End-of-Life Care in Nursing Homes with Greater versus Less Palliative Care Knowledge and Practice

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Abstract

Background: Many older adults in nursing homes (NHs) lack palliative care (PC) access; but little is known about whether access to PC knowledge and practice (beyond hospice) impacts residents' care.

Objective: The study objective was to evaluate how differing levels of NH PC knowledge and practice are associated with residents' end-of-life health care use.

Methods: In 2009/10 we surveyed a stratified random sample of U.S. NHs and asked directors of nursing (DONs) PC knowledge and practice questions from Thompson and colleagues' validated PC Survey. This study includes 1981 NHs with complete survey responses and the 58,876 residents who died in these facilities between July 2009 and June 2010. Medicare resident assessment (minimum data set [MDS]) and claims data from July 2009 through June 2010 were used to determine outcomes and a NH's hospice use. Multivariate logistic regressions examined whether residing in NHs with higher PC scores was associated with documented six-month prognoses and receipt of aggressive treatments, including hospital and emergency room (ER) use in the last 30 days of life.

Results: Controlling for NH hospice use, being in a NH with higher PC care knowledge scores was associated with residents having a higher likelihood of documented six-month prognoses and lower likelihoods of having feeding tubes, injections, restraints, suctioning, and end-of-life hospital and ER use. Being in a NH with higher PC practice scores was associated with a lower likelihood of having feeding tubes and ER visits.

Conclusion: Policies and advocacy promoting the development of NH PC knowledge and practices could potentially improve care and reduce hospital and ER use.

Introduction

DEATHS IN NURSING HOMES (NHs) are common; unfortunately so is unrelieved suffering.^{1,2} To relieve NH residents' suffering and improve their quality of life, widespread palliative care (PC) in NHs has been advocated.³ PC aims to optimize quality of life through an interdisciplinary care team who provides support for patients' and families' psychosocial needs and addresses patients' physical, intellectual, emotional, social, and spiritual needs while facilitating patient autonomy, access to information, and choice.⁴ In NHs, PC in the form of Medicare hospice has been shown to improve residents' symptom management and to lower acute care utilization.⁵⁻⁹ While there has been growth in NH hospice use,^{10,11} there are important barriers (policy and other) to its use and timely access.^{12,13}

The presence of PC teams in hospitals has increased substantially.¹⁴ Studies have shown the receipt of PC in hospitals is associated with lower costs;¹⁵ for outpatients with advanced cancer, PC has been shown to reduce hospital and emergency room (ER) use.^{16,17} To expand NH residents' access to PC, nonhospice approaches to its provision have emerged. These include PC consultations provided to NH residents and NH-staffed PC programs. Although anecdotal findings are promising,¹⁸ there is little empirical study of NH-staffed palliative programs. An exception is a recent study of one NH's PC consult program that found residents with consults (compared to matched nonconsult residents) were more likely to experience reductions in depression and in ER visits.¹⁹ Additionally, a NH quality improvement intervention that introduced PC staff training and leadership teams at seven NHs improved hospice enrollment and

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selected end-of-life care practices.²⁰ Staff education and higher intensity of NH hospice use also has been shown to be associated with better NH end-of-life care processes (i.e., symptom assessment and management);²¹ and Thompson and colleagues²² found higher prevalence of PC practice to be associated with higher-quality symptom management and caregiver satisfaction, less caregiver strain, and a higher likelihood of honored preferences.

This study extends the work of Thompson and colleagues by using items from their validated PC Survey²² to determine the levels of PC knowledge and practice in a nationally representative sample of U.S. NHs; and it evaluates how these levels are associated with residents' end-of-life health care use.

Methods

This research is part of a larger National Institute on Aging funded program project.²³ The program project entailed four studies dependent on NH director of nursing (DON) and NH national survey data.²³ The goal of the research presented here is to evaluate whether higher levels of PC knowledge and practice in NHs (per DON survey report) are independently associated with identification of six-month prognoses and receipt of aggressive treatments, including hospital and ER use in the last 30 days of life (see Table 1).

Setting and sample

Surveys were administered to a stratified, proportionate random sample of DONs at 4149 U.S. NHs and survey weights created to allow for generalization to U.S. NHs.²⁴ A DON contact was identified at 3695 of these facilities. Sur-

veys were completed between August 2009 and April 2011. The DON cooperation rate (i.e., response rate when contact was identified) was 61.6% ($N=2165$). No nonresponse bias was detected.²⁴ For this study 170 facilities (7.8%) were dropped because of (nonimputed) missing data for PC items ($n=1995$). Those NHs removed were similar to those that remained except that they were less likely to have special care units ($p<0.05$). Lastly, 11 facilities had no decedents in the study's time period ($n=1984$).

There were 62,553 residents in the 1984 study facilities with dates of death between July 1, 2009 and June 30, 2010; and the starting sample was the 59,656 residents (95.4%) with a resident assessment (minimum data set [MDS]) documented within four months of death (122 days). Of these, 326 (0.5%) were removed because they were comatose according to their last MDS, and 454 (0.8%) because they were Medicare ineligible. Therefore, the final starting sample was 58,876 NH residents within 1981 facilities. For the outcomes dependent on Medicare claims (i.e., hospital and ER use), 9473 additional decedents (16.1%) were removed, since they were enrolled in a Medicare Advantage plan in the last six months of life and Medicare claims were unavailable. Also, across all models, 1840 (3.1%) residents were removed from analyses due to missing data across one or more person- or NH-level variables. Model N s fluctuate because of outcome inclusions/exclusions and missing data on the outcome of interest (see Table 1).

Survey data

A goal for the parent study was to identify a concise set of DON survey items. Therefore, we began by choosing items

TABLE 1. STUDY OUTCOMES

<i>Study outcomes</i>	<i>Definition and/or inclusions and exclusions</i>
6-month terminal prognosis	Item J.5.c on MDS: Presence of end-stage disease; 6 months or less to live.
Aggressive care received (per last MDS)	<i>The below "care received" outcomes are from the resident's last MDS prior to death.</i>
Tube feeding ^a	Item K.5.b on MDS: Presence in the 7 days before MDS assessment of any type of tube to deliver food, nutritional substances/fluids/medications directly into the gastrointestinal system. Outcome includes only residents with advanced dementia—a cognitive performance score of 5 or 6.
IV treatment ^a	Item K.5.a on MDS: Any parenteral/IV fluids or hyperalimentation given continuously or intermittently in the 7 days before MDS assessment.
Injections ^b	Item O.3 on MDS: Any injection in the 7 days before MDS assessment.
Restraints ^a	Use of bed rails, trunk restraint, or limb restraint in 7 days before MDS assessment.
Suctioning ^c	Item P.1.i on MDS: Suctioning in the 14 days before MDS assessment.
Hospital Use^d	<i>The last MDS was merged to Medicare claims to determine the hospital use outcomes.</i>
Any hospitalization in last 30 days of life ^d	Excludes: Residents with less than a 30 day total nursing home stay.
≥ 2 hospitalizations in last 30 days of life ^d	Excludes: Residents with less than a 30 day total nursing home stay.
Died in acute care hospital ^d	Resident died in an acute care hospital within 7 days of transfer from the nursing home
Any ER visit in last 30 days of life ^d	Excludes: Residents with less than a 30 day total nursing home stay.

MDS, minimum data set.

^aExcluded short-stay residents (<90 day nursing home stay) and those who were in the hospital for any part of the 7-day pre-MDS assessment time period ($n=25,878$).

^bExcluded residents who were in the hospital for any part of the 7-day pre-MDS assessment time period ($n=13,381$).

^cExcluded residents who were in the hospital for any part of the 14-day pre-MDS assessment time period ($n=18,126$).

^dExcluded residents who were enrolled in a Medicare Advantage plan in the last 6 months of life ($n=9473$).

from the PC Survey that have been shown to have good psychometric properties.²² To understand the extent to which NHs have internal PC programs (e.g., pain management, consults) and staff with PC training we developed additional survey items. All items underwent testing using a cognitive-based interview approach. Based on this testing, wording of a PC survey item was sometimes changed, but original items remained essentially intact. However, we found that the additional survey items aimed at understanding the presence of PC programs and training could not be asked, because cognitive-based interviewing revealed DONs were frequently confused about the meaning of “palliative care,” and thus could not provide valid responses.²⁵

Given the above, the survey items used were almost exclusively from the PC Survey.²² To measure PC knowledge we chose three end-of-life items from the PC Survey that we believed reflected relatively elementary knowledge.²² For these items a resident scenario was presented and DONs were asked to choose the correct answer from multiple responses. Responses were coded as dichotomous, with 1s reflecting a correct answer. The total possible score ranged from 0 to 3. Two of the three items asked the DON what he or she would do, and one asked what staff would most likely do (see Appendix 1).

PC practice items²² reflected processes consistent with good PC. There was a total of nine items, eight from the PC Survey (see Appendix). Practice items reflected PC planning (two items), bereavement (two items), provider coordination (four items), and attention to spiritual needs (one—the newly created item). Responses were recorded and scored using a four-point rating scale ranging from 1 (rarely) to 4 (almost always), resulting in a possible total score ranging from 9 to 36.

Adequate reliability and construct validity had previously been demonstrated for the 15 PC practice and 11 end-of-life knowledge items included in the original PC Survey.²² Additionally, we had data to assess criterion validity for two knowledge items. In NHs with correct (versus incorrect) DON responses to the feeding tube and suctioning survey items, resident-level assessment data showed residents were half as likely to have feeding tubes or suctioning (6% versus 12% and 1% versus 2%, respectively).

Data sources and other variables of interest

Data. We used 2009–2010 Medicare NH assessment (MDS 2.0) Part-A claims and enrollment data (which includes vital statistics data and information on Medicare Advantage enrollment). These data were concatenated to create a residential history file (RHF)²⁶ that enabled us to identify NH residents’ who died from July 2009 through June 2010 and to track hospital and ER use in their last 30 days of life. To this resident-level file we merged the NH-level PC survey scores and covariate data from the Online Survey, Certification, and Reporting (OSCAR) database and county-level covariate data from the Area Resource File (ARF).

Outcome variables. The last MDS prior to a resident’s death was used to identify whether the resident had a feeding tube, restraints, intravenous treatment, injections, or suctioning. As shown in Table 1, individual treatments had different MDS look-back periods (7 or 14 days prior to the

assessment date) and differing inclusion and exclusion criteria (resulting in differing *ns* for analytic analyses). As noted above, we used the RHF to determine hospital and ER use in the last 30 days of life. Additionally, we identified whether the MDS 2.0 documented that a resident had an “end-stage disease; six months or less to live.” While many deaths may not be predictable, the greater recognition of six-month terminal prognoses is an important precursor to initiation of end-of-life PC.

Resident-level covariates. In multivariate models we controlled for resident demographic and social characteristics including age, gender, marital status, and race. Age was categorized as <85 and 85; race/ethnicity as non-Hispanic White, non-Hispanic Black, Hispanic, and other; and marital status as married versus other. We also controlled for whether the resident was bedfast prior to death and had congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), or any pathologic bone or hip fracture. Control variables additionally reflected whether a resident had cancer, dementia, both, or neither. To control for functional impairment we used an activities of daily living (ADL) scale, derived from the MDS and ranging from 0 to 28 (higher values indicating greater impairment). The Cognitive Performance Scale (CPS) was used to control for cognitive impairment; this scale ranges from 0 (intact cognition) to 6 (very severe cognitive impairment). Also, using the MDS 2.0 we identified whether residents had a do not resuscitate (DNR) or a do not hospitalize (DNH) order. Finally, we controlled for short (≤ 90 days) versus long (> 90 days) NH stays.

Nursing home and county-level covariates. In multivariate analyses we controlled for numerous NH-level variables taken from the OSCAR, including whether a NH is chain-affiliated, for-profit, and has any Alzheimer’s or other specially designated units or nurse practitioners/physician assistants. Continuous variables included a NH’s number of beds and its number of (RN/LPN) nurse hours per resident day, registered nurse to nurse ratio, occupancy rate, and percentage of Medicaid and Medicare residents. To control for the extent of hospice use, the RHF was used to identify the number of NH home days for all residents in each facility as well as the number of those days that were hospice days. The proportion of days that were hospice was calculated using these two counts. Using the ARF, and for the hospital and ER outcomes, we additionally controlled for county-level variables including the number of hospital beds, the number physicians per 100 individuals aged > 65 , and NH competition within a county (using the Herfindahl index).²⁷

Statistical analyses

Means (with standard deviations) were used to describe how PC knowledge and practice scores differed by NH characteristics, and t-tests and ANOVAs tested the statistical significance of the observed differences. These analyses were weighted to reflect survey design. For the resident-level multivariate analysis, we used logistic regressions with generalized estimating equations to estimate the independent effects of a one-point increase in the PC knowledge or practice scores, using Stata statistical software version 13.0 (StataCorp, College Station, TX). The generalized

estimating equation adjusts for the correlation occurring between residents from the same NH.

Results

Adjusting for survey design, we found the mean PC knowledge score to be 2.2 (standard deviation [SD] 0.85) and the median score to be 2. Twenty-one percent of NHs correctly responded to none or only one of the knowledge items, and 43% to all items. The mean PC practice score was 28.1 (SD 4.25), with scores ranging from 12 to 36. On average, 5.2% (SD 4.96) of NHs' resident days were spent on hospice, with a range of 0% to 38.1%. Table 2 shows mean PC score variation by NH characteristics. NHs with higher hospice use also had higher mean PC knowledge scores; however, PC practice scores were lower for the two higher groups of hospice users (compared to NHs with least use). NHs with significantly higher proportions of Medicaid residents had significantly lower PC knowledge scores (see Table 2).

The prevalence of study outcomes and results from logistic multivariate analyses are shown in Table 3. While all residents included in analyses had died, only approximately 16% had a six-month terminal prognosis documented on the last MDS prior to their death. High proportions of residents had injections (32.2%) and tube feeding (11.7%) near the end of life, 30.9% were hospitalized in the last 30 days of life, and 15% died in a hospital (see Table 3).

Controlling for NH hospice use, residents who died in NHs with a one point higher PC knowledge score had a 13% higher likelihood of having a six-month terminal prognosis documented (adjusted odds ratio [AOR] 1.13; 95% confidence interval [CI] 1.045, 1.216; see Table 3). Residents also had a significantly lower likelihood of having tube feedings, injections ($p=0.057$), restraints, and intravenous treatment. Considering hospital and ER use, residents in NHs with a one point higher knowledge score had a 7% lower likelihood of being hospitalized in the last 30 days of life (AOR 0.93; 95% CI 0.891, 0.961) and a 9% lower likelihood of dying in the hospital (AOR 0.91; 95% CI 0.876, 0.955). They also had a lower likelihood of having two or more hospitalizations ($p=0.098$) and any ER visits ($p=0.10$) in the last 30 days of life. A one point higher PC practice score was associated with a lower likelihood of having tube feedings ($p=0.075$) and a 1% lower likelihood of having an ER visit in the last 30 days of life (AOR 0.99; 95% CI 0.981, 0.997).

Discussion

This study presents the first nationally representative survey data on PC knowledge and practice in NHs. Controlling for NH hospice use, in NHs with higher scores on relatively elementary PC knowledge items, dying residents had a higher likelihood of having a documented six-month terminal prognosis and a lower likelihood of receiving aggressive end-of-life care. A higher PC practice score was associated with a lower likelihood of residents having tube feedings ($p=0.075$) and end-of-life ER visits. While these findings support the notion that higher levels of PC knowledge and practice can reduce futile aggressive care and acute care use, we cannot discount the possibility that it may not be the level of PC knowledge and practice per se that results in these outcomes but that there are greater levels of PC knowledge and practice in NHs that provide higher quality of care in

TABLE 2. PALLIATIVE CARE KNOWLEDGE AND PRACTICE SCORES BY NURSING HOME CHARACTERISTICS (N=1981)

Characteristics	Knowledge	Practice
	Mean (95% CI)	Mean (95% CI)
Percentage of NH days hospice		
≤0.999	2.0 (1.91, 2.09) ^a	28.5 (28.03, 28.87)
>0.999–5.995	2.2 (2.13, 2.24)	28.0 (27.69, 28.24)
>5.995	2.3 (2.23, 2.35)	28.0 (27.66, 28.32)
Average percentage Medicaid		
Q1: ≤50.34	2.3 (2.27, 2.40) ^a	28.3 (27.90, 28.61)
Q2–3: >50.34–74.26	2.2 (2.15, 2.26)	28.1 (27.85, 28.38)
Q4: >74.26	2.0 (1.92, 2.08)	27.8 (27.45, 28.25)
Average percentage Medicare		
Q1: ≤6.45	2.2 (2.10, 2.26)	28.0 (27.63, 28.43)
Q2–3: >6.45–17.53	2.2 (2.12, 2.23)	28.2 (27.97, 28.50)
Q4: >17.53	2.2 (2.12, 2.26)	27.8 (27.44, 28.18)
Any special care units		
No	2.1 (2.10, 2.19) ^a	28.1 (27.87, 28.30)
Yes	2.3 (2.24, 2.39)	28.0 (27.63, 28.45)
For profit		
No	2.3 (2.23, 2.35)	28.2 (27.90, 28.53)
Yes	2.1 (2.09, 2.18)	28.0 (27.78, 28.25)
Part of chain		
No	2.2 (2.14, 2.25)	28.3 (28.07, 28.61)
Yes	2.2 (2.11, 2.22)	27.8 (27.59, 28.11)
Average total beds		
Q1: 62	2.2 (2.15, 2.30)	28.5 (28.11, 28.86)
Q2–3: >62–124	2.2 (2.13, 2.24)	28.0 (27.77, 28.31)
Q4: >124	2.1 (2.07, 2.22)	27.8 (27.41, 28.17)
Average occupancy rate		
Q1: ≤0.784	2.1 (1.98, 2.13)	27.6 (27.17, 27.94)
Q2–3: >0.784–0.9416667	2.2 (2.13, 2.24)	28.2 (27.93, 28.46)
Q4: >0.9416667	2.30 (2.22, 2.37)	28.4 (27.99, 28.75)
Average percentage residents with dementia		
Q1: ≤37.93	2.0 (1.96, 2.12) ^a	27.7 (27.28, 28.05)
Q2–3: >37.93–60.28	2.2 (2.13, 2.24)	28.1 (27.79, 28.33)
Q4: >60.28	2.3 (2.25, 2.39)	28.5 (28.18, 28.90)
Average RUGS score (prevalence)		
Q1: ≤0.7644	2.1 (2.06, 2.22)	28.4 (28.04, 28.82)
Q2–3: >0.7644–0.8671	2.2 (2.16, 2.27)	28.2 (27.90, 28.43)
Q4: >0.8671	2.2 (2.08, 2.23)	27.6 (27.25, 28.00)
Average RUGS (CMI) score upon admission		
Q1: ≤1.010571	2.2 (2.15, 2.30)	28.4 (28.02, 28.80)
Q2–3: >1.010571–1.119	2.2 (2.13, 2.24)	28.0 (27.72, 28.26)
Q4: >1.119	2.1 (2.05, 2.21)	28.0 (27.59, 28.34)
Any nurse practitioners/physician assistants		
No	2.2 (2.11, 2.21)	28.1 (27.83, 28.30)
Yes	2.2 (2.15, 2.28)	28.1 (27.78, 28.42)
RN/LPN hours per patient day		
Q1: ≤0.9456	2.1 (2.06, 2.22)	28.5 (28.09, 28.86)
Q2–3: >0.9456–1.329	2.2 (2.12, 2.23)	27.9 (27.62, 28.15)
Q4: >1.329	2.2 (2.17, 2.31)	28.1 (27.69, 28.44)
RN to nurse ratio		
Q1: ≤0.176	2.1 (1.97, 2.13) ^a	28.3 (27.88, 28.63)
Q2–3: >0.176–0.413	2.2 (2.13, 2.23)	27.7 (27.42, 27.95)
Q4: >0.413	2.3 (2.26, 2.40)	28.7 (28.32, 29.08)

^aThe differences between groups is significant.

CMI, case mix index; LPN, licensed practical nurse; NH, nursing home; Q, quarter; RN, registered nurse; RUGS, resource utilization groups.

TABLE 3. PREVALENCE OF OUTCOMES AND MULTIVARIATE REGRESSION RESULTS^{a,b,c}

Outcome	Total	Prevalence	PC knowledge (per unit increase) ^c	PC practice (per unit increase) ^c
	N	Percent (n)	AOR [95% CI]	AOR [95% CI]
6-month prognosis documented	56,019	15.8% (8858)	1.13 (1.045, 1.216)**	1.00 (0.984, 1.011)
Care received (per last MDS)				
Tube feeding	10,316	11.7% (1202)	0.88 (0.795, 0.968)**	0.98 (0.963, 1.002) ^{MS}
IV treatment	28,571	4.3% (1233)	1.02 (0.917, 1.133)	1.00 (0.975, 1.016)
Injections (last 7 days of life)	40,498	32.2% (13,055)	0.96 (0.928, 1.001) ^{MS}	0.995 (0.988, 1.002)
Restraints	32,193	3.1% (997)	0.87 (0.770, 0.986)*	1.01 (0.984, 1.036)
Suctioning (last 14 days of life)	36,204	1.4% (520)	0.80 (0.686, 0.931)**	0.99 (0.960, 1.024)
Health care utilization				
Any hospitalization in last 30 days of life	40,596	30.9% (12,527)	0.93 (0.891, 0.961)**	1.00 (0.989, 1.002)
≥2 hospitalizations in last 30 days of life	40,596	6.3% (2545)	0.95 (0.898, 1.009) ^{MS}	1.00 (0.988, 1.012)
Any ER visit in last 30 days of life	40,596	16.7% (6778)	0.96 (0.922, 1.007) ^{MS}	0.99 (0.981, 0.997)**
Died in hospital	47,841	15.0% (7192)	0.91 (0.876, 0.955)**	1.00 (0.991, 1.008)

* $p \leq 0.05$ ** $p \leq 0.01$ *** $p \leq 0.001$ ^aAll models include PC knowledge and practice scores and percentage of hospice use simultaneously.^bAll models controlled for age, gender, race, marital status, bedfast, pathological bone or hip fracture, CPS scale, ADL scale 0–28, do not resuscitate, do not hospitalize, fewer than 90 continuous days in NH; and the following residents having any cancer, any dementia, both cancer and dementia, neither cancer or dementia, CHF, and emphysema/COPD. Models also controlled for NH characteristics including for-profit status, chain status, percentage residents with Medicaid as payer, percentage residents with Medicare as payer, nurse hours per patient day, RN to nurse ratio, any special care unit, any nurse practitioner / physician assistant (FTEs), total beds, occupancy rate. In models examining hospital and ER use, we also controlled for county characteristics including number of hospices serving NHs, Herfindahl index for NH beds, number of hospital beds per 1000 pop 65+, and number of doctors per 10,000 pop 65+.^cAOR, adjusted odds ratio; ER, emergency room; MDS, minimum data set; MS, marginally significant ($p \leq 0.10$); ADL, activities of daily living; AOR, adjusted odds ratio; CHF, chronic heart failure; CI, confidence interval; COPD, chronic obstructive pulmonary disease; CPS, cognitive performance scale; ER, emergency room; FTE, full time equivalent; MDS, minimum data set; MS, marginally significant ($p \leq 0.10$); NH, nursing home; PC, palliative care, RN, registered nurse.

general. Future research examining changes in NH PC knowledge and practice and outcomes is needed to disentangle these associations.

Given that the PC knowledge items represent a basic level of knowledge, our finding that 21% of NHs had no or only one survey item correct is of concern. Still, promising is that in 43% of NHs all knowledge questions were answered correctly, and for each additional survey item correctly answered there was a lower likelihood of dying residents receiving aggressive end-of-life care and a higher likelihood of a documented six-month prognosis. These findings are compatible with research by Hanson and colleagues,²⁰ who found the introduction of PC staff training and leadership teams resulted in an increased proportion of residents having pain assessments performed and in-depth end-of-life discussions. While determining a six-month prognosis for most NH residents is difficult, it may be that facilities more attuned to the changing needs of their residents are also more likely to assess terminal prognoses, and to perhaps have meaningful end-of-life discussions that alter subsequent care choices.

Higher PC practice scores were not as consistently associated with residents receiving less aggressive care. However, we did find a one point increase in this score to be significantly associated with residents having lower rates of ER and feeding tube ($p=0.075$) use. This ER finding is consistent with a matched retrospective cohort study conducted at one NH.¹⁹ While other research has shown greater PC practice was asso-

ciated with higher-quality symptom management and caregiver satisfaction, less caregiver strain, and a higher likelihood of honored preferences,²⁸ these outcomes were not studied here.

The need for improving NH staff PC knowledge and practice is generally agreed upon,^{1,12} and the efficacy of such improvement is supported by our study findings. However, the goal of achieving improvement across a wide range of NHs has been elusive. In 2013 interviews of administrators in NHs participating in our 2009/10 survey, hospice was the only resource administrators mentioned as helping their facilities improve their PC practice.²⁹ Also, these administrators noted little advancement in practice since the 2009/10 survey and were still confused about the meaning of PC. Conversely, these same NHs had advanced their implementation of person-centered care (“culture change”) practices and told of numerous motivating factors (including survey oversight) and of the abundance of resources used to assist in these efforts. To advance PC knowledge and practice in NHs, hospice and PC organizations should model efforts undertaken to advance NH culture change.^{30,31} Similar to culture change efforts, widespread mobilization of resources and mentors (beyond hospice) is likely needed to achieve PC improvements in NHs. Also needed is advocacy for Medicare/Medicaid NH home surveys and payment focusing on factors critical to high-quality PC. Additionally, implementation science research is needed to better understand how provision of high-quality PC is achieved in some NHs.

Limitations

We surveyed only the NH DON, and responses might have differed had we asked other NH staff. However, previous research has shown NH MDs, charge nurses, and social workers have identified the DON as the person best positioned to provide an accurate account of a facility's end-of-life care;³² and other research has supported the validity of using one NH manager to report on NH practices.³³ Also, facilities without a special care unit were more likely to have missing survey data items; however, this is unlikely to have affected the quality associations observed in resident-level adjusted analyses. Additionally, the survey was self-reported and thus scores are subject to social desirability bias.³⁴ We addressed this concern by using previously validated items and conducting cognitive-based testing; and we tested the criterion validity for two of the three knowledge items.

Conclusion

While the Institute of Medicine has called for increased access to skilled PC across settings,³⁵ at a basic level there is still confusion by many NH leaders about the meaning of PC.²⁹ It is clear that improvement is needed and this study's findings support the value of such improvement. To advance PC knowledge and practice in NHs will take advocacy for government policies and practices that motivate NH change. Also, widespread availability of PC resources (including mentors) is needed.

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APPENDIX 1. PALLIATIVE CARE PRACTICE AND KNOWLEDGE SURVEY QUESTIONS AND SCORING

Palliative care KNOWLEDGE questions

Scenario: Mrs. Davis has been in your nursing home for 3 MONTHS. On admission, she was not ambulatory and was a total assist with feeding. She was admitted with advanced heart disease, osteoporosis, a right-hip fracture, and Alzheimer's. She takes oxycodone 10mg EVERY 6 HOURS for pain. In the LAST MONTH, you notice that she is eating less, she has lost 10 pounds, and coughs when drinking. She no longer recognizes her family.

Please indicate if you agree or disagree with the following statement.	Agree	Disagree
"If Mrs. Davis continues to lose weight, even with nutrition supplements, she will need a feeding tube."	[0]	[1]
In the PAST FEW DAYS, Mrs. Davis has become unresponsive. Which statement BEST represents your evaluation of her need for pain medication? Please mark ONE answer.	Agree	
If she is not moaning or grimacing, she probably is not experiencing pain.	[0]	
I would stop her pain medication(s) to see if her mental status improves.	[0]	
Now that she is unresponsive, we can stop her pain medication.	[0]	
Because she was in pain when she was conscious, I would assume that she is still in pain.	[1]	
Mrs. Davis is nearing death and her respirations are shallow and rattling. Her daughter says, "I don't want her to suffocate." After acknowledging her daughter's concerns, which one of the following actions would your staff MOST likely take? Please mark ONE answer.	Agree	
Suction secretions from her mouth and throat.	[0]	
Percuss her back to loosen congestion.	[0]	
Use humidified oxygen to decrease her air hunger.	[1]	
Use medications to dry up the secretions from her mouth and throat.	[1]	

(Appendix follows →)

Palliative care PRACTICE questions

Planning questions

Thinking about a resident like Mrs. Davis at your nursing home, how often would you talk to her daughter about death and dying in the following situations? Please mark ONE answer for each question.

On admission	☐	☐	☐	☐
At the next care plan meeting	☐	☐	☐	☐

Bereavement and spiritual questions

The next questions are about how often the nursing home might engage in certain activities when a resident is dying. Please mark ONE answer for each question.

How often does your nursing home ...				
Discuss residents' spiritual needs at care planning conferences when residents have acute or chronic terminal illnesses?	☐	☐	☐	☐
Send a sympathy card to family members or significant others after a resident has died?	☐	☐	☐	☐
Follow up with roommate(s) or friend(s) in the nursing home to provide emotional support after a resident has died?	☐	☐	☐	☐

Care coordination questions

The next questions are also about residents at the end of life. Please mark ONE answer for each question.

When residents are at the end of life, how often ...				
Do physicians talk openly about end of life with family members?	☐	☐	☐	☐
Are physicians open to staff suggestions about care?	☐	☐	☐	☐
Do physicians make a referral for hospice?	☐	☐	☐	☐
Are residents' primary care physicians easy to contact?	☐	☐	☐	☐
Do physicians write orders for the appropriate amount of pain medication?	☐	☐	☐	☐