

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

Mary Ersek, PhD, RN, FAAN<sup>1,2</sup> and Joan G. Carpenter, CRNP, NP-C, GNP-BC, ACHPN<sup>3,4</sup>

## 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

**L**ONG-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.<sup>1</sup> 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.<sup>2</sup> Over half are totally dependent or need extensive assistance with bathing, dressing, toileting, and transferring.<sup>3</sup> Despite efforts to minimize institutionalized care, the NH population is expected to grow to more than three million people by 2050.<sup>4</sup> As more people live in NHs, so too will they die there. In 2007, 28% of adults  $\geq 65$  years died in a NH,<sup>5</sup> and nearly 70% of persons with advanced dementia die in this setting.<sup>6</sup>

Compared to other settings for LTC, per person and national expenditures for NH care are notably high. NHs cost between \$114–\$136 billion annually,<sup>2</sup> and these costs are highest in the last months of life, often for care that is unhelpful and unwanted.<sup>3,7</sup> 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,<sup>8–11</sup> bereaved family satisfaction with care is lower for NH decedents compared with those who receive hospice care,<sup>12</sup> and NH residents are subject to many unnecessary and burdensome transitions in the final months of life.<sup>11,13</sup>

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)<sup>14–16</sup> and assisted living facilities (ALFs),<sup>17–22</sup> 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<sup>23–27</sup> using several methodologies, including Minimum Data Set (MDS) documentation,<sup>25</sup> chart audit,<sup>27</sup> staff report,<sup>23,24</sup> family report,<sup>23,24</sup> resident interviews,<sup>28</sup>

<sup>1</sup>Center for Health Equity Research and Promotion, Philadelphia VA Medical Center, Philadelphia, Pennsylvania.

<sup>2</sup>University of Pennsylvania School of Nursing, Philadelphia, Pennsylvania.

<sup>3</sup>University of Utah College of Nursing, Hartford Center of Geriatric Nursing Excellence, Salt Lake City, Utah.

<sup>4</sup>Coastal Hospice and Palliative Care, Salisbury, Maryland.

Accepted April 1, 2013.

and physician opinion.<sup>26</sup> Many others have focused exclusively on pain.<sup>9,29–33</sup> Taken together, these studies show that common EOL symptoms include pain (40%–86%),<sup>23,24,27,29–31,34</sup> dyspnea (11%–75%),<sup>23,24,26,27</sup> feeding problems (28%–70%),<sup>23,27</sup> delirium (29%–47%),<sup>25,27</sup> incontinence (59%),<sup>24</sup> and noisy breathing (39%–59%).<sup>24,27</sup> Several studies provide evidence that these symptoms often are inadequately managed.<sup>23,24,27,33</sup> 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,<sup>35,36</sup> and limited policies and procedures to guide palliative care practices.<sup>37</sup>

### 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.<sup>38</sup> When asked, the majority of NH residents and their families choose to limit aggressive, life-prolonging therapies.<sup>39,40</sup> Despite these preferences, several large studies have documented that many NH residents are hospitalized in the final weeks of life<sup>13,41,42</sup> and receive burdensome treatments with little benefit; these treatments include tube feeding<sup>43–45</sup> and post-acute, rehabilitative care.<sup>11,46,47</sup>

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.<sup>48–51</sup> 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.<sup>52</sup>

### Goals of Care Discussions and Advance Directives

The proportion of NH residents with completed ADs increased dramatically over the past 15 years. Jones and colleagues<sup>53</sup> 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.<sup>40,53</sup>

Although documented preferences about resuscitation are common, decisions about other interventions, such as artificial nutrition and hydration, hospitalization, antibiotics, and comfort measures, are not.<sup>54</sup> 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.<sup>40,55</sup> Moreover, the POLST paradigm increases concordance between residents'/families' preferences and care received.<sup>39</sup>

### 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?<sup>56</sup> Will resident

outcomes include self-report, and if so, how should one measure these outcomes in residents with marked cognitive impairment?<sup>57–59</sup> Was the measure developed for or validated in NHs? Several published reviews have focused on dementia-specific<sup>60–63</sup> and nursing home specific palliative care measures.<sup>64</sup> Other authors review general palliative care tools that may be valid for use in NHs.<sup>65,66</sup> 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.<sup>57,67,68</sup> Thompson and colleagues<sup>69</sup> 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.<sup>70</sup> In addition, it has new and expanded clinically relevant variables related to pain and other symptoms, decision making, and goals of care.<sup>71</sup> 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.<sup>72</sup> 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,<sup>73–76</sup> only two RCTs aimed at enhancing pain management were identified.<sup>77,78</sup> 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) <sup>69,105</sup>	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 <sup>69</sup>	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) <sup>106,107</sup>	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 <sup>69,108,109</sup>	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 <sup>110,111</sup>	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 colleagues<sup>79</sup> 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<sup>39,40,55,80</sup> 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.<sup>81,82</sup> Morrison and colleagues<sup>82</sup> 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 colleagues<sup>81</sup> 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 colleagues<sup>81</sup> 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<sup>83,84</sup> 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.<sup>41</sup> 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 colleagues<sup>85</sup> 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.<sup>86</sup> Several observational studies have demonstrated that hospice enhances EOL care in NHs.<sup>46,87–92</sup> These results may be one of many reasons that the number of hospice beneficiaries residing in NHs increased by 40% from 2005–2011.<sup>93</sup>

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.<sup>4,85</sup> Thus there have been no rigorous evaluations of these models. Despite the lack of evidence supporting these models, Miller and colleagues<sup>94</sup> 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 colleagues<sup>95</sup> 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 colleagues<sup>96</sup> 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,<sup>58–60,97,98</sup> self-report is generally considered the gold standard for subjective experiences such as pain and QOL.<sup>99</sup> 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?<sup>59,77,98</sup> 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 dementia<sup>100</sup> or Loeb and colleagues' clinical pathway for pneumonia.<sup>41</sup> 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.<sup>101–103</sup> 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.<sup>104</sup> 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.

### Acknowledgments

The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States government.

Ms. Carpenter is a 2011–2013 Patricia G. Archbold Scholar supported by the John A. Hartford Foundation's National Hartford Centers of Gerontological Nursing Excellence Award Program.

### Author Disclosure Statement

No competing financial interests exist.

### References

- Huskamp HA, Kaufmann C, Stevenson DG: The intersection of long-term care and end-of-life care. *Med Care Res Rev* 12;69:3–44.
- Kaye HS, Harrington C, LaPlante MP: Long-term care: Who gets it, who provides it, who pays, and how much? *Health Aff (Millwood)* 2010;29:11–21.
- Jones A, Dwyer L, Bercovitz A, Strahan G: The National Nursing Home Survey: 2004 Overview. Hyattsville: National Center for Health Statistics, 2009.
- Center to Advance Palliative Care: *Improving Palliative Care in Nursing Homes*. New York: Center to Advance Palliative Care, 2008. [www.capc.org/support-from-capc/capc\\_publications/nursing\\_home\\_report.pdf](http://www.capc.org/support-from-capc/capc_publications/nursing_home_report.pdf). (Last accessed December 2, 2011.)
- National Center for Health Statistics: *Health, United States, 2010: With Special Feature on Death and Dying*. Hyattsville, MD: National Center for Health Statistics, 2011.
- Mitchell SL, Teno JM, Miller SC, Mor V: A national study of the location of death for older persons with dementia. *J Am Geriatr Soc* 2005;53:299–305.
- Goldfeld KS, Stevenson DG, Hamel MB, Mitchell SL: Medicare expenditures among nursing home residents with advanced dementia. *Arch Intern Med* 2011;171:824–830.
- Jablonski A, Ersek M: Nursing home staff adherence to evidence-based pain management practices. *J Gerontol Nurs* 2009;35:28–34.
- Teno JM, Kabumoto G, Wetle T, Roy J, Mor V: Daily pain that was excruciating at some time in the previous week: Prevalence, characteristics, and outcomes in nursing home residents. *J Am Geriatr Soc* 2004;52:762–767.
- Sengupta M, Bercovitz A, Harris-Kojetin LD: Prevalence and management of pain, by race and dementia among nursing home residents: United States, 2004. *NCHS Data Brief* 2010:1–8.
- Miller SC, Lima JC, Looze J, Mitchell SL: Dying in U.S. nursing homes with advanced dementia: How does health care use differ for residents with, versus without, end-of-life Medicare skilled nursing facility care? *J Palliat Med* 2012;15: 43–50.

12. Teno JM, Clarridge BR, Casey V, et al.: Family perspectives on end-of-life care at the last place of care. *JAMA* 2004; 291:88–93.
13. Gozalo P, Teno JM, Mitchell SL, et al.: End-of-life transitions among nursing home residents with cognitive issues. *N Engl J Med* 2011;365:1212–1221.
14. Schamp R, Tenkku L: Managed death in a PACE: Pathways in present and advance directives. *J Am Med Dir Assoc* 2006;7:339–344.
15. Ryan SD, Tuuk M, Lee M: PACE and hospice: Two models of palliative care on the verge of collaboration. *Clin Geriatr Med* 2004;20:783–794, viii.
16. Wieland D, Lamb VL, Sutton SR, et al.: Hospitalization in the Program of All-Inclusive Care for the Elderly (PACE): Rates, concomitants, and predictors. *J Am Geriatr Soc* 2000;48:1373–1380.
17. Jerant AF, Azari RS, Nesbitt TS, Edwards-Goodbee A, Meyers FJ: The Palliative Care in Assisted Living (PCAL) pilot study: Successes, shortfalls, and methodological implications. *Soc Sci Med* 2006;62:199–207.
18. Mitty EL: Assisted living: Aging in place and palliative care. *Geriatr Nurs* 2004;25:149–156, 163.
19. Jerant AF, Azari RS, Nesbitt TS, Meyers FJ: The TLC model of palliative care in the elderly: Preliminary application in the assisted living setting. *Ann Fam Med* 2004;2:54–60.
20. Cartwright JC, Miller L, Volpin M: Hospice in assisted living: Promoting good quality care at end of life. *Gerontologist* 2009;49:508–516.
21. Cartwright JC, Hickman S, Perrin N, Tilden V: Symptom experiences of residents dying in assisted living. *J Am Med Dir Assoc* 2006;7:219–223.
22. Cartwright JC: Nursing homes and assisted living facilities as places for dying. *Annu Rev Nurs Res* 2002;20:231–264.
23. Hanson LC, Eckert JK, Dobbs D, et al.: Symptom experience of dying long-term care residents. *J Am Geriatr Soc* 2008;56:91–98.
24. Reynolds K, Henderson M, Schulman A, Hanson LC: Needs of the dying in nursing homes. *J Palliat Med* 2002; 5:895–901.
25. Duncan JG, Bott MJ, Thompson SA, Gajewski BJ: Symptom occurrence and associated clinical factors in nursing home residents with cancer. *Res Nurs Health* 2009;32:453–464.
26. Brandt HE, Deliens L, Ooms ME, van der Steen JT, van der Wal G, Ribbe MW: Symptoms, signs, problems, and diseases of terminally ill nursing home patients: A nationwide observational study in the Netherlands. *Arch Intern Med* 2005;165:314–320.
27. Hall P, Schroder C, Weaver L: The last 48 hours of life in long-term care: A focused chart audit. *J Am Geriatr Soc* 2002;50:501–506.
28. Forbes-Thompson S, Gessert C: Nursing homes and suffering: Part of the problem or part of the solution? *J Appl Gerontol* 2006;25:234–251.
29. Bernabei R, Gambassi G, Lapane K, et al.: Management of pain in elderly patients with cancer: SAGE Study Group. Systematic Assessment of Geriatric Drug Use via Epidemiology. *JAMA* 1998;279:1877–1882.
30. Won A, Lapane K, Gambassi G, Bernabei R, Mor V, Lipsitz LA: Correlates and management of nonmalignant pain in the nursing home; SAGE Study Group. Systematic Assessment of Geriatric drug use via Epidemiology. *J Am Geriatr Soc* 1999;47:936–942.
31. Won AB, Lapane KL, Vallow S, Schein J, Morris JN, Lipsitz LA: Persistent nonmalignant pain and analgesic prescribing patterns in elderly nursing home residents. *J Am Geriatr Soc* 2004;52:867–874.
32. Teno J, Bird C, Mor V: The prevalence and treatment of pain in US nursing homes. 2002. The Center for Gerontology and Health Care Research, Brown University, Providence, RI. [http://www.chcr.brown.edu/dying/factsondying .htm](http://www.chcr.brown.edu/dying/factsondying.htm). (Last accessed September 9, 2003.)
33. Teno JM, Weitzen S, Wetle T, Mor V: Persistent pain in nursing home residents. *JAMA* 2001;285:2081.
34. Takai Y, Yamamoto-Mitani N, Okamoto Y, Koyama K, Honda A: Literature review of pain prevalence among older residents of nursing homes. *Pain Manag Nurs* 2010;11:209–223.
35. Rice KN, Coleman EA, Fish R, Levy C, Kutner JS: Factors influencing models of end-of-life care in nursing homes: Results of a survey of nursing home administrators. *J Palliat Med* 2004;7:668–675.
36. Tarzian AJ, Hoffmann DE: Barriers to managing pain in the nursing home: Findings from a statewide survey. *J Am Med Dir Assoc* 2004;5:82–88.
37. Hodgson N, Landsberg L, Lehning A, Kleban M: Palliative care services in Pennsylvania nursing homes. *J Palliat Med* 2006;9:1054–1058.
38. National Consensus Project for Quality Palliative Care: *Clinical Practice Guidelines for Quality Palliative Care*, Pittsburgh, 2009.
39. Hickman SE, Nelson CA, Moss AH, Tolle SW, Perrin NA, Hammes BJ: The consistency between treatments provided to nursing facility residents and orders on the physician orders for life-sustaining treatment form. *J Am Geriatr Soc* 2011;59:2091–2099.
40. Hickman SE, Tolle SW, Brummel-Smith K, Carley MM: Use of the Physician Orders for Life-Sustaining Treatment program in Oregon nursing facilities: Beyond resuscitation status. *J Am Geriatr Soc* 2004;52:1424–1429.
41. Loeb M, Carusone SC, Goeree R, et al.: Effect of a clinical pathway to reduce hospitalizations in nursing home residents with pneumonia: A randomized controlled trial. *JAMA* 2006;295:2503–2510.
42. Ouslander JG, Lamb G, Perloe M, et al.: Potentially avoidable hospitalizations of nursing home residents: Frequency, causes, and costs. *J Am Geriatr Soc* 2010;58:627–635.
43. Mitchell SL, Teno JM, Roy J, Kabumoto G, Mor V: Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. *JAMA* 2003;290:73–80.
44. Teno JM, Gruneir A, Schwartz Z, Nanda A, Wetle T: Association between advance directives and quality of end-of-life care: A national study. *J Am Geriatr Soc* 2007;55: 189–194.
45. Teno JM, Mor V, DeSilva D, Kabumoto G, Roy J, Wetle T: Use of feeding tubes in nursing home residents with severe cognitive impairment. *JAMA* 2002;287:3211.
46. Miller SC, Lima JC, Mitchell SL: Influence of hospice on nursing home residents with advanced dementia who received Medicare-skilled nursing facility care near the end of life. *J Am Geriatr Soc* 2012;60:2035–2041.
47. Aragon K, Covinsky K, Miao Y, Boscardin WJ, Flint L, Smith AK: Use of the Medicare posthospitalization skilled nursing benefit in the last 6 months of life. *Arch Intern Med* 2012;1–7.
48. Shah F, Burack O, Boockvar KS: Perceived barriers to communication between hospital and nursing home at time of patient transfer. *J Am Med Dir Assoc* 2010;11:239–245.

49. Boockvar KS, Liu S, Goldstein N, Nebeker J, Siu A, Fried T: Prescribing discrepancies likely to cause adverse drug events after patient transfer. *Qual Saf Health Care* 2009;18:32–36.
50. Boockvar KS, Fridman B, Marturano C: Ineffective communication of mental status information during care transfer of older adults. *J Gen Intern Med* 2005;20:1146–1150.
51. Coleman EA, Berenson RA: Lost in transition: Challenges and opportunities for improving the quality of transitional care. *Ann Intern Med* 2004;141:533–536.
52. LaMantia MA, Scheunemann LP, Viera AJ, Busby-Whitehead J, Hanson LC: Interventions to improve transitional care between nursing homes and hospitals: A systematic review. *J Am Geriatr Soc* 2010;58:777–782.
53. Jones A, Moss A, Harris-Kojetin L: *Use of Advance Directives in Long-term Care Populations*. Hyattsville, MD: National Center for Health Statistics, 2011. NCHS Data Brief No. 54.
54. Levy CR, Fish R, Kramer A: Do-not-resuscitate and do-not-hospitalize directives of persons admitted to skilled nursing facilities under the Medicare benefit. *J Am Geriatr Soc* 2005;53:2060–2068.
55. Hickman SE, Nelson CA, Perrin NA, Moss AH, Hammes BJ, Tolle SW: A comparison of methods to communicate treatment preferences in nursing facilities: Traditional practices versus the physician orders for life-sustaining treatment program. *J Am Geriatr Soc* 2010;58:1241–1248.
56. Forbes-Thompson S, Gajewski B, Scott-Cawiezell J, Dunton N: An exploration of nursing home organizational processes. *West J Nurs Res* 2006;28:935–954.
57. Kane RL, Kane RA, Bershadsky B, et al.: Proxy sources for information on nursing home residents' quality of life. *J Gerontol B Psychol Sci Soc Sci* 2005;60:S318–S325.
58. Kutner JS, Bryant LL, Beaty BL, Fairclough DL: Symptom distress and quality-of-life assessment at the end of life: The role of proxy response. *J Pain Symptom Manage* 2006;32:300–310.
59. Snow AL, Cook KF, Lin PS, Morgan RO, Magaziner J: Proxies and other external raters: Methodological considerations. *Health Serv Res* 2005;40:1676–1693.
60. Kiely DK, Volicer L, Teno J, Jones RN, Prigerson HG, Mitchell SL: The validity and reliability of scales for the evaluation of end-of-life care in advanced dementia. *Alzheimer Dis Assoc Disord* 2006;20:176–181.
61. Kiely DK, Shaffer ML, Mitchell SL: Scales for the evaluation of end-of-life care in advanced dementia: Sensitivity to change. *Alzheimer Dis Assoc Disord* 2012;26:358–363.
62. van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, et al.: Psychometric properties of instruments to measure the quality of end-of-life care and dying for long-term care residents with dementia. *Qual Life Res* 2012;21:671–684.
63. Volicer L, Hurley AC, Blasi ZV: Scales for evaluation of end-of-life care in dementia. *Alzheimer Dis Assoc Disord* 2001;15:194–200.
64. Parker D, Hodgkinson B: A comparison of palliative care outcome measures used to assess the quality of palliative care provided in long-term care facilities: A systematic review. *Palliat Med* 2011;25:5–20.
65. Dy SM, Shugarman LR, Lorenz KA, Mularski RA, Lynn J: A systematic review of satisfaction with care at the end of life. *J Am Geriatr Soc* 2008;56:124–129.
66. Mularski RA, Dy SM, Shugarman LR, et al.: A systematic review of measures of end-of-life care and its outcomes. *Health Serv Res* 2007;42:1848–1870.
67. Kane RA, Kling KC, Bershadsky B, et al.: Quality of life measures for nursing home residents. *J Gerontol A Biol Sci Med Sci* 2003;58:240–248.
68. Kane RL, Bershadsky B, Kane RA, et al.: Using resident reports of quality of life to distinguish among nursing homes. *Gerontologist* 2004;44:624–632.
69. Thompson SA, Bott M, Gajewski B, Tilden VP: Quality of care and quality of dying in nursing homes: Two measurement models. *J Palliat Med* 2012;15:690–695.
70. Saliba D, Buchanan J: Development and validation of a revised nursing home assessment tool: MDS 3.0. Santa Monica, CA: RAND Health, 2008.
71. Centers for Medicare and Medicaid Services: RAI Version 3.0 Manual. 2011. [www.cms.gov/NursingHomeQualityInits/45\\_NHQIMDS30TrainingMaterials.asp#TopOfPage](http://www.cms.gov/NursingHomeQualityInits/45_NHQIMDS30TrainingMaterials.asp#TopOfPage). (Last accessed October 22, 2011.)
72. Steel K, Ljunggren G, Topinkova E, et al.: The RAI-PC: An assessment instrument for palliative care in all settings. *Am J Hosp Palliat Care* 2003;20:211–219.
73. Horner JK, Hanson LC, Wood D, Silver AG, Reynolds KS: Using quality improvement to address pain management practices in nursing homes. *J Pain Symptom Manage* 2005;30:271–277.
74. Baier RR, Gifford DR, Patry G, et al.: Ameliorating pain in nursing homes: A collaborative quality-improvement project. *J Am Geriatr Soc* 2004;52:1988–1995.
75. Weissman DE, Griffie J, Muchka S, Matson S: Building an institutional commitment to pain management in long-term care facilities. *J Pain Symptom Manage* 2000;20:35–43.
76. Weissman DE, Griffie J, Muchka S, Matson S: Improving pain management in long-term care facilities. *J Palliat Med* 2001;4:567–573.
77. Ersek M, Polissar N, Pen AD, Jablonski A, Herr K, Neradilek MB: Addressing methodological challenges in implementing the nursing home pain management algorithm randomized controlled trial. *Clin Trials* 2012;9:634–644.
78. Jones KR, Fink R, Vojir C, et al.: Translation research in long-term care: Improving pain management in nursing homes. *Worldviews Evid Based Nurs* 2004;1(Suppl 1):S13–S20.
79. Lindner SA, Davoren JB, Vollmer A, Williams B, Landefeld CS: An electronic medical record intervention increased nursing home advance directive orders and documentation. *J Am Geriatr Soc* 2007;55:1001–1006.
80. Tolle SW, Tilden VP, Nelson CA, Dunn PM: A prospective study of the efficacy of the physician order form for life-sustaining treatment. *J Am Geriatr Soc* 1998;46:1097–1102.
81. Molloy DW, Guyatt GH, Russo R, et al.: Systematic implementation of an advance directive program in nursing homes: A randomized controlled trial. *JAMA* 2000;283:1437–1444.
82. Morrison RS, Chichin E, Carter J, Burack O, Lantz M, Meier DE: The effect of a social work intervention to enhance advance care planning documentation in the nursing home. *J Am Geriatr Soc* 2005;53:290–294.
83. Ouslander JG, Lamb G, Tappen R, et al.: Interventions to reduce hospitalizations from nursing homes: Evaluation of the INTERACT II collaborative quality improvement project. *J Am Geriatr Soc* 2011;59:745–753.
84. Ouslander JG, Perloe M, Givens JH, Kluge L, Rutland T, Lamb G: Reducing potentially avoidable hospitalizations of nursing home residents: Results of a pilot quality improvement project. *J Am Med Dir Assoc* 2009;10:644–652.

85. Carlson MD, Lim B, Meier DE: Strategies and innovative models for delivering palliative care in nursing homes. *J Am Med Dir Assoc* 2011;12:91–98.
86. Hanson LC, Ersek M: Meeting palliative care needs in post-acute care settings: “To help them live until they die.” *JAMA* 2006;295:681–686.
87. Baer WM, Hanson LC: Families’ perception of the added value of hospice in the nursing home. *J Am Geriatr Soc* 2000;48:879–882.
88. Gozalo PL, Miller SC: Hospice enrollment and evaluation of its causal effect on hospitalization of dying nursing home patients. *Health Serv Res* 2007;42:587–610.
89. Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL: Hospice use and outcomes in nursing home residents with advanced dementia. *J Am Geriatr Soc* 2010;58:2284–2291.
90. Miller SC, Gozalo P, Mor V: Hospice enrollment and hospitalization of dying nursing home patients. *Am J Med* 2001;111:38–44.
91. Miller SC, Mor V, Teno J: Hospice enrollment and pain assessment and management in nursing homes. *J Pain Symptom Manage* 2003;26:791–799.
92. Miller SC, Mor V, Wu N, Gozalo P, Lapane K: Does receipt of hospice care in nursing homes improve the management of pain at the end of life? *J Am Geriatr Soc* 2002;50:507–515.
93. Office of the Inspector General: *Medicare Hospices That Focus on Nursing Facility Residents*. Washington, DC: Office of the Inspector General, 2011.
94. Miller SC, Han B: End-of-life care in U.S. nursing homes: Nursing homes with special programs and trained staff for hospice or palliative/end-of-life care. *J Palliat Med* 2008;11:866–877.
95. Hanson LC, Reynolds KS, Henderson M, Pickard CG: A quality improvement intervention to increase palliative care in nursing homes. *J Palliat Med* 2005;8:576–584.
96. Casarett D, Karlawish J, Morales K, Crowley R, Mirsch T, Asch DA: Improving the use of hospice services in nursing homes: A randomized controlled trial. *JAMA* 2005;294:211–217.
97. Lobchuk MM, McClement SE, Daeninck PJ, Shay C, Elands H: Asking the right question of informal caregivers about patient symptom experiences: Multiple proxy perspectives and reducing interrater gap. *J Pain Symptom Manage* 2007;33:130–145.
98. Magaziner J: Use of proxies to measure health and functional outcomes in effectiveness research in persons with Alzheimer disease and related disorders. *Alzheimer Dis Assoc Disord* 1997;11(Suppl 6):168–174.
99. Herr KA, Ersek M: Measurement of pain and other symptoms in the cognitively impaired. In: Hanks G, Cherny N, Christakis N, Fallon M, Kaasa S, Portenoy RK (eds): *Oxford Textbook of Palliative Medicine, 4th ed*. New York: Oxford University Press, 2009, pp. 466–479.
100. Hanson LC, Carey TS, Caprio AJ, et al.: Improving decision-making for feeding options in advanced dementia: A randomized, controlled trial. *J Am Geriatr Soc* 2011;59:2009–2016.
101. Eccles MP, Armstrong D, Baker R, et al.: An implementation research agenda. *Implement Sci* 2009;4:18.
102. Madon T, Hofman KJ, Kupfer L, Glass RI: Public health: Implementation science. *Science* 2007;318:1728–1729.
103. Sobo EJ, Bowman C, Gifford AL: Behind the scenes in health care improvement: The complex structures and emergent strategies of Implementation Science. *Soc Sci Med* 2008;67:1530–1540.
104. Davis P, Hahn J, Morgan P, Stone J, Tilson S: *Medicare Provisions in the Patient Protection and Affordable Care Act (PPACA)*. Washington, DC: Congressional Research Service, 2011.
105. Thompson S, Bott M, Boyle D, Gajewski B, Tilden VP: A measure of palliative care in nursing homes. *J Pain Symptom Manage* 2010;41:57–67.
106. Munn JC, Zimmerman S, Hanson LC, et al.: Measuring the quality of dying in long-term care. *J Am Geriatr Soc* 2007;55:1371–1379.
107. Caprio AJ, Hanson LC, Munn JC, et al.: Pain, dyspnea, and the quality of dying in long-term care. *J Am Geriatr Soc* 2008;56:683–688.
108. Teno JM, Clarridge B, Casey V, Edgman-Levitan S, Fowler J: Validation of toolkit after-death bereaved family member interview. *J Pain Symptom Manage* 2001;22:752–758.
109. Teno JM, Casey VA, Welch LC, Edgman-Levitan S: Patient-focused, family-centered end-of-life medical care: Views of the guidelines and bereaved family members. *J Pain Symptom Manage* 2001;22:738–751.
110. Vohra JU, Brazil K, Hanna S, Abelson J: Family perceptions of end-of-life care in long-term care facilities. *J Palliat Care* 2004;20:297–302.
111. Vohra JU, Brazil K, Szala-Meneok K: The last word: Family members’ descriptions of end-of-life care in long-term care facilities. *J Palliat Care* 2006;22:33–39.

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



**This article has been cited by:**

1. Kelley Amy S., Langa Kenneth M., Smith Alexander K., Cagle John, Ornstein Katherine, Silveira Maria J., Nicholas Lauren, Covinsky Kenneth E., Ritchie Christine S.. Leveraging the Health and Retirement Study to Advance Palliative Care Research. *Journal of Palliative Medicine*, ahead of print. [[Abstract](#)] [[Full Text HTML](#)] [[Full Text PDF](#)] [[Full Text PDF with Links](#)]