UCSF

UC San Francisco Previously Published Works

Title

Original Research: Understanding Nursing Home Staff Attitudes Toward Death and Dying: A Survey.

Permalink

https://escholarship.org/uc/item/7hs3324b

Journal

American Journal of Nursing, 120(8)

ISSN

0002-936X

Authors

Bui, Nhat Halifax, Elizabeth David, Daniel et al.

Publication Date

2020-08-01

DOI

10.1097/01.naj.0000694336.19444.5a

Peer reviewed

Published in final edited form as:

Am J Nurs. 2020 August; 120(8): 24-31. doi:10.1097/01.NAJ.0000694336.19444.5a.

Understanding Nursing Home Staff Attitudes Toward Death and Dying::

A Survey

Nhat Bui, MSN, NP [adult gerontology NP],

Memory and Aging Center, Weill Institute for Neurosciences, University of California, San Francisco (UCSF).

Elizabeth Halifax, PhD, RN [assistant clinical professor],

UCSF School of Nursing.

Daniel David, PhD, RN [assistant professor],

New York University Rory Meyers College of Nursing in New York City.

Lauren Hunt, PhD, FNP-BC [assistant professor],

UCSF School of Nursing and at San Francisco Veterans Affairs Medical Center.

Edyssa Uy, MSN, NP [NP],

City of Hope Comprehensive Cancer Center in Duarte, CA.

Christine Ritchie, MD, MSPH [Kenneth L. Minaker Chair in Geriatrics and director of research],

Division of Palliative Care and Geriatric Medicine at Massachusetts General Hospital in Boston.

Caroline Stephens, PhD, RN, GNP-BC, FAAN [associate professor and the Helen Lowe Bamberger Colby Presidential Endowed Chair]

Gerontological Nursing at the University of Utah College of Nursing in Salt Lake City.

Abstract

Background: Nearly 70% of nursing home residents are eligible for palliative care, yet few receive formal palliative care outside of hospice. Little is known about nursing home staff attitudes, knowledge, skills, and behaviors related to palliative care.

Methods: We administered a modified survey measuring attitudes toward death to 146 nursing home staff members, including both clinical and nonclinical staff, from 14 nursing homes.

Results: Nursing home staff generally reported feeling comfortable caring for the dying, but half believed the end of life is a time of great suffering. Pain control (63%), loneliness (52%), and depression (48%) were the most important issues identified with regard to these patients, and there was ambivalence about the use of strong pain medications and the utility of feeding tubes at the end of life. Top priorities identified for improving palliative care included greater family

Contact author: Nhat Bui, nhat.bui@ucsf.edu.

The authors have disclosed no potential conflicts of interest, financial or otherwise.

involvement (43%), education and training in pain control (50%) and in management of other symptoms (37%), and use of a palliative care team (35%) at their facility.

Conclusions: Findings show there is a need for more palliative care training and education, which should be built on current staff knowledge, skills, and attitudes toward palliative care.

Abstract

Findings indicate that most staff need more education and training regarding palliative care.

Keywords

attitudes toward death; end-of-life care; nursing home; palliative care

Advances in medicine and public health programs mean that a greater proportion of the U.S. population is living longer. By the year 2030, experts project that 20% of the U.S. population (72 million people) will be age 65 years or older 1,2—and half a million of them will likely die in nursing homes. As the nursing home population rises, there will be an increased demand for palliative care in this setting. Per the Centers for Disease Control and Prevention (CDC), palliative care may be defined as "treatment given to relieve pain and control symptoms when there is no reasonable expectation of a cure," using a holistic approach to improve comfort and quality of life. Palliative care differs from hospice care in that it does not necessarily preclude curative efforts. But nursing home residents typically lack access to palliative care, even though many qualify because they have serious life-limiting illnesses such as cancer, dementia, chronic respiratory disease, heart failure, and stroke. A major challenge in meeting the needs of this population is the lack of nursing home staff who have education and training in palliative care.

BACKGROUND

According to the CDC, nearly 70% of older adults have been diagnosed with multiple serious illnesses. Such illnesses can lead to adverse outcomes such as physical or cognitive disability, diminished ability to perform activities of daily living (ADLs), and diminished quality of life. The loss of one's independence and ability to perform ADLs shifts the burden of care to family members, and can precipitate the need to transition from home to long-term care settings such as nursing homes.

It's been estimated that approximately 1.8 million older adults live in nursing homes⁷—and that number is expected to rise to over 3 million by 2030.⁸ According to the CDC, in 2011 and 2012 more than 85% of all nursing home residents were 65 years of age and older, and 42% of all residents were 85 years of age and older.⁹ The majority of these residents are frail, are cognitively or functionally impaired, or require assistance with ADLs such as ambulating, bathing, dressing, eating, and toileting; some will have a combination of these difficulties.⁹ Current nursing home resources will have to expand in order to meet the complex health care needs of this growing population.

Palliative care uses a team-based approach to provide care that focuses on relieving suffering and improving the quality of life for people of any age who have serious illnesses. ¹⁰ Unlike

hospice care, palliative care may or may not be offered in tandem with curative efforts. Patient and family needs, rather than prognosis, underlie this approach. The multidisciplinary palliative care team manages pain, coordinates care, and communicates with patients and their families to provide treatment that is aligned with their care goals. Previous research suggests that providing palliative care in nursing homes may be associated with enhanced symptom management, improved patient and family satisfaction with care, and higher quality of care, as well as fewer ED visits and hospitalizations. ¹¹⁻¹⁴ Similar benefits have been linked to providing palliative care in assisted living facilities. ^{15, 16} Experts argue that palliative care should be integrated into care provided by all clinicians serving the seriously ill, especially in the nursing home setting. ¹⁷

Yet palliative care services are often either unavailable or difficult to access, with wide differences seen across states and health care settings. ¹⁸ One recent study found that while nearly 70% of nursing home residents were eligible for palliative care services, none received them. ⁶ And a literature review by Aldridge and colleagues suggests that most residents are likely to die without receiving the benefits of palliative care or with palliation delayed until the last days of life. ¹⁹ Access to palliative care for nursing home residents is often provided through hospice services, ^{20, 21} with more than half enrolled for less than 30 days ²²—even though hospice care has been shown to improve end-of-life care in nursing homes (by reducing symptom burden, for example).

Multiple barriers to implementing palliative care in nursing homes have been identified. These include provider failure to recognize the approach of death, provider difficulty in discussing death with residents and their families, palliative care workforce shortages, and poor communication between nursing home and medical staff. ^{19, 23} But the most important barrier appears to be the lack of appropriate palliative care education and training for nursing home staff. ²³ Educational interventions that teach palliative care skills and enhance the skills of nursing home staff are needed. ²³ Unfortunately, little is known about the attitudes, behaviors, and existing knowledge and skill levels of such staff relative to death and dying.

Purpose.

The aims of this study were twofold: to increase our understanding of nursing home staff attitudes toward death and dying, and to identify staff needs regarding palliative care education and training.

METHODS

Design, sample, and setting.

This study used a cross-sectional design, offering an observational vantage point from which to collect data. The sample consisted of 146 nursing home staff from 14 nursing homes associated with a large, community-based, health system—nursing home collaborative project aimed at reducing the rate of hospital readmissions. All of the nursing homes were located in the San Francisco Bay Area, in urban and suburban areas with populations that are racially and ethnically diverse.

Data collection.

We assessed the perspectives of nursing home staff using a modified Attitudes Toward Death Survey. We initial surveys were handed out and administered to 35 staff members in a hospital conference room prior to the first palliative care training of the collaborative project. The remaining 111 nursing home staff, also involved in the collaborative project but not in attendance at the training, were surveyed at the nursing homes where they worked. All surveys were administered by external, neutral academic investigators (four of us, NB, EH, EU, CS). Directors of nursing were asked to invite staff to participate and collect completed surveys. Participation was voluntary, and the study was deemed exempt from the need for institutional review board approval. Data collection took place between September 1 and December 31, 2015.

Instrument.

The modified Attitudes Toward Death Survey has 13 items: 10 items requiring Likert-scale responses, two questions with 14 options each (11 specific, three general) and spaces for additional comments, and one open-ended question. This survey has not been validated, but after conducting an extensive literature search, we found no other validated tools that assess nursing home staff attitudes and educational needs in this area. This survey was selected because it is brief, accessible, and appears to have content validity in that it addresses aspects of palliative care relevant to nursing home care.

The first 10 items of the survey assessed nursing home staff attitudes by asking respondents to indicate their level of agreement with general statements regarding care for dying residents, using a 5-point Likert scale. Each of the next two questions had two parts and sought to elicit more detail regarding attitudes toward end-of-life care. Question 11 asked, "What do you think are the most important problems in caring for the dying residents in the nursing home?" and offered a list of 14 options (respondents could choose more than one), followed by space to describe other such problems. Question 12 asked, "What do you think would help improve end-of-life care in your facility?" and offered a list of 14 options (respondents could choose more than one), followed by space to provide other suggestions for improvements. The final question was open-ended: "How would you describe palliative care?" This question, which is a modification of the original survey, was added to assess respondents' knowledge and understanding of the definition of palliative care.

Data analysis.

Simple response frequencies were used to describe respondents' answers to the 10 items with Likert-scale options and to the two questions assessing attitudes toward end-of-life care. Responses to the final open-ended question were collated using content analysis, a method that organizes documented evidence by theme in an objective and systematic way. The analysis was completed by three members of the research team (NB, EH, CS) and discussed until consensus was reached.

RESULTS

A total of 146 respondents participated in the survey. Of these, 79% were female and 16% were male; 5% were unknown or did not respond. Half of all respondents were over 40 years of age. The sample was racially and ethnically diverse, with 36% identifying as Asian, 29% as black or African American, 13% as white, 5% as Native Hawaiian, and less than 1% as American Indian or Alaskan Native. Seven percent reported more than one racial identity, and another 10% were unknown or did not respond. A broad range of clinical and nonclinical staff roles were represented in the sample. Clinical staff included 22 RNs, 23 LVNs, and 57 certified nursing assistants, as well as one physician, three physical therapists, one occupational therapist, and two registered dietitians. Nonclinical staff included nine nursing home administrators, 10 people in administrative support, five in social services, three activities staffers, and one in housekeeping. Nine respondents did not identify their role or position. For more demographic details, see Table 1.

The responses of nursing home staff to the 10 Likert scale—based items are shown in Table 2. Overall, staff felt comfortable with providing care at the end of life. Forty-three percent agreed or strongly agreed with the statement "The end of life is a time of great suffering." Over 60% of respondents disagreed or strongly disagreed with the statement "The nursing home is not a good place to die." Regarding specific aspects of palliative care, the majority (93%) agreed or strongly agreed with the statement "Patients have the right to refuse a medical treatment, even if that treatment prolongs life." But there was no clear consensus for either of the following statements: "The use of strong pain medication can cause the patient to stop breathing" and "Feeding tubes should be used to prevent starvation at the end of life."

Respondents identified three top problem areas from 11 specific options concerning the care of dying residents: pain control (63%), loneliness (52%), and depression (48%). Other potential problem areas that garnered responses included communication issues with family and with providers, legal concerns, and "uncertainty about what is best care."

Respondents also identified top areas from 11 specific options concerning what would help improve end-of-life care in their facilities. Half of the respondents (50%) identified education and training in pain control as being most important. Greater family involvement was selected by 43% of respondents. Education and training in management of other symptoms (besides pain) was chosen by 37%. Detailed results are shown in Table 3.

Of the 66 respondents who answered the final open-ended question, "How would you describe palliative care?," a majority (77%) named some form of symptom relief such as *pain relief*, and 50% used the word *comfort*. The phrase *serious illness* was used by 20% of respondents, and 17% described palliative care as being exclusive to *death and dying*. Only 14% referred to a *team approach* in their description of palliative care. The concept of *quality of life* was mentioned only once, although it's a defining element of palliative care. Table 4 lists emergent themes and exemplar responses to this question.

DISCUSSION

As far as we know, this is the first multisite study to explore nursing home staff attitudes toward death and dying and to identify their needs regarding palliative care education and training. Their survey responses offer unique perspectives and insights regarding end-of-life care for millions of nursing home residents. We found that nursing home staff generally felt comfortable providing care to residents at the end of life and advocating patient and family autonomy (such as the right to decide whether to forgo life-prolonging treatment). But our findings also suggest that gaps in staff knowledge and skills can make the end-of-life experience suboptimal.

Half of the survey respondents believed that the end of life is a time of great suffering; yet they lacked consensus on whether the use of strong pain medication hastens death. Nearly all respondents felt that pain management is a top concern for nursing home residents at the end of life, a finding consistent with results from other studies. According to a 2018 joint position paper by the American Society for Pain Management Nursing and the Hospice and Palliative Nurses Association, the prevalence of end-of-life pain "remains unacceptably high," and actions to correct this underassessed and undermanaged symptom are warranted. Our respondents' ambivalence regarding pain control shows a need for more education on the use of pain medications and how to weigh potential benefits against risks.

Our findings also highlight the importance of addressing psychological and social concerns, including depression and loneliness, in nursing home residents near the end of life. While many clinicians who provide daily care for these residents are keenly aware of the impact of such concerns, depression and loneliness may still be underrecognized as sources of suffering. Incorporating a palliative care approach that emphasizes relief of pain and other physical symptoms and also addresses the psychological, social, and spiritual needs of seriously ill nursing home residents could help reduce their suffering. For example, the No One Dies Alone initiative, a volunteer program originating in 2001 at Sacred Heart Medical Center in Eugene, Oregon, provides comfort and companionship to imminently dying patients and offers respite and support to their families and caregivers. It has shown success in various settings and could be expanded to the nursing home environment. Other such programs might similarly prove effective.

Our findings revealed that nursing home staff were uncertain regarding whether feeding tubes should be used to prevent starvation in residents at the end of life. The American Geriatrics Society, in partnership with the American Board of Internal Medicine Foundation's Choosing Wisely campaign, does not recommend the use of feeding tubes in those with advanced dementia, ³³ as they have been associated with agitation, increased use of restraints, worsening pressure ulcers, and higher risk of ED visits. ^{34, 35} Our results indicate that nursing home staff need more education regarding the appropriateness of feeding tubes for dying residents who may have advanced dementia.

While other studies have reported on the palliative care education needs of nursing home staff, ^{23, 36-38} this is the first to ask staff for specific descriptions of the term *palliative care*. Their responses indicated an incomplete understanding of the components of palliative care,

and were inconsistent with consensus definitions of the term. The Center to Advance Palliative Care, expanding on the aforementioned CDC definition, describes such care as that which provides an extra layer of support aimed at lowering the symptom burden, minimizing suffering, and enhancing quality of life through a multidisciplinary team approach.³⁹ From respondents' descriptions of palliative care, we discovered that staff could not distinguish between hospice and palliative care. Furthermore, their descriptions frequently failed to include fundamental concepts such as a multidisciplinary team approach, quality of life, relief from suffering, and the specific care of serious illness. Providing nursing home staff with a more complete understanding of what palliative care is, how it differs from hospice care, and how it may improve residents' quality of life could enhance vital workforce skills in this setting.

Although our respondents found a comprehensive definition of palliative care elusive, overall their survey responses were consistent with a workforce focused on improving palliative care. In particular, respondents emphasized the need to address pain and improve pain relief, as well as to prioritize the management of nonpain symptoms. When asked how nursing home facilities could improve end-of-life care, respondents suggested enhancing communication with families and improving staff education on symptom management. This finding is consistent with earlier research in which families and nursing home residents reported concerns such as ineffective communication, infrequent physician visits leading to poor symptom management, and overall dissatisfaction with care. Reduced staff turnover as well as more and better trained nursing home staff have been recommended to improve care and care coordination for nursing home residents.

Implications.

Our findings have important practice and research implications. Establishing palliative care as integral to the nursing home setting can potentially improve care quality, resident and family satisfaction, and resource allocation, as well as reduce the incidence of preventable hospitalizations. As Stillman and colleagues have noted, short-term solutions won't suffice; rather, "a philosophy of palliative care and the relevant knowledge base and skill set" must be embedded within the nursing home culture. ²⁴ Given that palliative care specialists are limited in number, including nursing home staff–led palliative care as part of primary care is clearly necessary if we are to meet residents' needs.

To be successful, educational interventions for nursing home staff must reflect their values and current knowledge and skill levels, consider the available resources, and address the challenges they will face. Thus, further research is needed to accurately gauge their educational deficits and explore which interventions might be effective. It will also be necessary to assess patient and family outcomes (including preventable hospitalizations, pain control, quality of life, symptom experience, caregiver burden, and patient and family satisfaction) to determine whether improving staff palliative care education and training is associated with better outcomes. More research should be directed toward better understanding the palliative care needs of the aging U.S. population, especially those residing in nursing homes. Lastly, further research exploring how specific nursing roles are associated with nurses' attitudes toward death and dying would be useful.

Limitations and strengths.

This study surveyed nursing home staff from 14 nursing homes in one geographical area; it's unknown whether the findings are generalizable to nursing homes in other geographical areas. The survey items collected data by self-report. Although the surveys were administered in person by three external, neutral academic investigators, respondents' answers might have been influenced by concerns about privacy and possible scrutiny from their employers.

One strength of the study is the diversity of the respondents, who represented not only a broad range of ages and ethnicities, but also various clinical and nonclinical roles within the nursing home setting. Also, the modified Attitudes Toward Death Survey elicited both quantitative and qualitative data. Gathering qualitative information can yield further detailed insight into factors that affect the palliative care environment at individual facilities.

CONCLUSION

Most nursing home residents with serious illnesses live and die in environments with limited palliative care resources. Making palliative care integral to their primary care requires both clinical and nonclinical staff to champion such care in each unique workplace. This study sought to gain insight into nursing home staff attitudes toward death and dying, and to identify their educational needs regarding palliative care, in order to guide interventions that will improve end-of-life outcomes for patients and families. In the future, palliative care education and training must address symptom management and promote cultural changes that build on the staff's attitudes, knowledge, and skills. Further research investigating staff attitudes toward palliative care will support the development of tailored educational interventions that have the most potential to improve care for nursing home residents.

Acknowledgments

Support for this study included grants from the National Institute on Aging Paul B. Beeson Emerging Leaders Career Development Award (K76AG054862), the UCSF Pepper Center, and the National Institutes of Health (8 KL2 TR000143-08).

REFERENCES

- 1. Centers for Disease Control and Prevention. State of aging and health in America: data brief series. 2019 http://www.cdc.gov/aging/help/dph-aging/state-aging-health.html.
- 2. Colby SL, Ortman JM. Projections of the size and composition of the U.S. population: 2014 to 2060. Washington, DC: U.S. Census Bureau; 2014 3 3 P25–1143. Current population reports; https://www.census.gov/library/publications/2015/demo/p25-1143.html.
- 3. Mitchell SL, et al. A national study of the location of death for older persons with dementia. J Am Geriatr Soc 2005;53(2):299–305. [PubMed: 15673356]
- Centers for Disease Control and Prevention. Advance care planning: an introduction for public health and aging services professionals, version 1.0. Atlanta; 2011 https://www.cdc.gov/training/ ACP.
- 5. Lester PE, et al. Prevalence and description of palliative care in US nursing homes: a descriptive study. Am J Hosp Palliat Care 2016;33(2):171–7. [PubMed: 25395553]
- 6. Stephens CE, et al. Palliative care eligibility, symptom burden, and quality-of-life ratings in nursing home residents. JAMA Intern Med 2018;178(1):141–2. [PubMed: 29159368]

7. Kaye HS, et al. Long-term care: who gets it, who provides it, who pays, and how much? Health Aff (Millwood) 2010;29(1):11–21. [PubMed: 20048355]

- Center to Advance Palliative Care. Improving palliative care in nursing homes. New York, NY; 2008 https://media.capc.org/filer_public/95/b8/95b84a49-7151-427d-be72-200b634eed5b/ 3123_1606_nursinghomereport-rev.pdf.
- 9. Harris-Kojetin L, et al. Long-term care services in the United States: 2013 overview. Vital Health Stat 3 2013(37):1–107. [PubMed: 26158640]
- 10. Center to Advance Palliative Care. About palliative care: what is palliative care? n.d. https://www.capc.org/about/palliative-care.
- 11. Bercovitz A, et al. End-of-life care in nursing homes: 2004 National Nursing Home Survey. Natl Health Stat Report 2008;(9):1–23.
- 12. Hall S, et al. Interventions for improving palliative care for older people living in nursing care homes. Cochrane Database Syst Rev 2011;3:CD007132.
- Miller SC, et al. Palliative care consultations in nursing homes and end-of-life hospitalizations. J Pain Symptom Manage 2016;52(6):878–83. [PubMed: 27650008]
- 14. Miller SC, et al. Palliative care consultations in nursing homes and reductions in acute care use and potentially burdensome end-of-life transitions. J Am Geriatr Soc 2016;64(11):2280–7. [PubMed: 27641157]
- 15. Dougherty M, et al. Hospice care in assisted living facilities versus at home: results of a multisite cohort study. J Am Geriatr Soc 2015;63(6):1153–7. [PubMed: 26096389]
- 16. Hyde J, et al. The impact of enhanced programming on aging in place for people with dementia in assisted living. Am J Alzheimers Dis Other Demen 2015;30(8):733–7. [PubMed: 24509611]
- 17. Smedbäck J, et al. Palliative care during the final week of life of older people in nursing homes: a register-based study. Palliat Support Care 2017;15(4):417–24. [PubMed: 28049547]
- 18. Meier DE, et al. A national strategy for palliative care. Health Aff (Millwood) 2017;36(7):1265–73. [PubMed: 28679814]
- 19. Aldridge MD, et al. Education, implementation, and policy barriers to greater integration of palliative care: a literature review. Palliat Med 2016;30(3):224–39. [PubMed: 26405109]
- 20. 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(6):866–77. [PubMed: 18715179]
- 21. Miller SC, et al. The growth of hospice care in U.S. nursing homes. J Am Geriatr Soc 2010;58(8):1481–8. [PubMed: 20646101]
- National Hospice and Palliative Care Organization. NHPCO facts and figures, 2018 edition (revision 7-2-2019). Alexandria, VA; 2019 7 2 https://www.nhpco.org/wp-content/uploads/ 2019/07/2018_NHPCO_Facts_Figures.pdf.
- 23. Anstey S, et al. Education and training to enhance end-of-life care for nursing home staff: a systematic literature review. BMJ Support Palliat Care 2016;6(3):353–61.
- 24. Stillman D, et al. Staff perceptions concerning barriers and facilitators to end-of-life care in the nursing home. Geriatr Nurs 2005;26(4):259–64. [PubMed: 16109300]
- 25. Streubert HJ. Action research in practice, education, and administration In: Streubert HJ, Carpenter DR, editors. Qualitative research in nursing: advancing the humanistic imperative. 3rd ed. Philadelphia: Lippincott Williams and Wilkins; 2003 p. 269–98.
- 26. Caprio AJ, et al. Pain, dyspnea, and the quality of dying in long-term care. J Am Geriatr Soc 2008;56(4):683–8. [PubMed: 18266666]
- 27. Hanlon JT, et al. Pain and its treatment in older nursing home hospice/palliative care residents. J Am Med Dir Assoc 2010;11(8):579–83. [PubMed: 20889094]
- 28. Teno JM, et al. Family perspectives on end-of-life care at the last place of care. JAMA 2004;291(1):88–93. [PubMed: 14709580]
- 29. Coyne P, et al. American Society for Pain Management Nursing and Hospice and Palliative Nurses Association position statement: pain management at the end of life. Pain Manag Nurs 2018;19(1):3–7. [PubMed: 29258805]

30. Paque K, et al. Living in a nursing home: a phenomenological study exploring residents' loneliness and other feelings. Scand J Caring Sci 2018;32(4):1477–84. [PubMed: 30070385]

- 31. World Health Organization. Definition of palliative care. n.d. https://www.who.int/cancer/palliative/definition/en.
- 32. Cai C No One Dies Alone program offers patients end-of-life care. UCSF Medical Education 2018 10 8 https://meded.ucsf.edu/news/no-one-dies-alone-program-offers-patients-end-life-care.
- American Geriatrics Society. Ten things clinicians and patients should question. 2015 4 23
 Choosing wisely; https://www.choosingwisely.org/wp-content/uploads/2015/02/AGS-Choosing-Wisely-List.pdf.
- 34. Fischberg D, et al. Five things physicians and patients should question in hospice and palliative medicine. J Pain Symptom Manage 2013;45(3):595–605. [PubMed: 23434175]
- 35. Stephens CE, et al. Emergency department visits and hospitalizations by tube-fed nursing home residents with varying degrees of cognitive impairment: a national study. BMC Geriatr 2014;14:35. [PubMed: 24650076]
- 36. Cagle JG, et al. Caring for dying patients in the nursing home: voices from frontline nursing home staff. J Pain Symptom Manage 2017;53(2):198–207. [PubMed: 27815169]
- 37. Cronfalk BS, et al. Utilization of palliative care principles in nursing home care: educational interventions. Palliat Support Care 2015;13(6):1745–53. [PubMed: 26072965]
- 38. Whittaker E, et al. The palliative care education needs of nursing home staff. Nurse Educ Today 2006;26(6):501–10. [PubMed: 16517029]
- 39. Center to Advance Palliative Care. America's care of serious illness: a state-by-state report card on access to palliative care in our nation's hospitals. New York, NY; 2019 https://reportcard.capc.org/wp-content/uploads/2019/09/CAPC_ReportCard19-Digital_9_19.pdf.
- 40. Shield RR, et al. Physicians "missing in action": family perspectives on physician and staffing problems in end-of-life care in the nursing home. J Am Geriatr Soc 2005;53(10):1651–7. [PubMed: 16181162]

 $\label{eq:Table 1.}$ Demographics and Characteristics of Nursing Home Staff (N = 146)

Characteristic	n (%)
Sex	
Female	115 (79)
Male	24 (16)
Unknown/not reported	7 (5)
Race	
American Indian/Alaskan Native	1 (< 1)
Asian	52 (36)
Black/African American	42 (29)
White	19 (13)
Native Hawaiian	8 (5)
More than one	10 (7)
Unknown/not reported	14 (10)
Age	
18–30 years	29 (20)
31–40 years	41 (28)
41–50 years	36 (25)
Over 50 years	36 (25)
Unknown/not reported	4 (3)
Role	
RN	22 (15)
LVN	23 (16)
Certified nursing assistant	57 (39)
Other a	35 (24)
Unknown	9 (6)

^aOther includes physician (n = 1), physical therapists (n = 3), occupational therapist (n = 1), registered dieticians (n = 2), administrators (n = 9), administrative support (n = 10), social services (n = 5), activities staff (n = 3), and housekeeping (n = 1).

Note: Percentages may not sum to 100% because of rounding.

Author Manuscript

Table 2.

Nursing Home Staff Attitudes Toward End-of-Life Care, Death, and Dying (N = 146)

Survey Item	Agree Strongly n (%)	Agree n (%)	Not Sure/ Mixed n (%)	Disagree n (%)	Disagree Strongly n (%)	Did Not Answer n (%)
1. The end of life is a time of great suffering.	35 (24)	27 (18.5)	27 (18.5)	37 (25.3)	17 (11.6)	3 (2.1)
2. Little can be done to help someone achieve a sense of peace at the end of life.	18 (12.3)	22 (15.1)	11 (7.5)	50 (34.2)	45 (30.8)	0 (0)
3. The use of strong pain medication can cause the patient to stop breathing.	18 (12.3)	31 (21.2)	43 (29.5)	38 (26)	15 (10.3)	1 (0.7)
4. I am not comfortable caring for the dying patient.	3 (2.1)	15 (10.3)	11 (7.5)	66 (45.2)	48 (32.9)	3 (2.1)
5. I am not comfortable talking to families about death.	6 (4.1)	25 (17.1)	27 (18.5)	53 (36.3)	31 (21.2)	4 (2.7)
6. When a patient dies I feel that something went wrong.	4 (2.7)	13 (8.9)	25 (17.1)	64 (43.8)	39 (26.7)	1 (0.7)
7. Feeding tubes should be used to prevent starvation at the end of life.	11 (7.5)	26 (17.8)	40 (27.4)	39 (26.7)	24 (16.4)	6 (4.1)
8. The nursing home is not a good place to die.	6 (4.1)	17 (11.6)	27 (18.5)	55 (37.7)	34 (23.3)	7 (4.8)
9. Patients have the right to refuse a medical treatment, even if that treatment prolongs life.	81 (55.5)	54 (37)	1 (0.7)	4 (2.7)	5 (3.4)	1 (0.7)
10. Dying residents should be referred to hospice.	32 (21.9)	66 (45.2)	30 (20.5)	13 (8.9)	4 (2.7)	1 (0.7)

Note: Percentages may not sum to 100% because of rounding.

Author Manuscript

Table 3.

Responses to Questions Regarding Problem and Improvement Areas in End-of-Life Care (N=146)

11. What do you think are the most important problems in caring for the dying residents in the nursing home? (Can choose more than 1 option)	n (%)
Control of pain	92 (63)
Depression	70 (48)
Loneliness	76 (52)
Legal concerns	24 (16)
Regulatory concerns	12 (8)
Communication with doctor	30 (21)
Communication with other caregivers	33 (23)
Communication with family	66 (45)
Concern for other patients	15 (10)
Inability to meet spiritual needs	25 (17)
Uncertainty about what is best care	28 (19)
All of the above	5 (3)
Unknown	8 (5)
Other	(9) 6
Please describe what are the other important problems in caring for dying residents in the nursing home.	
• Ensuring that the hospice physician is in communication with the primary care physician. [AD]	
• Understanding the process and clear goals of care. [AD]	
• Emotional needs, communication of transition from curative care to palliative care. [AD]	
• Family questions and concerns, staff comfort and comprehension. [AD]	
Privacy concern for patients in all shared rooms. [SW]	
Therapy. [RN]	
• Lack of compassion and inability to confront death in a positive way from staff. Need to practice a ritual of goodbye, remembrance of person, etc. [AS]	rson, etc. [AS]
Necessary care supplies. We're always short on everything. [CNA]	
None. [CNA]	
12. What do you think would help improve end-of-life care in your facility? (Can choose more than I option)	n (%)
Education and training in pain control	73 (50)
Education and training in management of other symptoms	54 (37)
	•

Page 13

Author Manuscript	
Author Manuscript	
Author Manuscript	

Bui et al.

11. What do you think are the most important problems in caring for the dying residents in the nursing home? (Can choose more than I ontion)	(%) u	
Greater access to hospice services	37 (25)	
Greater physician involvement	30 (21)	
Greater involvement of staff	42 (29)	
Greater family involvement	63 (43)	
Education in legal and regulatory concerns	21 (14)	
Education in ethical issues	39 (27)	
Hospice or designated palliative care unit	42 (29)	
Use of a palliative care team	51 (35)	
Greater emphasis on spiritual care	24 (16)	
All of the above	5 (3)	
Unknown	11 (8)	
Other	7 (5)	

Please describe what other improvements you think would help end-of-life care in your facility.

- Staff may be hesitant to provide a "final" dose of medication. [AD]
- Space available for family to spend time with their loved ones, appropriate rooms designated for hospice patients, physician to understand the hospice goals and plan of care. [AD]
- Staff education and exploration—medical, spiritual beliefs—support. If staff are educated and comfortable with the process, this transfers to the patient and family. This includes nonnursing staff. [AD]
- Awareness among all staff of patien's goals. [RN]
- Nutrition. [RD]
- Education in cultural issues. [AS]
- Necessary care supplies. "Greater" care from nurses to ensure residents' comfort toward their end of life. [CNA]

AD = administrator; AS = activities staff; CNA = certified nursing assistant; RD = registered dietician; SW = social worker.

Page 14

Author Manuscript

Table 4.

Themes and Exemplar Responses in Descriptions of Palliative Care (n=66)

Themes	Examplar Responses	n (%) ^a
Pain relief	Care for people with terminal illness, which focuses on providing relief and comfort from symptoms and/or pain. [LVN]	51 (77)
Comfort care	Comfort care for individuals who are reaching the end of their life, to reduce their suffering. [PT assistant]	33 (50)
Serious illness	A medical care for people/residents with serious illness. [CNA]	13 (20)
Team approach	Involves the interdisciplinary team, patient/resident, family, and it's a team approach to how to care for patient/resident [and] keep patient/resident as comfortable as possible. [RD] Is a multidisciplinary approach to specialized medical care for people with serious illness, somewhat like comfort care. [CNA]	9 (14)
Death and dying	End-of-life stage making the resident pain free and comfort[able]. [CNA]	11 (17)
Quality of life	Is approach that improves the quality of life of patients. [CNA]	1 (2)
Other	A choice the person with the diagnosis should make. [LVN] I never heard/Not sure. [CNAs] $\frac{1}{2}$	5 (8)

CNA = certified nursing assistant; PT = physical therapist; RD = registered dietician.

 $^{^{2}\}mathrm{The}$ number of responses indicating this theme. Responses included more than one theme.