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Original Study

Developing Palliative Care Practice Guidelines and Standards for Nursing Home–Based Palliative Care Teams: A Delphi Study

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ABSTRACT

Context: Lack of nursing home (NH)-specific palliative care practice guidelines has been identified as a barrier to improving palliative and end-of-life (EOL) quality of care.

Objectives: The objectives of this study were to (1) assess which of the guidelines developed by the National Consensus Project, and the corresponding preferred care practices endorsed by the National Quality Forum, are important and feasible to implement in NHs; and (2) identify the operational standards for palliative care teams in NHs.

Methods: Two-round mail Delphi study. Based on the existing literature, a set of 7 domains with associated 22 palliative practice guidelines was drafted. We invited 48 NH leaders, including clinicians, to review the importance (10-point Likert scale) and the feasibility (5-point Likert scale) of these guidelines. Participants were also asked about palliative care team composition rounding frequency.

Results: The response rate to both rounds was 85%. With regard to importance, the mean rating for all guidelines was 8 or higher (ie, highly important), but there was variability in agreement with regard to 5 of the guidelines. The same 5 guidelines were also considered more difficult to implement (eg, costly, unrealistic). Overall, 17 palliative care guidelines were identified for use by NH palliative care teams. Five disciplines (social work, certified nurse assistant, nurse, physician, and nurse practitioner or physician assistant) were identified as comprising a core team and 3 were proposed as extended or ad hoc members.

Conclusion: The palliative care guidelines and team standards identified in this study may be helpful in providing practical direction to NH administrators and staff looking to improve palliative care practice for their residents.

By 2020, as the US population ages, 40% of all deaths are expected to occur in nursing homes (NHs).[1,2] Yet, there is also evidence that NHs are ill-prepared to provide high-quality care to their residents at the end of life (EOL), and a number of barriers to improving palliative and EOL quality of care in this setting have been identified.[3–6]

One such barrier is the lack of NH-specific palliative care practice guidelines.[7] Palliative care guidelines, developed by the National Consensus Project (NCP), and the preferred practices (PPs) subsequently identified and endorsed by the National Quality Forum (NQF), are now in their third edition. The development of these guidelines and PPs has been influenced mainly by leaders in outpatient and acute care settings. The NCP's 8 clinical domains (and their 27 corresponding guidelines)[8] and all 38 PPs identified by the NQF were purposefully selected and designed to be broadly applicable across settings, specifically "within and between hospitals, community

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centers, hospices, and home health agencies."[9] Nowhere, however, do they refer to "nursing homes" or "long-term care." In the absence of specific guidelines, NH staff has been left to devise their own practice standards for the provision of palliative and EOL care for their residents (perhaps in addition to contracting with hospice), and, not surprisingly, research reports significant variations across facilities. A study of nursing homes in New York State has demonstrated that almost half of all NHs do not regularly assess EOL residents for emotional needs, pain, and other symptoms, and only two-thirds of facilities reported having clinical policies for managing distressing EOL symptoms.[7]

Another obstacle to the provision of palliative and EOL care in NHs is the failure to integrate evidence-based palliative care practices into everyday care.[10,11] For example, although hospice use in NHs has been associated with better pain management and lower likelihood of terminal hospitalizations, integration of hospice into NHs has been difficult because of conflicting financial incentives and barriers to referral, often exacerbated by poor recognition of terminal illness by the nursing staff.[12,13] Furthermore, hospice benefit requires an assumption of life expectancy shorter than 6 months and an agreement to forgo curative treatment for the terminal condition. Thus, perhaps it is not surprising that hospice still plays a limited role in NHs.[14] Although there has been a rapid growth of palliative care teams (PCTeams) in hospitals, designed to improve quality of care and facilitate informed and patient-centered decision making in seriously ill patients, this trend has not been matched by similar developments in NHs.[15,16]

In 2013, with funding support from the Patient-Centered Outcomes Research Institute (PCORI), we began a randomized controlled trial designed to develop NH PCTeams and to evaluate their impact on care processes and on residents' outcomes. This ongoing study started with 31 NHs in upstate New York (15 controls and 16 interventions). There has been scant previous experience to guide us with regard to the structure or the operational standards of such teams. And although palliative care guidelines for other settings have been identified and promoted by such organizations as NQF, the American Academy of Hospice and Palliative Medicine, and many others, it has been unclear whether these guidelines are desirable and/or feasible in an NH environment and operational constraints.

In the context of this larger intervention project, the objectives of the study we are reporting here were twofold: (1) to assess which of the NCP's guidelines, and the corresponding NQF's PPs, for palliative care might be both important and feasible to implement in NHs; and (2) to identify the structural and operational standards that PCTeams in NHs should adopt.

Methods

We used a modified Delphi method to address the 2 study objectives. The goal was to elicit experts' views and to arrive at a consensus of opinions on issues that are uncertain. The Delphi technique has been found to be an effective, iterative research method for involving experts in arriving at a consensus on guidelines, PPs, or other clinical issues. The Delphi process is characterized by anonymity to protect the results from being influenced by group conformity. However, controlled feedback is built into the process, for example by communicating to the participants results of previous rounds.

The study protocol was reviewed and approved by the institutional review board.

Pre-Delphi: Drafting Guidelines for Evaluation by Our Core Group

The first round was qualitative and unstructured and involved a core group of 8 reviewers (the authors), 4 of whom are clinicians (medicine and nursing) with expertise in palliative care, geriatrics, hospice, and NH care. The objective of the overall intervention was to influence several specific care process (eg, communication among providers and between providers and residents/family members; shared decision making), and resident outcomes (eg, symptom management, in-hospital deaths). We therefore identified the specific NCP domains and guidelines that most closely correspond to these expected intervention outcomes. This process identified 7 of the 8 NCP palliative care domains. Of the 38 NQF PPs mapping onto these 7 domains, 28 were recommended by the core group. Of these, 22 were stated as clinical guidelines and the remaining 6 were presented as operational parameters for PCTeams. The external validity of each of these 28 practices was further confirmed by reviewing such relevant and widely used resources in geriatric palliative care as the AMDA Palliative Care Toolkit for Long-Term Care Setting,[17] AMDA Clinical Practice Guideline: Pain Management in the Long-Term Care Setting,[18] Medical Orders for Life-Sustaining Treatment (MOLST) and Advance Care Planning Resources Web site,[19] and the End-of-Life Nursing Education Consortium (ELNEC) curriculum.[20]

Table 1
Characteristics of Delphi Panelists (n = 38) and their Facilities (n = 16)

Characteristic	Frequency Distribution	Percent	Mean
Delphi panelists (n = 38)			
Profession/position			
Director of nursing	11	28.9	
Nurse manager	9	23.7	
Social work	13	34.2	
Physician or nurse practitioner	3	7.9	
Administrator	2	5.3	
Highest degree in chosen field			
Graduate degree	13	34.2	
Bachelor's degree	16	42.1	
Less than Bachelor's degree	9	23.7	
Years working in this nursing home			9.4
Years working in long-term care			17.7
Previous training in hospice or palliative care			
None	28	73.7	
Some	10	26.3	
Facilities (n = 16)			
Bed size			178.9
Urban location		56.3	
For profit		50.0	

Delphi Rounds 1 and 2: Evaluation by an Expert Panel of NH Providers

A panel of 48 leaders in the 16 intervention facilities was invited to evaluate the recommended guidelines via a mail-administered Delphi questionnaire. At least 2 staff members from each facility were to be clinical providers, including physician, director of nursing, nurse practitioner or physician's assistant, nurse leader, or social worker. Clinicians and administrators actively involved in the creation of PCTeams and/or who have had expertise in providing palliative and EOL care also were invited to participate. For both rounds 1 and 2, we provided 3 copies of the questionnaire to on-site coordinators in each participating NH and asked them to distribute to appropriate staff. All were assured of strict confidentiality, as any comments would only be shared anonymously with other Delphi participants, across sites, to assist in consensus building. Self-addressed and stamped return envelopes were provided with each questionnaire. Those who completed both rounds were sent a check for $200 in compensation-incentive for their participation.

Table 2
Experts' Ratings of Palliative Care Guidelines for Nursing Homes: Importance and Feasibility

NCP Domain (NQF PP)	Guideline Statement	Round 1 (Scale 1–10) Importance			Round 2 (Scale 1–5) Feasibility			Comments on Feasibility (Round 2) for Rejected Guidelines Only
		Mean	SD	Range	Mean	SD	Range	
Domain 1: Structure and Processes of Care (1)	Palliative and hospice care should be provided by a team approach that includes professionals and other stakeholders.	9.63	0.85	3	4.47	0.73	3	
Domain 1: Structure and Processes of Care (3)	The facility will provide continuing education to all staff on the *Domain*s of palliative and hospice care.	9.55	0.92	4	4.14	0.98	3	
Domain 1: Structure and Processes of Care (4)	The facility will provide adequate training and clinical support to ensure that PCTeam members are confident in their ability to provide palliative care to residents.	9.63	0.75	3	4.27	0.80	2	
Domain 1: Structure and Processes of Care (6)	The PCTeam will develop a care plan, supervise care, and regularly review the plan for residents referred to palliative care, based on interdisciplinary assessment.	9.34	1.19	4	4.26	0.83	3	
Domain 1: Structure and Processes of Care (7)	Upon a resident's transfer between health care settings, the PCTeam ensures there is timely, thorough communication of goals, preferences, values, and clinical information between settings.	9.26	1.41	5	3.81	1.08	4	current communication with hospitals is very poor need specific and constant contact person to relay information across settings frustrating; information does not always reach where it is intended to go
Domain 1: Structure and Processes of Care (10)	The PCTeam will enable referred residents/families to make informed decisions about their care by educating them on disease processes, prognoses, and benefits/burdens of interventions.	9.66	0.85	4	4.39	0.75	3	
Domain 2: Physical Aspects of Care (12–13)	The PCTeam will assess, document, and manage physical symptoms (eg, pain, dyspnea, constipation) and side effects in a timely, safe, and effective manner to a level acceptable to the resident and family.	9.74	0.69	3	4.53	0.69	2	
Domain 3: Psychological and Psychiatric Aspects of Care (14–15)	The PCTeam will assess, document and manage anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a timely, safe, and effective manner to a level acceptable to the resident and family.	9.76	0.59	2	4.32	0.71	2	
Domain 3: Psychological and Psychiatric Aspects of Care (16)	The PCTeam will recognize and support psychological reactions of residents and families to address emotional suffering (including stress and anticipatory grief) in an ongoing fashion.	9.55	0.98	4	4.16	0.75	3	
Domain 4: Social Aspects of Care (18)	The PCTeam will conduct regular resident and family meetings for referred residents, to provide information, discuss goals of care, disease prognosis, advanced care planning, and offer support.	9.32	1.14	4	4.05	0.96	4	
Domain 4: Social Aspects of Care (19)	The PCTeam will implement a comprehensive social plan of care, including the social, practical, and legal needs of referred resident/family members.	8.73	1.64	6	4.0	0.99	3	
Domain 6: Cultural Aspects of Care (24)	The PCTeam will incorporate cultural assessment as a component of comprehensive decision making.	9.0	1.52	6	3.71	1.01	4	our population has limited cultural diversity I do not see this happening we do not do this now, but would be interested
Domain 6: Cultural Aspects of Care (25)	The PCTeam will ensure professional interpreter services in the resident/family's preferred language are available for scheduled meetings, in cases of preferred language other than English.	8.82	2.26	8	3.59	1.19	4	our experience has not showed this to be an issue cost of interpreter, resources would need to be available
Domain 7: Care of the Patient at the End of Life (28)	For referred residents, the PCTeam will ascertain and document resident and family wishes about the preferred care setting for site of death.	8.84	1.50	5	4.08	1.08	4	

Domain 7: Care of the Patient at the End of Life (30)	The PCTeam will provide leadership in treating the body of a deceased resident with respect and with sensitivity to the emotional needs of the other residents, family members, and facility staff.	9.34	1.17	5	4.66	0.71	3	
Domain 7: Care of the Patient at the End of Life (31)	The PCTeam will develop and implement a bereavement care plan or support after the resident's death.	8.78	1.71	6	3.53	1.20	4	important, but unrealistic in NH setting would need to create a new position
Domain 7: Care of the Patient at the End of Life (26)	The PCTeam will recognize and document the transition to the active dying phase and communicate the expectation of imminent death.	9.39	1.31	5	4.19	0.78	3	
Domain 7: Care of the Patient at the End of Life (29)	The PCTeam will provide adequate dosage of analgesics and sedatives as appropriate and acceptable to the resident and family to achieve comfort during the active dying phase.	9.63	0.85	3	4.47	0.65	2	
Domain 8: Ethical and Legal Aspects of Care (32)	The PCTeam will ensure there is a designated surrogate decision maker for every resident who is referred for palliative care.	9.24	1.62	7	4.51	0.77	2	
Domain 8: Ethical and Legal Aspects of Care (33)	The PCTeam will ensure each referred resident's (or their surrogate's) preferences for (the residents) goals of care are documented.	9.50	1.06	5	4.43	0.80	3	
Domain 8: Ethical and Legal Aspects of Care (34–35)	The PCTeam will ensure each referred resident's treatment goals have been converted into medical orders using the MOLST.	9.46	1.04	4	4.50	0.81	3	
Domain 8: Ethical and Legal Aspects of Care (37)	The NH will establish or have access to ethics committees or ethics consultation to address ethical conflicts.	8.87	1.89	6	3.89	1.23	4	struggle to find people to commit to this committee not sure this is a realistic goal we have no ethics committee

MOLST, Medical Orders for Life-Sustaining Treatment; NCP, National Consensus Project; NH, nursing home; NQF PP, National Quality Forum preferred practice; PCTeam, palliative care team.
Shaded guidelines = rejected based on combined importance and feasibility.

Analytical Approach

A priori, we did not set any specific criteria for assessing respondents' agreement. In round 1, we asked them to rate each item in terms of its importance in guiding PCTeam NH practice. All items were rated on a 10-point Likert scale, ranging from "not at all important" or "completely disagree" to "very important" or "completely agree." Because of the very high level of agreement among the respondents that all guidelines were "important" to "very important," in round 2 we focused on the feasibility of implementing each guideline. Respondents were asked to consider the ease and the likelihood of implementing each practice into the care processes in their own NHs. They were asked to estimate, on a 5-point Likert scale, ranging from "not at all likely to happen" to "very likely to happen" how realistic the implementation would be given their specific institutional operations and protocols. In this round, they were also asked specific questions relating to the operation and structure of PCTeams. For each survey item, optional free-text comment fields were available to provide additional input.

Results

Forty-three (90%) of the 48 NH leaders returned questionnaires for round 1, and 38 (80%) completed both rounds 1 and 2 of the Delphi exercise. Respondents to both rounds included the following: 11 (28.9%) directors of nursing, 9 (23.7%) nurse managers, 3 (7.9%) physicians or nurse practitioners, 13 (34.2%) social workers, and 2 (5.3%) administrators. Most of the respondents had a bachelor's or higher degree (76.3%), had worked in long-term care for more than 17 years, and worked almost a decade at the current facility. Most (73.7%) had no previous training in hospice or palliative care (Table 1).

The draft set of guidelines comprised 22 NQF statements in 7 NCP domains (Table 2). For each guideline, we reviewed the respondents' assessment with respect to both its "importance" and "feasibility." On the importance scale, the mean ratings for all guidelines were 8 or higher (ie, considered highly important). Most disagreement, measured by at least 10% of respondents rating a guideline as "not" to "not at all" important, affected only 2 guidelines: NQF PP number 25, stating that "*the PCTeam will ensure professional interpreter services in the resident/family's preferred language…*" and PP31 calling for "*the PCTeam to develop and implement bereavement care plan or support after the resident's death.*" With respect to PP25, some of the dissenting comments suggested this may be a localized issue reflecting a relative homogeneity of the resident population ("*this is not a problem at our facility*; *if it is, the family helps us*"). But some respondents, in evaluating both PP25 and PP31, were also concerned about the additional costs associated with the implementation of these guidelines. They commented these may be "*unrealistic in a nursing home setting*" and questioned the costs associated with hiring of interpreters (PP25) or additional staff to implement a bereavement program (PP31).

There was also considerable agreement among the respondents with regard to the guidelines' feasibility. The mean rating for all guidelines was higher than 3.5 (ie, feasible or very feasible). However, more than 10% of respondents considered 5 guidelines to be difficult to implement. These same 5 guidelines also received less than enthusiastic appraisals in the free-text comments in round 1 with regard to their "importance." In total, 5 guidelines (7, 24, 25, 31, and 37) were rejected on the basis of greater difficulty of implementation and higher variation in their perceived importance (Table 2). Overall, 17 palliative care guidelines were identified for use by PCTeams in NHs. All intervention facilities received this final set of guidelines, were asked to implement them into their team operations, and were invited to comment.

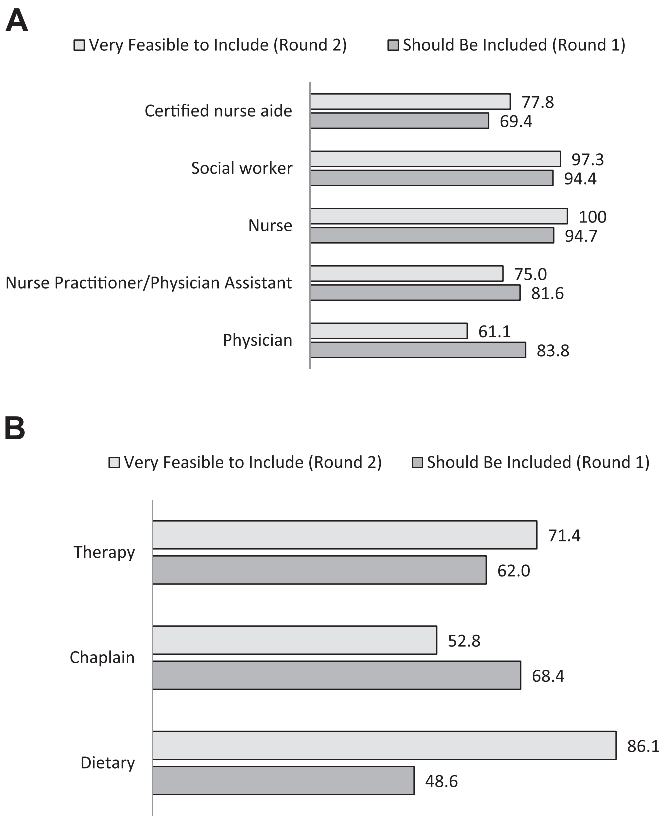

Fig. 1. (A) Composition of core PCTeam: Importance and feasibility. (B) Composition of extended PCTeam: Importance and feasibility.

In round 1, in addition to identifying the guidelines, a comprehensive list of possible disciplines to be represented on a PCTeam (including residents and family members) was presented. Respondents were asked to consider who should be included as core or extended team members, or not included at all. Based on the responses, 5 disciplines were clearly identified as belonging in the core team, and 3 as extended team members. In round 2, respondents were asked to assess the feasibility of including each discipline on their PCTeam. The extent of concordance between importance and feasibility for each discipline is presented in Figure 1A (core team) and Figure 1B (extended team). For example, although 83% of respondents thought physicians should be core team members, only 61% thought this was feasible in their facility (nurses and physicians tended to be more optimistic than social workers in this regard). A similar pattern was noted for nurse practitioners/physician assistants. The inclusion of social workers, certified nursing assistants, and nurses on the core team appeared to be much more feasible (with very little variation by respondents' profession). For extended team members, inclusion of chaplains, although considered generally important (68.4%), was perceived to be considerably less feasible (52.8%), as most NHs do not have chaplains on staff.

The Delphi participants also were queried about various aspects of the palliative care team's structure and function. They were asked to comment on team referrals, frequency of team rounding with the residents, team communication with staff and residents/family, palliative care education, and on bereavement and grief support. In round 1, the respondents rated all aspects of team structure and operations as uniformly highly important (mean scores ≥ 9 and median $= 10$ on all items), so we report here only their assessments of the feasibility of implementing the proposed guidelines (Table 3). Most respondents agreed it would be very feasible to have all

Table 3
Assessment of PCTeam's Structure and Function

PCTeam Structure and Function	Very Feasible (4–5), %	Feasible (3), %	Difficult (1–2), %
Referral			
All residents will be screened on admission to NH for appropriateness of referral to PCTeam	78.4	16.2	5.4
All residents will be reassessed for referral when condition changes, or at least quarterly	83.3	11.1	5.6
Frequency of PCTeam rounding			
The PCTeam will round on all palliative care residents at a minimum of once per week	64.9	18.9	16.2
Team communication			
PCTeam will communicate expected prognosis to the staff	86.5	10.8	2.7
PCTeam will communicate expected prognosis to residents and family members	97.3	2.7	0.0
PCTeam will address family members concerns/fears about additions to opioids or hastening death	94.6	5.4	0.0
PCTeam will address staff members concerns/fears about additions to opioids or hastening death	94.6	2.7	2.7
Education			
Staff should have exposure to palliative care through			
orientation training	86.8	7.9	5.3
mentoring/shadowing	76.3	7.9	15.8
in-service training	83.8	10.8	5.4
Bereavement/grief support			
How feasible in your facility is to provide bereavement or grief support for:			
deceased resident's family	36.8	31.6	31.6
other residents	52.6	26.3	21.1
NH staff	50.0	26.3	23.7

NH, nursing home; PCTeam, palliative care team.

residents screened at admission (78.4%) to determine their palliative care needs, and to reassess them when their condition changes or at least quarterly (83.3%). There also was a substantial agreement on the feasibility of team communication about disease prognosis with staff (86.5%) and family members (97.3%), and concerns about the use of opioids (94.6%). The respondents were, however, less unified on the feasibility of weekly team rounding, with 16.2% reporting this frequency as difficult (rating 1–2, on a scale of 1–5). Similarly, 15.8% assessed staff exposure to palliative care via mentoring/shadowing to be difficult. The lowest assessment of feasibility was with regard to providing facility-level bereavement or grief support for family of deceased residents (31.6% rated as difficult), for other residents (21.1%), and for NH staff (23.7%).

Discussion

Practice guidelines are most effective and sustainable when they are developed or adapted by those who are going to use them. Using a modified Delphi method, and using a multiprofessional panel of leaders, we identified a set of palliative and EOL guidelines and clinical practice standards for use by PCTeams operating in NHs.

We identified 17 practice guidelines distributed over 7 domains of care: structure and process, physical, psychosocial and psychiatric, social, cultural, EOL, and ethical and legal. In addition, several standards for NH PCTeam structure and operations were also defined, and these included team referrals and screening, frequency of rounding, communication with residents and other staff members, staff education, and bereavement and grief support. In round 1 of the Delphi process, we found a high level of agreement among the respondents that all 22 of the originally presented practice guidelines were important. In round 2, when respondents were asked to assess the feasibility of implementing each practice guideline in their own facility, 5 guidelines were identified as potentially difficult to implement. The rejected guidelines were deemed less feasible either because their implementation was not entirely within the control of the NH or because it would require additional resources that were not available. For example, respondents felt that PP7 (requiring transfer of information on resident's treatment goals, preferences, and values between care settings) would be difficult because "*our current communication with hospitals is very poor*" and "*information does not always reach where it is intended to go*." Yet, these are precisely the reasons why focusing on this practice guideline may lead to better care. The other 4 guidelines focused on cultural assessment/competency (PP24–25), on bereavement support (PP31), and on issues of ethics (PP37). Although important, they were considered least feasible because "*resources would need to be available*" and it was "*unrealistic to create new positions*" or "*to find people to commit to*" new goals. Thus, although at this time we choose not to include them in the list of guidelines adopted for our overall intervention, we note that all panelists considered them to be important. Therefore, future efforts at improvement should address the barriers preventing implementation of these 5 guidelines.

Several operational elements of PCTeams also were found to be potentially problematic. Those of particular concern involve possible absence of physicians/nurse practitioners and the frequency of team rounding. Although most respondents considered the presence of a physician and/or a nonphysician provider on PCTeams essential, substantially fewer respondents were confident their inclusion as core team members was feasible. Similarly, a significant number of respondents felt that weekly team rounding was not very feasible. On closer inspection it became apparent that these responses, which came from 2 NHs, may have been driven by the special challenges faced by these particular facilities rather than by the general difficulty of implementing the recommended frequency of rounding. Difficulties reported with regard to other elements of team operations were scattered across facilities and may reflect concerns about the need for additional resources. For example, a difficulty in providing exposure to palliative care through mentoring/shadowing may reflect the lack of palliative care knowledge among NH staff. The Delphi respondents themselves, identified as NH leaders, reported having had little if any exposure to palliative care. Not surprisingly, then, committing additional resources to provide bereavement and grief support services, which currently do not exist, is largely not feasible for most NHs.

Identifying appropriate and feasible palliative care guidelines is only the first step in building NHs' capacity to provide quality care to their residents at the EOL. Two of the guidelines point to the need for training, clinical support, and continuing staff education. This is indeed a critical need for most, if not all, NHs and their staff. A number of tools for improving competency in palliative and EOL care are currently available. For example, access to online modules (with tests and certificates) developed by ELNEC can be made available to NH staff and be required as part of in-service training. However, it is not clear whether in absence of regulatory requirements for staff training, and without additional resources, most NHs are able and/or willing to undertake, and more importantly to sustain such initiatives on their own.

Several limitations should be noted. First, as reported, most respondents had no previous training in hospice or palliative care. Although lack of familiarity with palliative care may be a limitation for those working in this care setting, it is not a reflection of a poor selection of panelists, but rather reflects on the reality of workforce knowledge and skills available in NHs. Similarly, very few of the panelists were physicians or nurse practitioners, again reflecting the availability of these clinicians in an NH practice. Furthermore, the study was conducted in a geographically limited area, thus our findings and their applicability may not be generalizable to all regions and NHs.

In conclusion, through the Delphi process we identified 17 palliative care practice guidelines and 9 standards for palliative care team structure and function, which key stakeholders considered to be both important and feasible for implementation in NHs. These guidelines and team standards may be helpful in providing practical direction for NH professionals seeking to implement quality assurance and to improve palliative care practice for their residents. Evaluating the implementation of these guidelines and standards in the PCORI-funded intervention will be our next objective.

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