

# Hospice and Palliative Care in Nursing Homes: Challenges and Opportunities for Enhanced Access

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## ABSTRACT

The use of hospice care in nursing homes (NHs) has grown exponentially, but an increasing concern is the lack of access to resident and family-centered palliative care when residents do not elect hospice, and in time periods prior to election. This concern is amplified by the high magnitude of palliative care needs present for NH residents (and their families) when the NH will be their final residence; and, it is amplified because of short hospice stays, half of which are 22 days or less. This manuscript describes the use of the Medicare hospice care in NHs and discusses the policy, staff and physician barriers to timely hospice referral. It also describes the challenges NHs face in expanding residents' access to palliative care. Opportunities and approaches for increasing palliative care expertise and practice in NHs are presented.

**KEYWORDS:** Hospice, palliative care, nursing homes, Medicare

## INTRODUCTION

This manuscript discusses the barriers to timely hospice care for nursing home (NH) residents and the associated need for expansion of nonhospice palliative care in NHs.

Hospice care provided in NHs is now common. While 14% of dying NH residents nationally received hospice in 1999, in the first six months of 2010, this proportion rose to 40% (see Figure 1); and, in 2010 it was 68% in Rhode Island. This growth in hospice use is believed to be beneficial to NH residents, given the substantial research showing hospice enrollment to be associated with lower end-of-life hospital use, lower use of aggressive end-of-life treatments (e.g., tube feeding, intravenous fluids, other), higher-quality symptom management, and family reports of superior care.<sup>1-6</sup> However, there are concerns regarding the high rates of short hospice stays and thus the limited exposure to palliative care expertise by residents and their families. In NHs, major barriers to timely referral are the high proportion of residents with chronic terminal illnesses (for which determination of prognoses

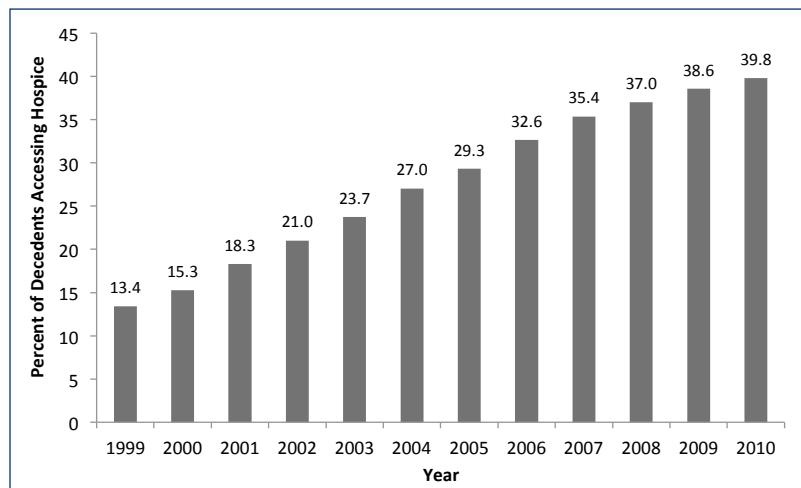
are difficult) and the use of Medicare Part A Skilled Nursing Facility (SNF) care by terminally ill (often dying) residents who cannot simultaneously choose hospice.

## CONTEXT OF HOSPICE AND PALLIATIVE CARE USE IN THE NH

Sixty-three percent of hospice enrollees in 2012 had non-cancer diagnoses,<sup>7</sup> but the proportion was closer to 80% in NHs. Also, 67% of older adults dying with dementia die in NHs.<sup>8</sup> To be enrolled in Medicare hospice, physicians must certify that patients have a six-month terminal prognosis (if the disease runs its normal course). For NH residents with chronic terminal illnesses, and in particular with dementia, the determination of a six-month prognosis is imprecise in practice; research attempting to predict mortality has had only limited success.<sup>9</sup> Given this difficulty and the high prevalence of chronic terminal illness in NHs, hospice NH residents have high proportions of both very short and very long hospice stays. In 2012, for example, the median length of hospice stays was 27 days for patients receiving home hospice compared to 22 days for NH hospice. Still, while 50% of NH hospice patients had stays of 22 days or less, 10% had stays of 335 days or longer, resulting in an average hospice length of stay of 112 days in NHs compared to 90 days for home hospice.<sup>10</sup>

In addition to the above, the admission or readmission

Figure 1. Growth in Nursing Homes Hospice Use – 1999 through 2010.



of NH residents to Medicare Part A SNF care when they are near death or actively dying has a profound impact on Medicare hospice use since Medicare disallows simultaneous hospice and SNF care (if SNF care is related to the terminal condition). Still, 12% of Medicare SNF residents die within 90 days of admission.<sup>11</sup> Residents admitted or returning to NHs from (3-day) hospital stays qualify for NH SNF care when skilled observation and assessment are required or when they receive therapy or complex services (e.g., intravenous feeding, intramuscular injections, other). There are financial incentives for choosing Medicare SNF care instead of private-pay or Medicaid NH care, and thus there is concern about its inappropriate use. For private-pay residents/families, with SNF enrollment, a substantial Medicare co-payment is received and out-of-pocket expenditures are substantially reduced. For NHs, admission of Medicare/Medicaid (dually) enrolled residents to SNF care translates into NHs receiving the substantially higher Medicare per diem payment instead of the lower Medicaid payment. Research on NH decedents with advanced dementia (i.e., moderately severe to severe dementia) found 40% received Medicare SNF care in the 90 days prior to death. Of these, 30% received hospice compared to 46% of those without SNF care; and, 40% of hospice enrollees (post-SNF) had short hospice stays ( $\leq 7$  days) compared to 19% of those

without SNF care. Additionally, 14% of residents with end-of-life SNF care died in a hospital compared to 9% of those without SNF care.<sup>12</sup>

While hospice eligibility guidelines and Medicare payment restrictions challenge timely hospital referral, other referral challenges exist as well. NH staff practices and knowledge also influence the timing of hospice referral. Through interviews conducted in RI, we found earlier hospice referral was facilitated when NH staff was able to recognize the familiar signs of terminal decline, took initiative in raising and discussing the option of hospice with physicians, residents and families, and when staff believed hospice added value and was not only for the "very end."<sup>13</sup> Also, at the time of our study none of the study NHs had written procedures regarding assessment of residents' prognoses or eligibility for hospice, or for communicating with physicians, residents and families regarding such outcomes. However, according to new CMS surveyor interpretive guidelines,<sup>14</sup> surveyors are instructed to assess whether NHs have practices in place to regularly assess whether residents are "approaching end-of-life;" and surveyors are instructed to look for evidence that interdisciplinary teams have addressed the discussions and considerations regarding advance care planning needed to clarify residents' goals and care preferences.<sup>14</sup>

**Figure 2.** "Pocket Care" Information on When to Consider Palliative or Hospice End-of-Life Care

| Terminal Indicators, 3"x5"   |        |
|--|--------|
|  | side 1 |
| <b>WHEN TO CONSIDER PALLIATIVE AND/OR HOSPICE END-OF-LIFE CARE</b>   |        |
| Palliative and/or hospice end-of-life care can assist with:  |        |
| <ul style="list-style-type: none"> <li>▪ Pain and symptom control</li> <li>▪ Emotional, social, and spiritual suffering</li> <li>▪ Home services, medications, nurse case management</li> <li>▪ Determining eligibility for additional supportive services</li> <li>▪ Facilitating patient and family conferences to define goals of care, including advance directives</li> </ul> |        |
| <b>ALS</b>   |        |
| Rapid progression in last year   |        |
| Impaired breathing at rest   |        |
| Insufficient nutrition/hydration   |        |
| Recurrent aspiration pneumonia   |        |
| Upper urinary tract infection  |        |
| Sepsis   |        |
| Recurrent fever  |        |
| Decubitus ulcers   |        |
| <b>Coma (any etiology)</b>   |        |
| Abnormal brain stem response   |        |
| Absent verbal response   |        |
| Absent withdrawal to pain  |        |
| Serum creatinine > 1.5 mg/dl   |        |
| Age over 70 years  |        |
| <b>Dementia</b>  |        |
| Inability to walk  |        |
| Incontinence   |        |
| Fewer than six intelligible words  |        |
| Albumin<2.5 or decrease PO intake  |        |
| Frequent ER visits   |        |
| <b>Failure to thrive</b>   |        |
| Frequent ER visits   |        |
| Albumin < 2.5  |        |
| Unintentional weight loss  |        |
| Decubitus ulcers   |        |
| Homebound/bed-confined   |        |
| <b>Diseases with short prognosis</b>   |        |
| Esophageal cancer  |        |
| Pancreatic cancer  |        |
| Glioblastoma   |        |
| Liver cancer and intra-hepatic bile ducts  |        |
| Gall bladder cancer and extra-hepatic bile ducts   |        |
| Any cancer with generalized metastases; metastasis to brain, liver, bone; or inoperable  |        |
| <b>Heart disease</b>   |        |
| CHF symptoms at rest   |        |
| EF of < 20%  |        |
| New dysrhythmia  |        |
| Cardiac arrest, syncope, or CVA  |        |
| Frequent ER visits for symptoms  |        |
| <b>HIV disease</b>   |        |
| CD4+ Count < 25  |        |
| Persistent viral load > 100,000  |        |
| Decreased functional status  |        |
| MAC untreated or unresponsive  |        |
| CNS or systemic lymphoma   |        |
| Progressive multifocal leukoencephalopathy   |        |
| Visceral Kaposi's sarcoma-unresponsive   |        |
| <b>Renal disease</b>   |        |
| Not a candidate for dialysis   |        |
| Creatinine clearance of < 15 ml/minute   |        |
| Serum creatinine > 6.0   |        |
| <b>Stroke – Acute</b>  |        |
| Secondary coma > 3 days  |        |
| Dysphagia  |        |
| <b>Stroke - Chronic</b>  |        |
| Post-stroke dementia   |        |
| Poor functional status   |        |
| Unintentional weight loss  |        |
| Serum albumin < 2.5  |        |
| <b>Lung Cancer</b>   |        |
| Advanced disease stage   |        |
| LDH twice normal   |        |
| Albumen < 2.5  |        |
| Calcium $\geq$ 12.0  |        |
| Metastases to brain, bone  |        |
| Decreasing functional status   |        |
| <i>Source: Bailey, Amos. The Palliative Response. (Modified for previous BCBSRI/Brown University project.) For more information, go to <a href="http://www.hospice.va.gov/Amosbaileybook/">www.hospice.va.gov/Amosbaileybook/</a></i>  |        |

## HOW PHYSICIANS AFFECT HOSPICE REFERRAL

Ultimately, residents and their families (and NH staff) rely on physicians for information regarding prognosis, and for referral to hospice. Thus, physician behavior is a key determinant in enabling hospice access. However, several physician-related barriers to timely hospice referral have been found, including lack of knowledge about hospice, negative perceptions of hospice, discomfort communicating poor prognoses, fear of losing control of the patient, and delaying the discussion of hospice until the patient was actively dying.<sup>15,16</sup> To assist physicians with determining when palliative or hospice care should be considered, “pocket card” information has been developed (see **Figure 2**). Also, the American Medical Directors Association (AMDA) has developed a palliative care tool kit to assist physicians in providing optimal care to long-term care residents with chronic and progressive illnesses.<sup>17</sup> In particular, this tool kit addresses how “all members of the interdisciplinary team can help physicians become more proficient in the assessment and relief of suffering.”<sup>17</sup> As discussed below, surveyor interpretive guidelines address the expected care practices when residents are assessed to be approaching end of life.

For NH residents approaching end of life, the Medicare/Medicaid surveyor interpretive guidelines ask surveyors to determine whether care is driven by resident preferences and is palliative – patient and family-centered care that optimizes quality of life by anticipating, preventing and treating physical or psychological suffering.<sup>14</sup> This surveyor guideline pertains to all residents regardless of their hospice status; thus, it intensifies the need for NHs to increase the availability of palliative care expertise to enable assessment and management of residents’ physical *and* psychosocial needs. Since many RI NHs through their “culture change” efforts have adopted practices and environments enabling patient and family-centered care, they are well-equipped to meet this aspect of the guideline. However, these and other NHs may lack the palliative care expertise needed to ameliorate intractable symptoms such as persistent pain or dyspnea or the staffing or expertise to address residents’ (and families’) psychosocial and spiritual needs. NHs can gain this expertise internally through education and training efforts or through selected recruitment; and, it can be obtained externally as discussed below.

Medicare hospice expands the availability of palliative care expertise to NH residents, but for residents unable or unwilling to access hospice and prior to hospice enrollment, other approaches are needed. One approach for expanding access to palliative care expertise is the use of palliative care consults. These consults may be provided by internal NH experts but are also often available to NH residents by external providers (most often through hospice-affiliated organizations).<sup>18</sup> Physicians order palliative care consults (often at the suggestion of NH staff) to assist in managing intractable physical symptoms or to assist in addressing resident/family psychosocial needs, including the need for help

with end-of-life care decision making. There are no prognosis requirements associated with receipt of palliative care consults, and they can be provided to residents enrolled in Medicare SNF care. Anecdotal findings show the efficacy of palliative care consults in NHs to be promising,<sup>18</sup> but there has been little comparative research of their benefits. However, one NH with a NH-staffed consult program found residents with consults had greater reductions in depression and in emergency room visits, compared to its matched residents without consults.<sup>19</sup> Also, preliminary findings from our ongoing longitudinal research show that when NHs introduce palliative care consults, their residents’ rates of end-of-life hospital use decrease, compared to rates of NHs who have not yet introduced consults.<sup>20</sup>

## EDUCATION AND TRAINING EFFORTS

Selective staff recruitment and staff and medical director education and training are other ways for NHs to increase the presence of palliative care expertise. In recent interviews of NH administrators, most cited hospice alone as their only resource for providing staff with palliative care education.<sup>21</sup> However, other resources for education and training are available but are certainly not in abundance. Through the End-of-Life Nursing Education Consortium (ELNEC) project a train-the-trainer education program in palliative care was developed, and there is palliative care geriatric curriculum.<sup>22</sup> NHs can send a nurse for ELNEC training, and when they return, they can convey this information to other NH nurses and aides. Attendees also have the opportunity to become certified in hospice and palliative care. Also, in addition to AMDA’s palliative care tool kit discussed earlier, other relevant clinical guidelines are available.<sup>23</sup> For example, guidelines on pain management and on managing an “acute change of condition” are available.

In addition to the above, quality improvement organizations (QIO) or culture change coalitions in some states have led initiatives to assist in improving NH staff’s palliative care knowledge and practice.<sup>23-25</sup> In Rhode Island, for example, the QIO (Healthcentric Advisors) recently conducted a NH palliative care collaborative with staff from 16 facilities. Staff-initiated improvement efforts focused on one of six hallmarks of palliative care: identifying proxy decision-makers, advance care planning, pain assessment, discussion of resident prognosis, discussion of resident goals, and assessment and access to spiritual care. The palliative care collaborative facilitated improvement through staff sharing of information on their change efforts and resulting achievements.<sup>24</sup> In addition, other PC education was provided to staff, and 20 NH nurses were funded to attend ELNEC training. A product of this RI initiative is a palliative care toolkit that is available for free on Healthcentric Advisors’ website.<sup>25</sup> This tool kit contains a wealth of information including guidance on assessing pain and having resident/family discussions regarding prognoses and goals of care. It also contains links to numerous palliative care organizations and guidelines.

## CONCLUSION

While there has been a large increase in hospice use in NHs, many residents still do not access hospice or access it only weeks prior to death. To adequately care for residents with chronic and progressive illnesses, an increase in the presence of palliative care expertise within NHs is needed. This increase can be achieved through earlier hospice referral, use of external palliative care expertise, selected staff recruitment, or by investing in the training and education of staff and physicians. Resources are available to assist in this effort.

## References

1. Miller SC, Mor V, Teno J: Hospice enrollment and pain assessment and management in nursing homes. *J Pain Symptom Manage.* 2003;26(3):791-799.
2. Teno JM, Clarridge BR, Casey V, et al.: Family perspectives on end-of-life care at the last place of care. *JAMA.* 2004;291(1):88-93.
3. Gozalo PL, Miller SC: Hospice enrollment and evaluation of its causal effect on hospitalization of dying nursing home patients. *Health Serv Res.* 2007;42(2):587-610.
4. Baer WM, Hanson LC: Families' perception of the added value of hospice in the nursing home. *J Am Geriatr Soc.* 2000;48(8):879-882.
5. Miller SC, Mor V, Wu N, et al.: Does receipt of hospice care in nursing homes improve the management of pain at the end of life? *J Am Geriatr Soc.* 2002;50(3):507-515.
6. Kiely DK, Givens JL, Shaffer ML, et al.: Hospice use and outcomes in nursing home residents with advanced dementia. *Journal of the American Geriatrics Society.* 2010;58(12):2284-2291.
7. National Hospice and Palliative Care Organization: NHPCO's Facts and Figures: Hospice Care in America. Alexandria, VA2014.
8. Mitchell SL, Teno JM, Miller SC, et al.: A national study of the location of death for older persons with dementia. *J Am Geriatr Soc.* 2005;53(2):299-305.
9. Mitchell SL, Miller SC, Teno JM, et al.: Prediction of 6-month survival of nursing home residents with advanced dementia using ADEPT vs hospice eligibility guidelines. *JAMA.* 2010;304(17):1929-1935.
10. MedPac: Report to the Congress: Medicare and the Health Care Delivery System. Washington DC: Medicare Payment Advisory Commission; 2013, pp. 117-142.
11. Magaziner J, Zimmerman S, Gruber-Baldini AL, et al.: Mortality and adverse health events in newly admitted nursing home residents with and without dementia. *J Am Geriatr Soc.* 2005;53(11):1858-1866.
12. 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(11):2035-2041.
13. Welch LC, Miller SC, Martin EW, et al.: Referral and timing of referral to hospice care in nursing homes: the significant role of staff members. *Gerontologist.* 2008;48(4):477-484.
14. Center for Medicare & Medicaid Services: CMS Manual System Pub. 100-07 State Operations Provider Certification. Appendix PP/F tag 309. Quality of Care- Advance Copy. Baltimore, MD: Department of Health and Human Services; 2012.
15. Shield R: Physicians' perspectives on end-of-life care: a qualitative inquiry. *Med Health R I.* 2007;90(12):391-392.
16. McGorty EK, Bornstein BH: Barriers to physicians' decisions to discuss hospice: insights gained from the United States hospice model. *J Eval Clin Pract.* 2003;9(3):363-372.
17. American Directors Medical Association: Palliative Care Toolkit. 2014; <http://www.amda.com/resources/ltcis.cfm#LTCPC1>. Accessed December 4, 2014.
18. Carlson MD, Lim B, Meier DE: Strategies and innovative models for delivering palliative care in nursing homes. *J Am Med Dir Assoc.* 2011;12(2):91-98.
19. Comart J, Mahler A, Schreiber R, et al.: Palliative care for long-term care residents: effect on clinical outcomes. *Gerontologist.* 2013;53(5):874-880.
20. Miller SC, Lima J, Dahal R, et al.: The Provision of Palliative Care Consultations in Nursing Homes and End of Life Hospitalizations. Paper presented at: Poster session presented at: Making Connections From Cells to Societies. 67th Annual meeting of the Gerontological Society of America; November 5-9, 2014; New Orleans, LA.
21. Tyler DA, Shield RR, Miller SC: Diffusion of Palliative Care in Nursing Homes: Lessons from the Culture Change Movement. *Journal of pain and symptom management.* 2014.
22. American Association of Colleges of Nursing (AACN): End-of-Life Nursing Education Consortium (ELNEC) Fact Sheet. 2014; <http://www.aacn.nche.edu/el nec/about/fact-sheet>. Accessed November 25, 2014.
23. American Medical Directors Association: Clinical Practice Guidelines in the Long-Term Care Setting. 2012; <http://www.amda.com/tools/guidelines.cfm>. Accessed December 4, 2014.
24. Healthcentric Advisors: Nursing Home Palliative Care Collaborative. 2014; <http://www.healthcentricadvisors.org/nhpcc.html>. Accessed November 25, 2014.
25. Healthcentric Advisors: Nursing Home Palliative Care Tool Kit. 2014; <http://www.healthcentricadvisors.org/resources/alphaindex/resources/n.html>. Accessed November 25, 2014.

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## Disclaimer

The author has no conflicts of interest to report

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