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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.