

Hospice and Palliative Nurses Association

2015-2018 Research Agenda



Hospice and palliative nursing occurs in most practice settings, at all stages of serious illness, for persons of all ages. The Hospice and Palliative Nurses Association (HPNA) is the professional organization for all nurses interested or engaged in hospice or palliative care. In 2009, HPNA developed a program of tri-annual research agendas to: 1) provide focus for graduate students and researchers, 2) guide organizational research funding, and 3) illustrate to other stakeholders the importance of specific research foci. An agenda, at its simplest, is a list of things that will be considered or done; but at its best, an agenda is a means to change the future.¹ This agenda seeks to provide research direction for palliative nursing research over the next three years by highlighting gaps in knowledge identified by our members as barriers to delivering quality palliative nursing care and outlining new processes to assist palliative nurses improve patient and family experiences through the generation of new knowledge or the translation of research into clinical practice. The agenda also begins to outline a procedure for HPNA development and endorsement of clinical practice guidelines. The resulting document has been developed for all HPNA members regardless of role; clinical, academic, or research.

The Clinical Practice Guidelines for Quality Palliative Care, released by the National Consensus Project for Quality Care (NCP)², provide the conceptual framework for this agenda and describe essential elements of high-quality palliative care services within eight specific domains. These domains are: structures and processes of care, physical aspects of care, psychological and psychiatric aspects of care, social aspects of care, spiritual, religious, and existential aspects of care, cultural aspects of care, care of the patient at end of life, and ethical and legal aspects of care. To prepare this agenda, the HPNA Research Advisory Council surveyed HPNA members to determine which of the eight NCP domains presented the most pressing gaps in knowledge and deserved priority consideration. While all research in palliative

care is important to patients and families, data from HPNA members identified specific areas needed to move the science of palliative nursing forward and on which to focus the organization's research efforts. Based upon the 2014 member survey, the priority domains for this HPNA Research agenda repeat two of the domains highlighted by the 2012-2015 HPNA Research agenda: 1) structure and processes of care and 2) physical aspects of care. The third component of this agenda, also member driven, will focus on the process of research translation in palliative nursing.

Structure and processes of palliative nursing care affect patient and family outcomes, although many links remain understudied. The Affordable Care Act and other policy changes have created an environment of rapidly evolving models of health care. As palliative nursing responds to these rapid changes, research must be directed to discerning the fixed components of the care environment from the aspects that can be modified to achieve better patient and family outcomes. In particular, the issue of new and innovative delivery systems and the infrastructure needed to maintain them needs further exploration. This area of study supports multiple methods of inquiry and can generate policy implications to move the field forward.

Building on the work of the previous two HPNA Research agendas (2009-2012; 2012-2015), the emphasis within the domain of physical aspects of care in this agenda (2015-2018) remains on the three understudied symptoms of dyspnea, fatigue, and constipation. However, in this cycle, the agenda addresses issues of family management of symptoms among persons experiencing serious illness as well as the need for patient and family-centered interventions. Common to all three symptoms is the need for: assessment tools adequate for the population; evidence based interventions for effective symptom management; examination of roles of family caregivers in symptom management; and population-specific understanding of mechanisms of

symptoms (for example, in older adults, cancer patients, children, neonates).

Finally, this research agenda highlights the importance of research translation. It outlines plans for a process by which HPNA will work with its members to ensure the systematic evaluation of evidence supporting existing practice guidelines and to identify areas where substantial evidence is currently available but evidence-based protocols have not yet been developed or implemented. The long term goal will be a mechanism for expert evaluation and HPNA endorsement of palliative nursing guidelines and protocols.

STRUCTURE AND PROCESSES OF CARE

Within the NCP Guidelines, the Structure and Processes of Care domain addresses the core components of palliative care practice: interdisciplinary composition, engagement and collaboration, volunteer involvement, education and training of team members, the quality improvement process, staff support, and appropriateness of the care setting.² The breadth of topics included within this domain go beyond the traditional interpretation of the term “structure and process of care” and include all aspects of health services research. In 2000, the Academy for Health Services Research and Health Policy defined health services research as the multidisciplinary field of scientific investigation that studies how social factors, financing systems, structures and processes, health technologies, and personal behaviors affect access to healthcare, the quality and cost of healthcare, and ultimately our health and well-being. Units of analyses include individuals, families, organizations, institutions, communities, and populations. Multiple theoretical and conceptual frameworks (e.g. contingency, learning, network, institutional, economic and population ecology theories) are appropriate, along with the structure-process-outcome framework. While recognizing the complexity of palliative nursing care, we offer a set of priorities within this domain that highlight the need for research related to health care technology, delivery systems, team work and nurse work environment.

Priority: Research is needed to understand effective data systems and technology infrastructure in hospice and palliative care organizations.

The proliferation of electronic health records (EHR) has presented enormous opportunities to examine the influence of both the structures and processes of palliative care with established metrics such as those identified by the National Quality Forum², the ASSIST and ACOVE projects^{3,4}, and the Measuring What Matters Project.⁵ Nurses, with their knowledge of

care processes, are well situated to lead research teams using EHR data or to serve as consultants or team members on these research teams. Moreover, nurses are acutely aware of issues faced by patients and families dealing with serious illness and thus are in a pivotal position to examine the use of EHRs to improve late life experiences. In addition, nurses are the largest consumers of EHRs information (for entering, accessing, planning and evaluating patient level data) and thus are uniquely positioned to guide the development of informatics tools to improve patient and family outcomes. Potential research topics include: how EHRs influence the provision of palliative nursing; and how we leverage the information being collected to improve patient and family outcomes.

Priority: Research is needed on the types of new and innovative delivery systems in hospice and palliative care.

While specific models of care such as the patient centered medical home or accountable care organizations were developed to improve particular outcomes, little is known about how these models influence palliative care metrics, or how palliative care is best integrated throughout diverse models of care, or across various settings (e.g., acute and non-acute, rural and urban). Through interagency collaboration, individuals from different organizations frequently provide care through joint efforts, resources, and decision making that results in shared ownership of the final service provided. This collaboration ranges from co-operation among direct care providers, such as care coordinators, nurses, patients, and family members, to collaborative relationships between policy-makers and administrators charged with the responsibilities of addressing organizational mandates, financing, and management. Nurses, by virtue of being present in all aspects of care across the care continuum, are in an ideal position to examine the effects of palliative care on models of care across the care continuum. Potential

research topics include: how hospice and palliative care is integrated across care settings (e.g., inpatient, medical home, concurrent care); how hospice and palliative care is integrated across populations (e.g., vulnerable populations such as patients who are homeless, or with both a psychiatric illness and a life limiting physical illness, or low socioeconomic status); what types of governance structures for interagency collaboration are associated with the best outcomes; what governance structures best leverage limited resources.

Priority: Research is needed to explore the effects of the hospice and palliative structural environment on patient, family and organizational outcomes.

With increasing attention on allocating resources to programs that support patient and family centered outcomes, palliative nursing presents an unequalled opportunity to improve quality care concurrently with improving costs. Much has been written on the importance of specific structures suggested to support palliative care quality (knowledgeable, well trained providers, diverse interdisciplinary team (IDT) members, appropriately trained volunteers, etc.).⁶⁻

¹⁴ Yet more knowledge is needed to determine the optimal IDT team composition, the effect of palliative nursing certification on patient/family outcomes, and which volunteer educational programs are associated with the best outcomes. Potential research topics include: the impact of the structure of IDTs on palliative care metrics: the optimum structure of an IDT; characteristics needed to meet “right person” qualification; how current hospice and palliative care team members can enhance their skills and communication to ensure successful IDT membership; how hospice and palliative care teams within the IDT are defined and perceived, across different settings, or within the continuum of care; whether the structure of the team influences the care processes or outcomes (or both); how that influence is mediated; what models of empowerment can be utilized to demonstrate success for an individual and IDT member; and the influence of

type or number of nurse certifications, at different levels of certification, on quality of care.

Other potential structural environment topics could include expansion or restriction of hospice eligibility or the expansion of palliative care into outpatient and primary care settings.

PHYSICAL ASPECTS OF CARE

Within the NCP Guidelines, the Physical Aspects of Care domain addresses the core components of palliative care such as the assessment of physical symptoms using standardized scales and the timely treatment of symptoms using multidimensional interventions.² Since the initial agenda, the body of work related to the etiology and management of dyspnea, fatigue, and constipation has expanded markedly. After highlighting the importance of physical symptoms through two cycles of agendas, the current agenda focuses on the significant deficits in evidence concerning roles of family caregivers in symptom management, the need for adequate assessment, evidence based intervention for effective symptom management, and the need for population specific understanding of physical issues particularly in the pediatric and neonatal populations.

Dyspnea

Since publication of the 2012-2015 HPNA Research Agenda, investigators have made advancements in understanding dyspnea prevalence, assessment and treatment. Studies are now beginning to address the multiple dimensions of dyspnea: its prevalence, intensity and the distress associated with the experience.¹⁵ The limitations of symptom assessment via patient self-report have been validated, showing that as many as 30% of patients cannot directly provide information about their dyspnea.¹⁵ And although the trajectory of dyspnea intensity and its sequelae varies between lung cancer patients and patients with COPD, palliative care needs have found to be comparable.¹⁶

Priority: Research is needed on family management of dyspnea

Families become the primary caregivers of patients at home. As the patient's

functionality wanes family caregivers responsibilities increase, with little or no formal preparation.¹⁷ Patient and family outcomes are dependent on the quality of family caregivers' ability to accurately assess the patient and provide the relevant interventions. Dyspnea is particularly difficult for family caregivers' to manage as evidenced by the report that home hospice patients with heart or lung diseases were more likely to have an acute hospital admission and a non-preferred site of death than patients with other diagnoses.¹⁸ Little is known about what factors influence caregiving in dyspnea or what preparation these caregivers receive and to what extent family management interventions are needed.

Priority: Research is needed on dyspnea in patients unable to self-report

A consensus among international experts in advanced disease was reached for a definition, categorization, and terminology for episodic breathlessness.¹⁹ Yet, the prevalence of respiratory distress in patients unable to self-report, such as typifies patients near death or those with cognitive impairment, remains unknown. The numeric rating scale remains the most highly recommended means of assessing dyspnea among patients with advanced disease.²⁰ The Respiratory Distress Observation Scale (RDOS)²¹ is still the only instrument for use in evaluating distress when the patient is unable to self-report dyspnea. Campbell et al. recently established RDOS ≥ 3 as the cut-point for distinguishing little to no respiratory distress from any.²² Now that there is a means to measure dyspnea in this population rigorous clinical trials need to be designed.

Priority: Research is needed on interventions in dyspnea

First, there is a need for assessment tools and evaluation criteria that appropriately and accurately detect meaningful improvement in dyspnea for the palliative care patient population.

Clinically important differences in dyspnea were identified in retrospective analysis from 213 datasets with a change of 10mm (0-100mm visual analog scale) identified as important for clinical practice and trial design.²³ Second, research is needed in commonly used treatments such as oxygen, opioids, and mechanical ventilation. Recent research has shown that oxygen use was not supported for patients with refractory dyspnea whose PaO₂ is >55 mm Hg,²⁴ whereas a hand-held fan directed at the face does reduce dyspnea.²⁵ Oxygen use is also not supported for patients who are near death and displaying no respiratory distress behaviors.²⁶

Opioids, specifically immediate release and oral or parenteral formulations of morphine and fentanyl, continue to be the only known medication to relieve dyspnea at the end of life. Oral transmucosal fentanyl was not effective in a clinical trial of exertional dyspnea in advanced lung cancer.²⁷ There continues to be a lack of evidence to support inhaled fentanyl to relieve dyspnea.^{28, 29} Powered, randomized controlled or crossover trials for inhaled fentanyl are indicated to generate evidence based interventions to relieve symptoms at the end of life. Promising results, however, are forthcoming regarding sustained release morphine.³⁰ Gaps continue with regard to initial dosing, frequency of dosing, and optimal titration schedules for morphine or fentanyl.

Non-invasive ventilation (NIV) has a role for treating respiratory failure or end-of-life dyspnea which warrants study. Patient discomfort from the mask is a predicted limitation for NIV as a palliative option for dyspnea. Nava et al. conducted a randomized feasibility trial of NIV vs. oxygen in 234 patients with solid tumors and acute respiratory failure.³¹ NIV was more effective than oxygen in reducing dyspnea and decreasing the doses of morphine needed.³¹ Hypercarbic patients, as expected, had greater benefit than those with normal carbon dioxide. NIV was discontinued due to discomfort in 11% of patients.³¹ Ventilator withdrawal entails the

cessation of mechanical ventilation to allow a natural death. However, there is little empirical evidence to guide the conduct of this common procedure.

Fatigue

Most of the content related to fatigue discussed in the previous agenda remains relevant. Fatigue continues to be reported as the most common, debilitating symptom experienced by palliative care patients. Fatigue can present from the time of diagnosis throughout the trajectory of treatment and beyond into survivorship and finally at the end of life.³²⁻³⁶ It is characterized by individual variability in clinical expression, determinants and sequelae.³⁴ It is also a potentially modifiable symptom if caused by underlying physiological or psychological abnormalities such as in electrolyte imbalances, thyroid function or blood dyscrasias, mood states such as depression, or results from infection and dehydration.³⁵ Given the prevalence, effect on quality of life, and potential to ameliorate fatigue, research is needed in specific areas such as the role of the informal caregiver in managing fatigue, the role and mechanism in fatigue in older adults, and elucidating the mechanisms of fatigue in specific diseases such as cancer.

Priority: Research is needed to determine the role of informal caregivers in managing fatigue.

In palliative care informal caregivers, while considered a co-recipient of care, also serve as co-providers of care. As in other symptoms the day to day management of fatigue falls upon the individual and their families. Yet very little is known about the role of the caregiver in managing fatigue. A recent search using the terms *fatigue, symptom management, family, caregiver* found no studies where the engagement in or impact of informal caregivers on patient fatigue was studied. Preliminary descriptive work is needed to first understand the role of informal caregivers in managing fatigue. Subsequent studies related to identifying predictors,

modifiers, and mediators of successful management of fatigue are then needed. When the caregivers' role has been carefully delineated then interventions that support and activate caregivers are needed.

Priority: Research is needed in the role and mechanisms of fatigue in aging populations.

In 2012 the Geriatrics – Hospice and Palliative Medicine Work Group of the American Geriatrics Society and the Palliative Medicine Leadership Collaboration released a landmark report that described interdisciplinary research, care coordination, and the patient and family as a unit of care as core principles shared by both specialties.³⁷ As our population continues to age the importance of multiple chronic conditions associated with fatigue has garnered increased attention. A recent integrative review found the one or more comorbidities were significantly associated with the prevalence and severity of cancer-related fatigue.³⁸ The major comorbidities associated with increased fatigue were arthritis, hypertension and cardiac disease. The authors of the review recommend more research exploring the associations between MCCs and cancer-related fatigue so that tailored interventions can be developed to manage patients' symptoms and improve their quality of life.

Gaps in the science of geriatric-palliative care related to fatigue include the following: lack of an understanding between “aging physiology and symptom perception which is critical to inform effective symptom assessment and treatment”.³⁹ Additional gaps include the need to validate measurement tools for fatigue in older adults with serious illness. Although the Patient Outcomes Measurement Information System (PROMIS) toolset is comprehensive and standardized it has not been validated in older adults with multiple chronic conditions.³⁹ Finally, there is scant evidence to guide both the pharmacological and non-pharmacological treatment of fatigue in these older adults.³⁹

Priority: Research is needed into cancer related fatigue.

Since the publication of the previous research agenda, researchers have continued exploring the molecular mechanisms of cancer-related fatigue including the role of the immune system and inflammation.⁴⁰ Individual variability in fatigue and sleep disturbances in cancer patients and their caregivers related to genetic variation has been the focus of several research teams.^{41, 42} Exercise is the evidence-based intervention most frequently recommended to resolve cancer related fatigue.(CRF).⁴³ Having reported on the state of the science related to cancer-related fatigue Mitchell³⁴ (p. 364) concluded that:

“Rigorously designed and adequately powered randomized trials are warranted to (1) determine the effectiveness of promising approaches and (2) identify the interventions that are most effective in treating CRF in specific subpopulations (e.g., stem cell transplant recipients, older adults, patients with lung or colorectal cancers, survivors, and those at the end of life). Studies to elucidate the biologic expression profiles of CRF, to explicate the mechanisms through which particular interventions impact CRF, and to identify the mediators and moderators of fatigue outcomes will ultimately permit individually tailored approaches for the treatment of CRF. “

Constipation

As noted in the 2012-2015 research agenda, the science of constipation remains underdeveloped despite the prevalence of constipation among palliative care patients which ranges from 30-90%.⁴⁴ In palliative care, constipation is generally a side effect of opioid use and referred to as opioid-induced constipation (OIC). OIC affects 15-90% of patients using opioid medications, with a higher burden noted in patients with cancer and advanced disease.⁴⁵ Further common factors that impact constipation in palliative care include the use of anti-cholinergic

medications to manage oral secretions or anxiety.⁴⁴

Priority: Research is needed to determine the role of informal caregivers in managing constipation.

There is a vast gap in the literature related to family caregivers of patients with constipation, the impact of constipation on the informal caregiving experience, and the ways in which informal caregivers participate in care planning and treatment of constipation. In reviewing the literature, we found one study that focused on informal caregivers' response to patient constipation (and this was specific to OIC).⁴⁶ Other articles that include caregivers are frequently devoted to caregiver-patient congruence in symptom report,⁴⁷ the impact of general patient symptoms to caregiver distress⁴⁸ or caregiver contribution to pain management.⁴⁹ What is known is that 25% of caregivers in one national study reported that constipation was the greatest threat to patient quality of life.⁴⁶ Concerns around constipation led 43% of caregivers to reduce, stop or switch opioids and 88% felt that pain management would be easier if constipation were better controlled.⁴⁶ Caregivers reported that patient constipation not only impacted patient quality of life, but also impacted their own – many caregivers reduced their time spent at work or with friends due to assisting the patient with OIC.⁴⁶ In examining predictors of caregiver distress, Hirdes and colleagues found that gastrointestinal problems, including constipation and fecal impaction, increased the risk of caregiver distress.⁴⁸

There have been conflicting data on the congruence of caregivers' and patients' symptom reports. Investigators have found that caregivers are either congruent with or over-report patient symptoms when compared to patient reports. Caregivers participate in decisions surrounding pain management with opioids and decisions regarding constipation management by reporting pain and constipation to providers, and by either altering dosages themselves or encouraging the

patient to alter/stop/switch opioids.^{46, 49} There is a major gap in the literature around what instruction informal caregivers receive on managing constipation, particularly OIC. We do not yet know how best to provide such teaching, what other supports caregivers may require when it comes to managing constipation or in fact, what education we should be providing.

Priority: Research is needed to standardize the definition, measurement and management of constipation in palliative care.

The effect of OIC goes beyond its actual occurrence, as patients and caregivers have been documented to alter opioid use due to fear of OIC.⁴⁶ While gastroenterologists have a clear definition of functional constipation, the definition and measurement of functional constipation and OIC varies in palliative care.⁴⁵ Due to this variation comparison of treatment efficacy can be difficult to conduct.

Priority: Research, particularly randomized control trials, is needed to evaluate commonly used pharmacological therapies vs. non-pharmacological therapies.

There are three major modalities of treatment for constipation: pharmacological, behavioral and complementary/alternative medicine. Sennosides and docusate have long been a mainstay of pharmacological treatment for constipation. But several randomized control trials demonstrated that adding docusate in addition to either sennosides or placebo yields no appreciable benefit.^{50, 51} The use of oral petroleum jelly (or “Vaseline balls”) is another widespread practice with no evidence to support it (although no evidence to contradict it).⁵² However, a 2013 systematic review and meta-analysis of pharmacological therapies for OIC concluded that μ -Opioid receptor antagonists (methylnaltrexone, naloxone and alvimopan) are safe and effective for the treatment of OIC.⁵³

Behavioral management approaches such as bowel training and digital rectal stimulation have been found to yield moderate improvement in adult patients post-stroke, but there is no palliative or hospice literature to support its use, particularly in the patient with progressive disease.⁵⁴ CAM approaches to constipation, such as acupuncture, abdominal massage and moxibustion, have been studied extensively.^{55, 56} A systematic review of acupuncture use noted that acupuncture yielded the same or better results as traditional medical therapy, while the efficacy of moxibustion is still in question.^{55, 56} However, it should be noted that the majority of the studies on these CAM practices were conducted outside the US, particularly in China and South Korea and it is unknown whether the effects would be the same in different populations.⁵⁵ Abdominal massage, on the other hand, has been more extensively studied in multiple populations and has been found to be effective in the treatment of constipation.⁵⁷⁻⁶⁰

RESEARCH TRANSLATION

Results from the Research Council's 2014 survey of HPNA members suggest that clinicians recognize the need to translate research evidence into practice, but continue to see slow progress in moving this evidence to the bedside. Examples of specific pressing gaps noted by members include: 1) theoretically guided interventions for symptom management; 2) consistent evidence based practice; 3) a stronger evidence base for symptom management. Much of the evidence exists yet member-perceived gaps remain. This highlights the need for a more systematic translation of evidence into clinical practice. However, this translation requires that clinicians have access to high quality, appropriate evidence presented in a manner that aids in clinical decision-making. Since some available evidence is not currently applied to bedside practice, such as the continued use of docusate for OIC, this agenda both addresses potential barriers to implementation and makes a recommendation that HPNA develop a member-driven process to create a web-based resource for clinical practice guidelines.

Implementation Science

Implementation science is defined by the National Institutes of Health as: “the study of methods to promote the integration of research findings and evidence into healthcare policy and practice. It seeks to understand the behavior of healthcare professionals and other stakeholders as a key variable in the sustainable uptake, adoption and implementation of evidence-based interventions”.⁶¹ Within nursing, the content of educational programs leading to a Doctorate of Nursing Practice (DNP) is designed to provide nurses with the skills in evidence-based practice, quality improvement and systems thinking to enable them to provide leadership in improving care through research implementation.⁶²

Priority: Research is needed to better understand the structural, environmental, and workforce factors that influence the implementation of evidence-based practice.

There is a high level of complexity in developing the palliative care science because it is provided across settings. What might be appropriate care in one setting, such as an acute care hospital, may not be appropriate in another such as nursing home, outpatient clinic, or home hospice. Therefore, in order to move the field forward, and to assist palliative care leaders at institutions and nationwide to implement evidence based practice, more research needs to be performed examining how organizational factors influence whether palliative care practice guidelines are implemented in real world organizations, rather than in controlled scientific experiments.

Priority: Research is needed regarding costs and organizational needs for creating and maintaining a strong culture of evidence-based practice.

Research is needed to determine the costs and organizational resources needed to maintain evidence-based palliative nursing practice over the long term. Given the organizational culture, research should include how to effectively engage organizational leaders at both the bedside and management levels, how to be flexible with implementing a clinical guideline without changing the intervention itself, and finally, how to evaluate the effectiveness and adoption of the intervention. One example of how this can be performed is given by Demiris et al, where they provide a basic background on implementation science in hospice and palliative care, and then provide two case studies from their own work of how they implemented and evaluated their intervention using the RE-AIM framework.^{63 64}

Disseminating Existing Clinical Practice Guidelines

Priority: Create a Clinical Practice Guideline task force to review existing clinical guidelines for applicability to palliative nursing and make these guidelines available to members via a web-based resource.

The starting place for finding clinical guidelines is the National Guideline Clearinghouse at www.guideline.gov. National Guideline Clearinghouse (NGC) is an initiative of the Agency for Healthcare Research and Quality which provides detailed information about clinical practice guidelines that can be used for dissemination and clinical practice. The guidelines on this site include both “macro-guidelines” which provide conditions under which high quality care can be provided and key elements necessary for quality care and “micro-guidelines” which provide recommendations for best practice in assessment and clinical intervention. While the macro-guidelines are broad in nature and do not provide specific guidance on assessment, or recommended interventions for specific clinical situations, they do outline desired results for the profession. Many of these are macro-guidelines such as the clinical guidelines produced by the National Consensus Project for Quality Palliative Care. A search of this site revealed 274 guidelines when using the term “palliative care”.

Micro-guidelines can be found through other sources including literature databases such as PubMed and Cumulative Index of Nursing and Allied Health (CINAHL) and through other professional organizations. The Oncology Nursing Society, through their Putting Evidence into Practice (PEP) initiative, have produced evidence-based clinical guidelines with clear recommendations that are easily accessible to clinicians and which are appropriate for both registered nurses (RNs) and advanced practice nurses (APNs). The ONS PEP guidelines cover 20 topics, most of which are important in palliative care and are openly available at

<http://www2.ons.org/Research/PEP/Topics> . The guidelines, on topics including anxiety, caregiver strain, dyspnea, fatigue, and pain are strongly evidence-based and the site provides links to the evidence.⁶⁵

Other professional organizations have published guidelines that are appropriate for palliative nurses including the Registered Nurse Association of Ontario⁶⁶ and the American College of Critical Care Medicine.⁶⁷ These cover topics ranging from supporting families of intensive care patients to nursing care in the last days and hours of life. The recommendations cover decision making, nursing assessment, symptom management, models of care delivery including family conferences, nursing education, communicating prognosis and grief and bereavement. There are many other examples available in the literature from the US and around the world. Some of these guidelines are appropriate for all nurses, while others are more focused on the APN role. It is recommended that a HPNA Clinical Practice Guideline Project task force be convened to review all of these resources to identify those guidelines applicable to palliative nursing. A web portal for dissemination should be developed subsequent to the identification of applicable guidelines.

Priority: Identify and publicize the gaps where published guidelines currently do not exist to support palliative nursing practice

Despite the numerous published guidelines, a number of gaps are evident. In most cases the gaps are related to limitations in the research base on a topic. For example, there are few guidelines that address specific assessments and appropriate interventions for cultural aspects of nursing care. While there are a number of guidelines that include evidence-based recommendations for assessment and management of common symptoms, there is a dearth of guidelines that address signs and symptoms that only appear in the last hours or days of death

such as terminal delirium or audible secretions. These signs and symptoms are frequently the ones for which palliative nurses are most in need of evidence-based recommendations. Other topics that would benefit from nursing guideline development include communication with the family, especially to prepare them for caregiving and the experience of death. Finally, and most notably, there is a lack of evidence-based guidelines related to the structure and process of nursing care including practices that have been confirmed by research such as consistency in providers. Structure and process guidelines are also lacking for particular aspects of care in various settings like on-call practices for hospice nurses and consultation teams in palliative care.

One potential resource to support the development of evidence based guidelines for quality palliative care is to tap into DNP programs. These are experiencing a period of exponential growth – 241 programs currently exist in 49 states.⁶⁸ Nurses seeking this degree are generally required to engage in a capstone project that demonstrates advanced skills in leadership and practice. These students provide human capital that can aid in the creation of clinical practice guidelines for areas where research evidence is beginning to accumulate but where guidelines do not currently exist. It is recommended that HPNA include plans to disseminate the results of the gap analysis of the Clinical Practice Guideline project to schools of nursing with DNP programs.

Summary

The 2015-2018 HPNA Agenda provides research direction for palliative nursing for the next three years. We have highlighted gaps in knowledge identified by our members which serve as barriers to quality palliative nursing care. In addition, we have outlined new processes to assist palliative nurses improve patient and family experiences through the generation of new knowledge and the translation of research into clinical practice. Furthermore, this agenda has delineated a procedure for HPNA stimulation and endorsement of clinical practice guidelines. This agenda joins the previous agendas in calling for well-designed studies to provide the necessary evidence-based foundation for optimal care of patients and families along the full trajectory of serious illness.

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References

1. Merriam-Webster Inc. *The Merriam-Webster dictionary*. Springfield, Mass.: Merriam-Webster; 2005.
2. National Consensus Project for Quality Palliative Care . Clinical practice guidelines for quality palliative care. . 2013; 3rd Edition:<http://www.nationalconsensusproject.org>. Accessed 11/18/14.
3. Lorenz KA, Dy SM, Naeim A, et al. Quality measures for supportive cancer care: the Cancer Quality-ASSIST Project. *Journal of Pain and Symptom Management*. 2009;37:943-964.
4. Wenger NS, Shekelle PG. Assessing care of vulnerable elders: ACOVE project overview. *Annals of Internal Medicine*. 2001;135:642-646.
5. Measuring What Matters. 2014; <http://aahpm.org/quality/measuring-what-matters>. Accessed 11/18/14.
6. Block EM, Casarett DJ, Spence C, Gozalo P, Connor SR, Teno JM. Got volunteers? Association of hospice use of volunteers with bereaved family members' overall rating of the quality of end-of-life care. *Journal of pain and symptom management*. 2010;39:502-506.
7. Claxton-Oldfield S, Banzen Y. Personality characteristics of hospice palliative care volunteers: the "big five" and empathy. *American Journal of Hospice and Palliative Medicine*. 2010;27:407-412.
8. Pesut B, Hooper B, Lehbauer S, Dalhuisen M. Promoting Volunteer Capacity in Hospice Palliative Care A Narrative Review. *American Journal of Hospice and Palliative Medicine*. 2014;31:69-78.
9. Parker-Oliver D, Bronstein LR, Kurzejeski L. Examining variables related to successful collaboration on the hospice team. *Health & social work*. 2005;30:279-286.
10. Mosenthal AC, Murphy PA. Interdisciplinary model for palliative care in the trauma and surgical intensive care unit: Robert Wood Johnson Foundation Demonstration Project for Improving Palliative Care in the Intensive Care Unit. *Critical care medicine*. 2006;34:S399-S403.
11. Lindley LC. Pediatric Hospice Care Knowledge: A Transaction Cost Perspective. *Journal of Hospice & Palliative Nursing*. 2013;15:485-490.
12. Meier DE, Beresford L. The palliative care team. *Journal of Palliative Medicine*. 2008;11:677-681.
13. VON GUNTEN CF, MULLAN PB, HARRITY S, et al. Residents from five training programs report improvements in knowledge, attitudes and skills after a rotation with a hospice program. *Journal of Cancer Education*. 2003;18:68-72.
14. Wittenberg-Lyles E, Goldsmith J, Ferrell B, Burchett M. Assessment of an Interprofessional Online Curriculum for Palliative Care Communication Training. *Journal of palliative medicine*. 2014;17:400-406.
15. Puntillo KA, Arai S, Cohen NH, et al. Symptoms experienced by intensive care unit patients at high risk of dying. *Crit Care Med*. 2010;38:2155-2160.
16. Weingaertner V, Scheve C, Gerdes V, et al. Breathlessness, Functional Status, Distress, and Palliative Care Needs Over Time in Patients With Advanced Chronic Obstructive Pulmonary Disease or Lung Cancer: A Cohort Study. *J Pain Symptom Manage*. 2014.
17. Schumacher KL, Stewart BJ, Archbold PG, Caparro M, Mutale F, Agrawal S. Effects of caregiving demand, mutuality, and preparedness on family caregiver outcomes during cancer treatment. *Oncology nursing forum*. 2008;35:49-56.
18. Woolley DC, Old JL, Zackula RE, Davis N. Acute hospital admissions of hospice patients. *Journal of palliative medicine*. 2013;16:1515-1522.
19. Simon ST, Weingartner V, Higginson IJ, Voltz R, Bausewein C. Definition, categorization, and terminology of episodic breathlessness: consensus by an international Delphi survey. *J Pain Symptom Manage*. 2014;47:828-838.

20. Mularski RA, Campbell ML, Asch SM, et al. A review of quality of care evaluation for the palliation of dyspnea. *American journal of respiratory and critical care medicine*. 2010;181:534-538.
21. Campbell ML, Templin T, Walch J. A Respiratory Distress Observation Scale for patients unable to self-report dyspnea. *Journal of palliative medicine*. 2010;13:285-290.
22. Campbell ML, Templin TN. Intensity cut-points for the Respiratory Distress Observation Scale. *Palliative Medicine*. pii: 0269216314564238. [Epub ahead of print].
23. Johnson MJ, Bland JM, Oxberry SG, Abernethy AP, Currow DC. Clinically important differences in the intensity of chronic refractory breathlessness. *J Pain Symptom Manage*. 2013;46:957-963.
24. Abernethy AP, McDonald CF, Frith PA, et al. Effect of palliative oxygen versus room air in relief of breathlessness in patients with refractory dyspnoea: a double-blind, randomised controlled trial. *Lancet*. 2010;376:784-793.
25. Galbraith S, Fagan P, Perkins P, Lynch A, Booth S. Does the use of a handheld fan improve chronic dyspnea? A randomized, controlled, crossover trial. *J Pain Symptom Manage*. 2010;39:831-838.
26. Campbell ML, Yarandi H, Dove-Medows E. Oxygen is nonbeneficial for most patients who are near death. *J Pain Symptom Manage*. 2013;45:517-523.
27. Pinna, M. Á. C., Bruera, E., Moralo, M. J. R., Correas, M. Á. S., & Vargas, R. M. (2013). A randomized crossover clinical trial to evaluate the efficacy of oral transmucosal fentanyl citrate in the treatment of dyspnea on exertion in patients with advanced cancer. *American Journal of Hospice and Palliative Medicine*, 1049909113513063.
28. Simon ST, Koskeroglu P, Gaertner J, Voltz R. Fentanyl for the relief of refractory breathlessness: a systematic review. *J Pain Symptom Manage*. 2013;46:874-886.
29. Bausewein, C., & Simon, S. T. Inhaled nebulized and intranasal opioids for the relief of breathlessness. *Current opinion in supportive and palliative care*. 2014. 8(3), 208-212.
30. Currow DC, Quinn S, Greene A, Bull J, Johnson MJ, Abernethy AP. The longitudinal pattern of response when morphine is used to treat chronic refractory dyspnea. *Journal of palliative medicine*. 2013;16:881-886.
31. Nava S, Ferrer M, Esquinas A, et al. Palliative use of non-invasive ventilation in end-of-life patients with solid tumours: a randomised feasibility trial. *The lancet oncology*. 2013;14:219-227.
32. Berger AM, Abernethy, A., Atkinson, A., Breibart, W., Brothers, B. Cella, D....Piri, W.R. . NCCN guidelines: Cancer-related fatigue [v.1.2013]. 2013; nccn.org/professionals/physicians_gls/f_guidelines.asp#fatigue, 2013. Accessed 11/18/14.
33. Minton O, Berger A, Barsevick A, et al. Cancer-related fatigue and its impact on functioning. *cancer*. 2013;119:2124-2130.
34. Mitchell SA. Cancer-related fatigue: state of the science. *PM&R*. 2010;2:364-383.
35. Adler ED, Goldfinger JZ, Kalman J, Park ME, Meier DE. Palliative care in the treatment of advanced heart failure. *Circulation*. 2009;120:2597-2606.
36. Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *Journal of Pain and Symptom Management*. 2006;31:58-69.
37. Report of the Geriatrics-Hospice and Palliative Medicine Work Group: American Geriatrics Society and American Academy of Hospice and Palliative Medicine leadership collaboration. *J Am Geriatr Soc*. 2012;60:583-587.
38. Wright F, Hammer MJ, Melkus GD. Associations of Multiple Chronic Conditions and Cancer-Related Fatigue: An Integrative Review. Paper presented at: NURSING RESEARCH2013.

39. Combs S, Kluger BM, Kutner JS. Research priorities in geriatric palliative care: Nonpain symptoms. *Journal of palliative medicine*. 2013;16:1001-1007.
40. Bower JE, Lamkin DM. Inflammation and cancer-related fatigue: Mechanisms, contributing factors, and treatment implications. *Brain, behavior, and immunity*. 2013;30:S48-S57.
41. Aouizerat, B., Dodd, M., Lee, K., West, C., Paul, S., Cooper, B., ... & Miaskowski, C. (2009). Preliminary evidence of a genetic association between tumor necrosis factor alpha and the severity of sleep disturbance and morning fatigue. *Biological research for nursing*. doi: 10.1177/1099800409333871
42. Barsevick A, Frost M, Zwinderman A, Hall P, Halyard M. I'm so tired: biological and genetic mechanisms of cancer-related fatigue. *Quality of Life Research*. 2010;19:1419-1427.
43. Mishra, S. I., Scherer, R. W., Snyder, C., Geigle, P. M., Berlanstein, D. R., & Topaloglu, O. (2012). Exercise interventions on health-related quality of life for people with cancer during active treatment. *The Cochrane Library*. DOI: 10.1002/14651858.CD008465.pub2
44. Clark K, Currow DC. Constipation in palliative care: what do we use as definitions and outcome measures? *Journal of pain and symptom management*. 2013;45:753-762.
45. Panchal SJ, Muller-Schwefe P, Wurzelmann JI. Opioid-induced bowel dysfunction: prevalence, pathophysiology and burden. *International journal of clinical practice*. 2007;61:1181-1187.
46. Lentz J, McMillan SC. The impact of opioid-induced constipation on patients near the end of life: Perspectives of patients, family caregivers, and nurses. *Journal of Hospice & Palliative Nursing*. 2010;12:29-38.
47. Libert Y, Merckaert I, Slachmuylder JL, Razavi D. The ability of informal primary caregivers to accurately report cancer patients' difficulties. *Psycho-Oncology*. 2013;22:2840-2847.
48. Hirdes JP, Freeman S, Smith TF, Stolee P. Predictors of caregiver distress among palliative home care clients in Ontario: evidence based on the interRAI Palliative Care. *Palliative and Supportive Care*. 2012;10:155-163.
49. García-Toyos N, Escudero-Carretero MJ, Sanz-Amores R, Hoyos GD, Melchor-Rodríguez JM, Tamayo-Velázquez MI. Preferences of Caregivers and Patients Regarding Opioid Analgesic Use in Terminal Care. *Pain Medicine*. 2014;15:577-587.
50. Tarumi Y, Wilson MP, Szafran O, Spooner GR. Randomized, double-blind, placebo-controlled trial of oral docusate in the management of constipation in hospice patients. *J Pain Symptom Manage*. 2013;45:2-13.
51. Hawley PH, Byeon JJ. A comparison of sennosides-based bowel protocols with and without docusate in hospitalized patients with cancer. *Journal of palliative medicine*. 2008;11:575-581.
52. Tavares CN, Kimbrel JM, Protus BM, Grauer PA. Petroleum Jelly (Vaseline Balls) for the Treatment of Constipation: A Survey of Hospice and Palliative Care Practitioners. *The American journal of hospice & palliative care*. 2013.
53. Ford AC, Brenner DM, Schoenfeld PS. Efficacy of pharmacological therapies for the treatment of opioid-induced constipation: systematic review and meta-analysis. *The American journal of gastroenterology*. 2013;108:1566-1574; quiz 1575.
54. Lim SF, Childs C. A systematic review of the effectiveness of bowel management strategies for constipation in adults with stroke. *International journal of nursing studies*. 2013;50:1004-1010.
55. Zhang T, Chon TY, Liu B, et al. Efficacy of acupuncture for chronic constipation: a systematic review. *The American journal of Chinese medicine*. 2013;41:717-742.
56. Lee MS, Choi TY, Park JE, Ernst E. Effects of moxibustion for constipation treatment: a systematic review of randomized controlled trials. *Chinese medicine*. 2010;5:28.
57. Lamas K, Lindholm L, Stenlund H, Engstrom B, Jacobsson C. Effects of abdominal massage in management of constipation--a randomized controlled trial. *International journal of nursing studies*. 2009;46:759-767.

58. McClurg D, Hagen S, Hawkins S, Lowe-Strong A. Abdominal massage for the alleviation of constipation symptoms in people with multiple sclerosis: a randomized controlled feasibility study. *Multiple sclerosis*. 2011;17:223-233.
59. McClurg D, Lowe-Strong A. Does abdominal massage relieve constipation? *Nursing times*. 2011;107:20-22.
60. Sinclair M. The use of abdominal massage to treat chronic constipation. *Journal of bodywork and movement therapies*. 2011;15:436-445.
61. National Institutes of Health. Implementation Science Information and Resources. HYPERLINK "http://www.fic.nih.gov/researchtopics/pages/implementationsscience.aspx.%20" <http://www.fic.nih.gov/researchtopics/pages/implementationsscience.aspx>. Accessed 07/01/2014.
62. Sperhac AM, Clinton P. The essentials of doctoral education for advanced nursing practice. *Journal of Pediatric Health Care*. 2008;22:146-151.
63. Glasgow RE, McKay HG, Piette JD, Reynolds KD. The RE-AIM framework for evaluating interventions: what can it tell us about approaches to chronic illness management? *Patient education and counseling*. 2001;44:119-127.
64. Demiris G, Parker Oliver D, Capurro D, Wittenberg-Lyles E. Implementation science: implications for intervention research in hospice and palliative care. *The Gerontologist*. 2014;54:163-171.
65. Oncology Nursing Society. ONS PEP topics. <http://www2.ons.org/Research/PEP/Topics>. Accessed 07/08/2014, 2014.
66. Registered Nurses Association of Ontario. End-of-life care in the last days and hours. <http://rnao.ca/bpg/guidelines/endoflife-care-during-last-days-and-hours>. Accessed 7/8/14.
67. Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. *Critical Care Medicine*. 2007;35:605-622
610.1097/1001.CCM.0000254067.0000214607.EB.
68. DNP Fact Sheet. 2014; <http://www.aacn.nche.edu/media-relations/fact-sheets/dnp>. Accessed 11/18/14.