palliative care.

Two intervention trials sought to increase hospice and palliative care use in NHs. Hanson and colleagues⁹⁵ tested a quality improvement intervention to increase palliative care in nine NHs (seven intervention and two control sites) using a pre-post study design. The intervention involves the recruitment and training of interdisciplinary palliative care leadership teams. These teams were provided six technical assistance meetings and educational sessions. Teams also received feedback on hospice enrollment, pain management, and advance care planning at baseline and at three and six month follow-up. Results showed a modest, significant increase in hospice enrollment and substantial, significant increase in pain assessments and physicians orders for nondrug pain treatments in the intervention facilities. Discussions with residents and families about EOL care preferences also significantly increased at the intervention sites. In contrast, outcomes at control sites did not change.

Casarett and colleagues⁹⁶ examined the effectiveness of a structured interview about resident preferences and physician notification on increasing hospice enrollment and enhancing families' evaluations of EOL care. The treatment group was compared to usual care. Trained research assistants interviewed all residents or surrogates to identify hospice appropriateness, defined as the resident/surrogate: (1) verbalized comfort-focused goals of care, (2) refused CPR/mechanical ventilation, and (3) identified at least one palliative care need. For residents assigned to the treatment group who were also hospice appropriate, investigators faxed a summary of the interview to the resident's physician, also informing the physician that the resident might be eligible for hospice care. Compared to the usual care group, intervention residents were significantly more likely to enroll in hospice and had fewer hospitalizations. In addition, families of intervention residents rated the residents' care more favorably than those in the control group.

Gaps in the Research Literature and Research Priorities for the Future

Most of the existing research about palliative care in NHs is descriptive. This body of evidence highlights several potential targets for intervention studies. In addition to identifying a need for clinical trials, there are concerns about measurement that need to be addressed.

The first measurement issue is that continued psychometric evaluation and refinement of existing tools is necessary. Although the existing psychometric data are promising, none of the instruments listed in Table 1 has undergone extensive testing and refinement. A second area for further research is to investigate statistically and clinically sound methods for measuring residents' symptoms, QOL, and evaluation of care—concepts that generally rely on self-report. While surrogate reports are widely accepted for nonverbal persons,^{58–60,97,98} self-report is generally considered the gold standard for subjective experiences such as pain and QOL.⁹⁹ Even though many NH residents, including those with moderate to severe dementia, can reliably report about experiences such as current pain, some residents are completely nonverbal. How then should

investigators measure these outcomes in studies that include both verbal and nonverbal residents, knowing that self-report and surrogate report are affected by different biases?^{59,77,98} A third direction for research is to examine the ongoing validity and reliability of the MDS 3.0 as a potential descriptive, process, and outcome measure for palliative care. The reason for this is threefold. First, substantial resources have been devoted to developing and testing the MDS. Therefore, the psychometric foundation for this measure likely exceeds that of existing tools. Second, it is nearly universally used both in the United States and several other countries. The number and diversity of NH facilities and residents captured by this measure allows for large-scale analyses. Third, the measure is already being collected by NH staff educated in systematic and standardized data collection, thereby minimizing time and costs of primary data collection.

There are many avenues for future research that tests the efficacy and effectiveness of novel interventions. Some interventions may be relatively circumscribed, such as Hanson and colleagues' test of a decision aid about feeding options in NH residents with advanced dementia¹⁰⁰ or Loeb and colleagues' clinical pathway for pneumonia.⁴¹ Many of the potential interventions, however, will have multiple, interconnected components that reflect the complexity of palliative care delivery in NHs. It will be important to identify which components of these multifaceted interventions are associated with the largest positive changes in processes and outcomes.

Although RCTs are the gold standard for assessing the efficacy of interventions, increasing attention is given to effectiveness, dissemination, and implementation research.^{101–103} These research areas move clinical science deeper into the netherworld of real-life practice, where the focus on internal validity meets the need to generalize and adapt interventions to meet local challenges and individual needs. Palliative care research has also been closer to the unpredictable and variable exigencies of actual clinical practice than the relatively firmly controlled world of bench science. Thus, palliative care investigative teams will need to embrace and refine dissemination and implementation methodologies to meet the mission and needs of different NHs.

Another area for intervention trials is to test and compare various models of palliative care delivery in LTC settings (e.g., hospice compared with internal palliative care teams). It is unlikely that one model will emerge as universally superior; thus, studies should also aim at identifying factors that are associated with successful implementation of a particular palliative care delivery model.

Finally, it is essential to examine the effects of health policy and financing strategies on palliative care delivery and outcomes. For example, the Affordable Care Act includes a requirement to initiate demonstration projects that allow patients to access the Medicare Hospice Benefit along with other Medicare services.¹⁰⁴ This strategy may lead to enhanced EOL care for NH patients receiving services under the skilled nursing facility (SNF) benefit. Other NH financing strategies (e.g., Pay for Performance, Accountable Care Organizations, and bundling of payments) should examine palliative care approaches and outcomes.

This paper focused on NHs as a setting for integrating palliative care into LTC. As noted earlier, however, growing numbers of frail elders are cared for in other settings, and emergent LTC models are being developed and evaluated.

Therefore, future studies should also examine the integration and outcomes of palliative care for older adults living in assisted living facilities, continuing care retirement communities, adult family homes, and nontraditional NH models (e.g., Green House). In addition, research should also examine palliative care processes and outcomes for older persons receiving care through PACE, patient-centered medical homes, and home-based primary care.

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Address correspondence to:
Mary Ersek, PhD, RN, FAAN
Philadelphia Veterans Affairs Medical Center
3900 Woodland Avenue Annex
Philadelphia, PA 19104

E-mail: ersekm@nursing.upenn.edu