

## **American Nurses Association Professional Issues Panel**

# **Call for Action: Nurses Lead and Transform Palliative Care**

**Approved by ANA Board of Directors  
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**Developed in Partnership With Organizational Affiliate  
Hospice and Palliative Nurses Association**



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## Executive Summary

In January 2016, the American Nurses Association (ANA) and the Hospice and Palliative Nurses Association (HPNA) convened the Palliative and Hospice Nursing Professional Issues Panel (the Panel). The role of the Panel was to: (a) complete an environmental assessment, (b) examine palliative care nursing within today's healthcare system, and (c) identify steps and strategies for nurses to lead and transform palliative care. The Panel focused on identifying a future state for palliative care that promotes health equity and improves access, safety, and quality of palliative care.

The diverse palliative nursing experts on the Steering Committee identified five palliative care focus areas to examine. These areas were (1) practice, (2) education, (3) administration, (4) policy, and (5) research. A larger Advisory Group's contributions informed the work and development of the resultant recommendations for action. The draft *Call for Action: Nurses Lead and Transform Palliative Care* was broadly disseminated for public comment in September 2016. This examination yielded extensive feedback and excellent recommendations for additional resources and revisions, which were reviewed by the Steering Committee and integrated into the final document as warranted. The Steering Committee completed a final review and deemed the Call for Action ready for final examination and approval by members of ANA and HPNA Boards of Directors.

**The conclusion of this Call for Action is that seriously ill and injured patients, families, and communities should receive quality palliative care in all care settings. This is achieved by the delivery of primary palliative nursing by every nurse, regardless of setting.** The recommendations that follow support this conclusion.

## Recommendations

1. Adopt the End of Life Nursing Education Consortium (ELNEC) curricula (Core, Geriatric, Critical Care, Pediatric, Advanced Practice Registered Nurse [APRN], and Online for Undergraduate Nursing Students) as the standard for primary palliative nursing education for pre-licensure, graduate, doctoral, and continuing education for practicing registered, vocational, and practical nurses and advanced practice registered nurses.
2. Petition the National Council for State Boards of Nursing to increase palliative care content on the pre-licensure NCLEX-RN and NCLEX-PN exams.

3. Encourage state boards of nursing with continuing education re-licensure requirements to mandate inclusion of palliative care content.
4. Advocate the use of the National Consensus Project for Quality Palliative Care *Clinical Practice Guidelines for Quality Palliative Care* in the development, implementation, and evaluation of specialty, evidence-based palliative care services for all organizations.
5. Recommend that all specialty nursing organizations review registered nurse (RN) and APRN practice standards to include primary palliative nursing care and develop resources and position papers to support and advance primary palliative nursing.
6. Fund, develop, and evaluate innovative palliative care models to address workforce challenges and the needs of communities of color, underserved populations, and other vulnerable groups, such as Native Americans, persons with intellectual and developmental disabilities, and others in rural and urban areas.
7. Convene a thought leader summit to address practice barriers and develop initiatives to implement primary palliative care.
8. Incorporate primary palliative nursing as part of the American Nurses Credentialing Center Magnet Recognition Program<sup>®</sup> and Pathway to Excellence Program<sup>®</sup>, American Association of Critical Care Nurses Beacon Award for Excellence, Academy of Medical-Surgical Nurses Prism Award, and other organizational and unit-based credentialing and recognition programs.
9. Conduct intervention studies testing strategies to alleviate compassion fatigue and moral distress to maintain a healthy workforce.
10. Promote equitable reimbursement and reduction of barriers by all payers for RN and APRN services related to palliative and hospice care.
11. Support the funding and development of palliative care services for communities with limited resources.
12. Position nurses at decision-making and policy-setting venues, such as healthcare and regulatory boards, to address palliative care needs.

## Introduction

The success of both biomedical technologies in prolonging lives and of public health policies in reducing environmental and behavioral determinants of illness and injury has resulted in increased numbers of infants, children, adolescents, and adults living with serious and often critical illnesses or injuries. This prospect of longevity was unimaginable in the past. The resulting burden of congenital, chronic, and progressive illnesses and injuries, and the demands of treatment, require patients, families, and healthcare professionals to make difficult decisions about treatments that affect the quality of life, and, at times, the quality of dying. As members of the largest healthcare professionals' cohort, the nation's 3.6 million nurses must be prepared to actively contribute insights about holistic person-centered care, identification and respect for patient choices, as well as access and provision of palliative care from prenatal to end of life.

Consequently, the American Nurses Association (ANA) and the Hospice and Palliative Nurses Association (HPNA) have partnered to issue this **Call for Action: Nurses Lead and Transform Palliative Care**.

Registered nurses (RNs) and advanced practice registered nurses (APRNs) constitute the primary audience for this Call for Action. The identified resources, opportunities, and subsequent actions characterize how registered nurses and advanced practice registered nurses in practice, education, administration, research, policy, and other venues can lead and transform palliative care. Other stakeholders may find value in the discussion and listed resources.

Nursing is uniquely qualified to issue and accept this Call for Action by its commitments to facilitate healing, alleviate suffering, and advocate in the care of individuals, families, groups, communities, and populations (adapted from the *Nursing: Scope and Standards of Practice, 3rd Edition*, p. 1). The ultimate goal of this Call for Action is to enhance and leverage the efforts of all nurses, nursing organizations, and interprofessional teams to promote access and ensure delivery of safe, quality, and person-centered palliative care to all in need.

## **Purpose**

The purpose of this Call for Action is to urge nurses in various roles and settings to lead and transform palliative care in practice, education, administration, policy, and research. Every nurse should have the knowledge, skills, and abilities to provide primary palliative nursing.

## Definitions

Understanding the differences among palliative care, primary palliative nursing, and specialty palliative nursing is critical to this Call for Action.

### ***Palliative Care***

Palliative care is defined as patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering throughout the continuum of illness or injury, through the provision of holistic person-centered care (physical, intellectual, emotional, social, and spiritual) to support autonomy through informed decision-making (modified from C. Dahlin, Ed., 2015, *Clinical Practice Guidelines for Quality Palliative Care, 3rd Edition*). Palliative care includes care of the terminally ill, i.e., hospice care.

By definition, palliative care is provided by interprofessional teams of physicians, nurses, social workers, chaplains, and other health professionals. Recognizing and addressing the breadth of patient and family needs requires many collaborating partners, with nurses always being present as one of the core palliative care team members. Palliative care is by its very definition team-based care.

In the current state of nursing, nurses receive less than optimal palliative and hospice care education. This is a result of little *explicit* palliative care content in undergraduate nursing education (White, Coyne, & White, 2012; White, Coyne, & Lee, 2011; White, Roczen, Coyne, & Wiencek, 2014). However, since nursing care, by definition, involves alleviation of suffering through the diagnosis and treatment of human response and advocacy in the care of individuals, families, communities, and populations, nurses may *implicitly* learn aspects of palliative nursing. For example, by virtue of their role, all nurses provide psychosocial support. Nurses have the necessary skills to assess and assist advance care planning, promote illness understanding, and identify spiritual issues and cultural concerns. Few graduate nursing programs focus on hospice and palliative care as reflected at <http://hpna.advancingexpertcare.org/education/graduate-program-listing/>.

### ***Primary Palliative Nursing***

The English Oxford Living Dictionary defines *palliate* as "to make a disease (or its symptoms) less severe without removing the cause" <https://en.oxforddictionaries.com/definition/us/palliate>.

Historically, nursing has cared for the ill and injured, created environments that promote healing, and educated patients and family caregivers about health and coping with illness and injury. Palliative nursing is the essence of all nursing care.

Primary palliative nursing includes the assessment and management of pain and other illness-related symptoms and treatment side effects; preparation of patients and families for what they might expect as the disease progresses; and assessment of how patient and family are coping with illness and injury, i.e., their hopes, concerns, and needs for support. Primary palliative nursing also incorporates the respectful care of those who are dying and support for their survivors (Dahlin, 2015a).

### ***Specialty Palliative Nursing***

Specialty palliative nursing includes both the registered nurse (RN) and advanced practice registered nurse (APRN) roles and involves the management of complex and refractory symptoms, advanced skills in communication and conflict resolution, and navigating the changing care needs across the trajectory of life. Specialty palliative care occurs in a variety of settings such as inpatient palliative care services, home and residential hospice programs, and disease-specific palliative care programs, such as oncology or heart failure supportive and palliative care services. Specialty palliative nursing requires additional educational preparation, practice in a palliative care setting, and demonstration of identified competencies. (See *Palliative Nursing: Scope and Standards of Practice: An Essential Resource for Hospice and Palliative Nurses* [ANA & HPNA, 2014]). Specialty practice competence is further demonstrated through the process of national certification in a specialty practice. (See Hospice and Palliative Credentialing Center [HPCC] at <http://hpcc.advancingexpertcare.org/>.)

## **Background**

Many individuals, groups, agencies, organizations, and reports call for healthcare reform that moves health care from an illness, disease, sickness, cure model to an environment that focuses on health, wellness, prevention, person-centered choices, care, and quality outcomes.

In January 2016, the American Nurses Association (ANA) and the Hospice and Palliative Nurses Association (HPNA) convened the Palliative and Hospice Nursing Professional Issues Panel (the Panel). The role of the Panel was to (a) complete an environmental assessment, (b) examine palliative care nursing within today's healthcare system, and (c) identify steps and strategies for nurses to lead and transform palliative

care. The Panel focused on identifying a future state for palliative care that promotes health equity and improves access, safety, and quality of palliative care.

The Steering Committee members began deliberations by reflecting upon the contemporary definition of nursing, the competencies delineated in *Nursing: Scope and Standards of Practice, 3rd Edition* (ANA, 2015), and those competencies described in the nursing specialty resource, *Palliative Nursing: Scope and Standards of Practice: An Essential Resource for Hospice and Palliative Nurses* (ANA & HPNA, 2014). To reiterate, all nurses by the nature of their basic preparation have the requisite skills to promote understanding of illness, identify spiritual issues and cultural concerns, provide physical and psychosocial support, assess, implement care planning, and employ symptom management interventions.

The following themes emerged during the professional issues panel deliberations:

- Health equity improves health services, access, quality, and safety for all by resolving disparities.
- Each patient, family, group, community, or population has choices, and needs available resources to make those meaningful choices and changes for optimal health outcomes throughout the life span.
- Palliative care has the potential to promote the health and well-being of all individuals and communities and therefore needs the attention and integration into practice by all nurses, no matter the practice area or population served.
- Nurses are leaders in developing, promoting, implementing, and sustaining interprofessional teamwork in palliative care.
- Educational and other resources for palliative care exist but are not widely known and remain hidden for many individuals and groups.

The diverse palliative nursing experts on the Steering Committee identified five palliative care focus areas to examine. These areas were (1) practice, (2) education, (3) administration, (4) policy, and (5) research. A larger Advisory Group's contributions informed the work and development of the resultant recommendations for action. The draft *Call for Action: Nurses Lead and Transform Palliative Care* was broadly disseminated for public comment in September 2016. This yielded extensive feedback and excellent recommendations for additional resources and revisions, which were reviewed by the Steering Committee and integrated into the final document as warranted. The Steering Committee completed a final review and deemed the *Call for Action* ready for final examination and approval by members of ANA and HPNA Boards of Directors.



The following sections explore concerns, issues, opportunities, resources, and specific recommendations for action by nurses to lead and transform palliative care in the practice, education, research, administration, and policy domains.

## **Nurses Lead and Transform Palliative Care in Practice**

Nurses have a profound role in the care of individuals and families living with serious and life-altering illness or injury. Nurses are often the first to recognize palliative care issues, needs, and associated distress. Nurses play an essential role in advocating for palliative care services for individuals and families, whether by delivery of direct care or team referral processes. Nurses can educate patients about the characteristics and value of palliative care.

However, in today's healthcare environment, person-centered care planning, which identifies and respects values, preferences, and choices across transitions, is often absent or underdeveloped. In addition to managing symptoms and providing psychosocial support, palliative care elicits the person's goals of care and assists in the planning to achieve those goals. This process is referred to as advance care planning.

Nurses are critical partners in those processes. Nurses apply their astute listening and communication skills during goals of care conversations or care planning discussions. Such activities help identify the person's goals of care and then establish a plan to meet those goals and outcomes. Development of written advance care directives and review of existing advance care directives are components of such planning activities. Advocacy becomes critical for assurance that care plans and advance care directives are known, understood, and respected by everyone in every setting (<https://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000472.htm>). See the Practice section in Appendix A for valuable resources addressing care planning and advance directives.

Full appreciation of cultural diversity and preferences and the need for equity and inclusion must characterize palliative care practice. Support and respect for cultural preferences during the illness continuum and end of life are integral to the delivery of culturally congruent care. Culturally congruent practice also addresses the need for diversity of caregivers and educators. Development and dissemination of culturally sensitive, patient-focused educational materials must be an integral component of palliative care services. Some available resources addressing culturally congruent practice are identified in the Education section of Appendix A.

This Call for Action seeks to enable and promote the voices of **all** patients and families, nurses, and other members of the team asking for goal-oriented care that prioritizes meaning and quality of life, not exclusively disease intervention and management.

Many practice barriers exist that prevent access to quality palliative care in acute-care settings, academic medical centers, community, and critical access hospitals. Hierarchies and system barriers often prevent nurses from full and open access to palliative care specialists and resources. Cultural, economic, and reimbursement barriers often affect access to palliative care. Nurses report moral distress related to disparities in care of patients who are seriously ill or injured or at end of life or when provided treatments and therapies seem only to increase patient or family suffering. This reality further underscores the need for education and preparation of all nurses with primary palliative care skills.

Given the limited capacity and access to specialty palliative care services, nurses in community hospitals and clinics, academic medical centers, underserved and rural or frontier communities, homes, and other healthcare settings need to be prepared to provide primary palliative nursing to promote health equity for all.

This Call for Action further seeks to remove obstacles in acute, long-term, and community care settings that prevent access to specialist palliative care. To be successful in leading and transforming palliative care practice, an interprofessional effort will require nursing, medicine, healthcare leaders and administrators, policy experts, and other stakeholders to remove the constraints and incentives that perpetuate care focused on unwanted high technology interventions that very often are not evidence-based.

## **Nurses Lead and Transform Palliative Care in Education**

All nurses must learn about care of seriously ill and other vulnerable populations and the associated requisite prioritizations. Educational challenges associated with palliative care practice include the lack of preparatory education and exposure to palliative care principles within the nursing curriculum, lack of palliative nursing clinical practicum experiences, and lack of professional mentoring. Additionally, palliative nursing specialty practice, including hospice, has often been overlooked within healthcare institutions and within nursing academic and professional development curricula.

Learners include paraprofessionals who learn nursing care (e.g., nursing assistants and home care aides); licensed vocational and practical nurses; pre-RN licensure students at the diploma, associate, baccalaureate, and master's levels; advanced practice

registered nurses who obtain masters' degrees or higher; and an often forgotten learner cohort, nursing faculty. Further specialty palliative care academic progression includes preparation through completion of certificate, graduate, and doctoral work.

How best to educate and prepare nurses to provide primary palliative nursing has yet to be determined based on a scoping review of the literature by the nurse researchers on the Steering Committee. In literature mainly from outside of the U.S., a few conclusions have been suggested.

1. Continuing education models that emphasize the need for lifelong learning will be necessary to improve the competencies of professional staff, paraprofessional staff, and volunteers (Billings, Jenkins, & Black, 2011).
2. Curriculum standardization will safeguard quality in palliative care given the inconsistencies across training programs (McDermott, Selman, Wright, & Clark, 2008; similarly, Cheng & Teh, 2014).
3. Models that provided scholarship funding increased physician workforce palliative care capacity in Australia (O'Connor & Peters, 2014).
4. Models that recognize the need to educate all nurses on palliative and end-of-life skills will be necessary to meet the growing needs for care (Chiarella & Duffield, 2007).
5. Different learners (paraprofessional, professional, community workers, etc.) will have different learning needs, knowledge, and demonstrated skills given the populations they serve and roles that they fill (Krongyuth, Campbell, & Silpasuwan, 2014; Unroe, Cagle, Lane, Callahan, & Miller, 2015).
6. Best practices for education and training required for generalists to provide primary palliative nursing care and appropriate levels of education and training for certified nursing assistants (CNAs) and licensed practical nurses (LPNs), who often serve as the front-line palliative care workforce are unknown.

### ***Resources for Curriculum Content***

Content about palliative care and palliative nursing can be included in any curriculum in academic and staff development settings. Resource guides addressing required curriculum content for a successful accreditation process are included in the Education section in Appendix A. The National Council of State Boards of Nursing (NCSBN) provides a regulatory voice related to state licensure for RNs, licensed vocational nurses (LVNs), and LPNs, and controls the development and administration of the qualifying licensure exam. Recent NCSBN publications address palliative care activities and are referenced in Appendix A. Several books deemed helpful for faculty are listed there as well.

Various organizations and agencies have prepared and disseminate learning materials for palliative nursing and palliative care. ELNEC, HPNA, and CARES (Competencies And Recommendations for Educating Undergraduate Nursing Students) resources are incorporated in the Education section in Appendix A.

### ***Palliative Nursing Staff Development Initiatives***

New registered nurses, new advanced practice registered nurses, and experienced RNs and APRNs transitioning from another practice area to palliative care, are not equipped to provide primary, much less specialty-level, palliative care. Such preparation could be supported with establishment of increased numbers of residency and fellowship training programs. Currently, a very limited number of RN residencies and APRN palliative fellowships exist, most of which are affiliated with palliative medicine fellowship programs. Enhanced funding and increased support for the establishment of residencies, internships, fellowships, externships, post degree certificates, immersion courses, and other innovative solutions to increase the palliative nursing workforce capacity are critical.

### ***Educating Patients***

Nurses lead and transform palliative care in education by recognizing and embracing their role as educators for patients. Patient, family, caregiver, interprofessional team, community, and population education can be supported by one-to-one counseling and group support and via a long-term, expanded, telehealth, and coordinated social media campaigns. Social media and other existing and emerging technology solutions such as Facebook, Twitter, YouTube, LinkedIn, other online platforms, and dedicated patient portals provide innovative technologies for meeting the educational and support needs of patients. See the Education section in Appendix A for a selection of resources.

## **Nurses Lead and Transform Palliative Care in Research**

The aging demographic and increased chronic disease burden in the United States will create growing demands for palliative care. Because of a lack of adequate numbers of palliative care specialists, this demand requires the development of a skilled and knowledgeable nursing workforce to meet primary palliative nursing needs. Consequently, the Research Workgroup focused its attention on exploring the available knowledge and evidence gaps to address the palliative nursing workforce needs.

Addressing the current workforce challenges and future needs in the ever-changing U.S. healthcare system is difficult because workforce development involves multiple

factors. To inform the assessment of professional nursing workforce challenges in providing primary palliative nursing care and to identify research gaps, nurse researchers conducted a scoping review of the current literature in the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, and Web of Science. Search terms used were *workforce AND palliative care* or *workforce AND hospice*. Articles published in English in peer-reviewed journals (N = 185) were reviewed and briefly summarized as below. Gaps in evidence were identified and were the basis for recommendations. Some of the results of the scoping review have been incorporated throughout this Call for Action.

### ***Anticipating Workforce Shortage***

Few articles from the U.S. discussed the nursing workforce shortage for palliative care; instead, most reports focused on physician workforce shortage. Connor (2007) provided a historical overview of hospice and palliative care and the anticipated shortage. Lupu (2010) provided an estimated gap between current supply and hypothetical demand to reach mature palliative medicine physician staffing levels to be 2787 to 7510 FTEs (equivalent to 6,000–18,000 individual physicians in palliative medicine). Meier (2011) and Unroe and Meier (2013) expanded on Connor's work, outlining key areas for workforce challenges, along with elaborating on funding issues from the U.S. Appropriations Committee.

The most recent publication by Kamal et al. (2016) made an attempt to differentiate the workforce as the interprofessional team. However, measures used to analyze the data grouped the clinical role as "physician clinicians vs non-physician clinicians." Non-physician clinicians included registered nurses, advanced practice providers, chaplains, and social workers, which made identification of specific nurse shortages difficult. No studies examined specific workforce shortages of nurses. Therefore, the magnitude of the palliative care nursing workforce shortage and its impact are unknown.

### ***Roles of Primary and Specialty Palliative Care***

Chiarella and Duffield (2007) discussed the need to approach workforce issues by generating clinicians to provide primary palliative care rather than depending on specialty palliative care, meaning palliative care services by specialists. A study in Thailand found different palliative care use based on the intensity of patients' needs, suggesting that, while patients with severe symptom burden and distress would require palliative care services by specialists, patients with a low level of palliative care needs may well be managed by primary care (Pang, Qu, Wong, Tan, Poulouse, & Neo, 2015). Griffiths, Simon, Richardson, & Corner (2013) further delineated the roles of primary

and specialty palliative care in nursing in the United Kingdom (UK) and pointed out a lack of clarity between nurses receiving additional education in palliative care versus clinical nurse specialists in palliative care. A lack of clarity exists in definitions of primary and specialty palliative care, including role expectation and care delivered.

### ***Addressing Workforce Wellness***

Workforce wellness is critical in the delivery of palliative care and for recruitment and retention of a healthy palliative care workforce. Palliative care clinicians bear witness to patient and family suffering; consequently, compassion fatigue and burnout can occur. Exhaustion, around-the-clock demands, and moral distress compound these issues. While these phenomena are known to exist, only a handful of studies examined the complex factors that underlie compassion fatigue and burnout (Huynh, Winefield, & Xanthopoulou, & Metzger, 2012; Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2013) and even fewer tested interventions to alleviate compassion fatigue and prevent burnout, to ensure a healthy sustainable workforce (Perez, Haime, Jackson, Chittenden, Mehta, & Park, 2015).

### **Nurses Lead and Transform Palliative Care in Administration**

Establishment of sustainable, quality palliative care programs involves complex planning, financing, and implementation activities. Of key concern is the procurement and retention of an appropriate palliative care workforce as noted earlier. Current federal and philanthropic workforce development funding efforts focus on preparation of palliative care physicians, thereby neglecting the largest available palliative workforce cohort, all members of the nurse community (LPN, LVN, RN, and APRN levels).

The majority of Americans receive their care in community hospitals or community health settings, yet there is little support for primary or specialty level palliative RN or APRN role development in this setting. Many nurses only get *on-the-job training*, often led by physicians and based on a medical model. Opportunities exist for community hospitals and health systems to affiliate with graduate schools of nursing, to develop both an RN residency in hospice and palliative care and an APRN fellowship in the advanced practice nursing model of interprofessional palliative care, with a focus on both clinical and leadership skills. Nurses are best mentored and supervised by an Advanced Certified Hospice and Palliative Nurse (ACHPN<sup>®</sup>) or Certified Hospice and Palliative Nurse (CHPN<sup>®</sup>). Upon completion of the residency program, the RN should be eligible to apply for the CHPN<sup>®</sup> certification. Upon completion of the fellowship program, the APRN should be eligible to apply for the ACHPN<sup>®</sup> certification.

In addition to community hospital settings, innovative care models are needed in the United States to address diverse cultural, geographic, and economic population needs and resource availability, as well as workforce challenges. The Institute of Medicine's (IOM) 2014 report, *Dying in America*, called for the exploration and implementation of new and effective models of care delivery to optimally address community needs and the changing landscape of health care to improve palliative care in the U.S. (IOM, 2014).

New models of care have been suggested by colleagues around the globe to deliver palliative care across the care continuum (MacGeorge, 2014; Maynard & Lynn, 2014; Swetenham, 2014; McDermott, Selman, Wright, & Clark, 2008; Clark, Wright, Hunt, & Lynch, 2007), such as acute care, intensive care, community-based, and long-term care. Innovative care delivery models include hospice day programs using volunteers in English-speaking countries (New Zealand, Canada, and the UK) and integrated community-based home-care programs in Africa. McDermott et al. (2008) suggested a home-care model in India adapted from Western models to fit within the appropriate cultural groups. More research is needed to understand novel care delivery models, especially those that are nurse-led. Studies that examine patient outcomes associated with these models are imperative to determine quality and to justify financing.

The Joint Commission (TJC) currently offers “specialty advanced certification” in palliative care for hospital, hospice, and home health palliative care programs. The Community Health Accreditation Partner (CHAP) offers specialty palliative care certification to programs in the community, such as hospice, home health programs, and healthcare practices. Nurses play a critical role in specialty palliative care certification for organizations as core members of interprofessional teams. Therefore, nurses need to continue to participate in the development and revision of standards for such certifications. Nurses must lead or participate in organizational processes to obtain specialty palliative care certification for their organizations.

Finally, other recognition programs, such as the American Nurses Credentialing Center Magnet Recognition Program<sup>®</sup> and Pathway to Excellence Program<sup>®</sup>, American Association of Critical Care Nurses Beacon Award for Excellence, Academy of Medical-Surgical Nurses Prism Award, and other organizational and unit-based credentialing and recognition programs, should address the provision of palliative nursing education and primary and specialty palliative nursing care delivery in evaluation of the quality of care provided in acute-care hospitals.

## **Nurses Lead and Transform Palliative Care in Policy**

The Institute of Medicine (IOM; now known as the National Academy of Medicine) report, *Future of Nursing: Leading Change, Advancing Health* (2011), calls nurses to assume a greater role in America's increasingly complex healthcare system. The IOM report emphasized the need for significant change in nurses' roles, responsibilities, and education so that nurses are prepared to meet the increased demand for care created by healthcare reform and the aging of the population.

This Professional Issues Panel recommends that nurses fully engage with other health professionals and assume greater leadership roles in redesigning health care in the United States. Such engagement and leadership initiatives are particularly critical in the drive to implement primary palliative care and palliative nursing across all advanced serious illness and injury trajectories. For this to happen, nurses need to educate themselves about current policy initiatives and organize with other nurses and community stakeholders to advocate for removal of organizational, institutional, legislative, and regulatory barriers to nurses' leadership in palliative care. Two palliative policy concerns are highlighted below.

### ***APRNs and Advance Care Planning Billing and Reimbursement***

Advance care planning is the process whereby patients determine what their wishes would be for life-sustaining treatment in the event they are no longer able or willing to speak for themselves. The process of advance care planning, depending on the state, typically results in documentation of their wishes.

While advance care planning typically does not require the participation of a healthcare provider, many Americans find the involvement of such a provider is helpful (<http://kff.org/health-costs/poll-finding/kaiser-health-tracking-poll-september-2015/>). However, less than 30% of all Americans have advance directives (Rao, Anderson, Lin, & Laux, 2014). This low percentage is often attributed to the perception that there is not typically enough time in a clinical visit or encounter for such things to be adequately discussed.

In recognition of insufficient time during clinical encounters to address patient goals for care, the Centers for Medicare and Medicaid Services (CMS) developed Current Procedural Terminology (CPT<sup>®</sup>) billing codes to compensate for the time for such advance care planning discussions starting in 2016. CPT<sup>®</sup> codes 99497 and 99498 can now be submitted by APRNs, as well as physicians and physician assistants, to report advance care planning services provided. The codes can be used more than once per



patient in recognition that persons with progressive or chronic illness may change their wishes and goals as their diseases progress. The codes do not require that advance directives documents result from the conversation. CMS' answers to frequently asked questions about these codes can be accessed at

<https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeeSched/Downloads/FAQ-Advance-Care-Planning.pdf>.

### ***Maximizing Nursing Opportunities via Leadership in Palliative Care and Care Coordination***

Increasing clinician-patient and clinician-family communication, interdisciplinary collaboration, and coordination of care across settings are three key recommendations for improving palliative care in the U.S. as noted in the Institute of Medicine's 2014 *Dying in America* report. As noted earlier in this Call for Action, the IOM report calls for the exploration and implementation of new and effective models of care delivery to optimally address community needs and the changing landscape of health care.

Nurses serve as highly qualified care coordinators and leaders in safe, quality palliative care. Efforts to support these recommendations include embracing and enacting the recommendations from the 2015 American Nurses Association and American Academy of Nursing *Policy Agenda for Nurse-led Care Coordination*. These recommendations include recognizing bachelor's-prepared nurses as qualified care coordinators and expanding reimbursement mechanisms to allow for these nurses to bill for care coordination services. Policy initiatives present in both palliative care and care coordination serve as opportunities to achieve the recommendations set forth by both reports and improve the quality of life and care delivery for patients and families in need of palliative care services.

## **Recommendations**

**Seriously ill and injured patients, families, and communities should receive quality palliative care in all care settings. This is achieved by the delivery of primary palliative nursing by every nurse, regardless of setting.** The following recommendations support this conclusion:

1. Adopt the End of Life Nursing Education Consortium (ELNEC) curricula (Core, Geriatric, Critical Care, Pediatric, Advanced Practice Registered Nurse [APRN], Online for Undergraduate Nursing Students) as the standard for primary palliative nursing education for pre-licensure, graduate, doctoral, and continuing education

for practicing registered, vocational, and practical nurses and advanced practice registered nurses.

2. Petition the National Council for State Boards of Nursing to increase palliative care content on the pre-licensure NCLEX-RN and NCLEX-PN exams.
3. Encourage state boards of nursing with continuing education re-licensure requirements to mandate palliative care content.
4. Advocate the use of the National Consensus Project for Quality Palliative Care *Clinical Practice Guidelines for Quality Palliative Care* in the development, implementation, and evaluation of specialty, evidence-based palliative care services for all organizations.
5. Recommend that all specialty nursing organizations review registered nurse (RN) and APRN practice standards to include primary palliative nursing care and develop resources and position papers to support and advance primary palliative nursing.
6. Fund, develop, and evaluate innovative palliative care models to address workforce challenges and the needs of communities of color, underserved populations, and other vulnerable groups, such as Native Americans, persons with intellectual and developmental disabilities, and others in rural and urban areas.
7. Convene a thought leader summit to address practice barriers and develop initiatives to implement primary palliative care.
8. Incorporate primary palliative nursing as part of the American Nurses Credentialing Center Magnet Recognition Program<sup>®</sup> and Pathway to Excellence Program<sup>®</sup>, American Association of Critical Care Nurses Beacon Award for Excellence, Academy of Medical-Surgical Nurses Prism Award, and other organizational and unit-based credentialing and recognition programs.
9. Conduct intervention studies testing strategies to alleviate compassion fatigue and moral distress to maintain a healthy workforce.
10. Promote equitable reimbursement and reduction of barriers by all payers for RN and APRN services related to palliative and hospice care.

11. Support the funding and development of palliative care services for communities with limited resources.
12. Position nurses at decision-making and policy-setting venues, such as healthcare and regulatory boards, to address palliative care needs.

Additional opportunities for actions to advance palliative care are noted in Appendix B.

## **Summary**

As members of the largest healthcare professionals' cohort, the nation's 3.6 million nurses must be prepared to actively contribute insights about holistic person-centered care, identification and respect for patient choices, and access and provision of palliative care from prenatal to end of life. Significant changes in healthcare delivery, workforce education and capacity-building, and financing are predicted for the coming years. These changes will provide innumerable opportunities for nurses to actively engage in designing new palliative care programs, improving educational services, developing policy, and appropriately crafting regulatory and legislative language to address access, safety, quality, and payment reform for palliative care services. Such committed nursing action will lead and transform palliative care, moving the nation closer to affirmation that "Everyone should have access to palliative care" identified in the 2015 IOM's report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*.

## Glossary

**Family:** The diverse network of care-related persons, chosen family, friends, volunteers, partners, and other designated people who journey with a person through life-limiting illness until death. “Family of origin or significant others as identified by the healthcare consumer.” (ANA, 2015, p.87)

**Interdisciplinary team:** An interdisciplinary team (IDT) provides services to the patient and family consistent with the care plan. In addition to chaplains, nurses, physicians, and social workers, other therapeutic disciplines who provide palliative care services to patients and families may include: child-life specialists, nursing assistants, nutritionists, occupational therapists, respiratory therapists, pharmacists, physical therapists, massage, art, and music therapy, psychologists, and speech and language pathologists.

**Interprofessional team:** The interprofessional team relies on the overlapping knowledge, skills, and abilities of each professional team member. This reliance can drive synergistic effects by which outcomes are enhanced and become more comprehensive than a simple aggregation of the individual efforts of team members (ANA, 2015, p. 88).

**Nursing:** “Nursing is the protection, promotion, and optimization of health and abilities, prevention of illness and injury, facilitation of healing, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, groups, communities, and populations.” (ANA, 2015, p. 1)

**Palliative care:** “Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing the physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice” (Dahlin, 2015a, p. 9). Persons dealing with serious injury also can benefit from palliative care services.

**Primary palliative nursing:** ‘Fundamental care of patients with serious or life-threatening illness or injury and their families provided by nonpalliative care specialty registered nurses builds upon their basic nursing education. This allows nurses to provide “patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering” (NCP, 2013, p. 9)’ (ANA & HPNA, 2014, p. 66).

**Specialty palliative nursing:** Specialty palliative nursing includes both the generalist (RN) and advanced practice registered nurse role (APRN) and involves the management of complex and refractory symptoms, advanced skills in communication and conflict resolution, and navigating the changing care needs across the trajectory of life. Specialty palliative care occurs in a variety of settings such as inpatient palliative care services, home and residential hospice programs, and disease-specific palliative care programs, such as oncology or heart failure supportive or palliative care services. (ANA & HPNA, 2014)

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## Appendix A. Additional Resources

### Authors

### Resources

#### Practice

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<p>National Academies of Sciences, Engineering, and Medicine.</p>	<p><i>Families caring for an aging America</i>. (2016). Washington, DC: The National Academies Press.  <a href="http://www.nationalacademies.org/hmd/Reports/2016/families-caring-for-an-aging-america.aspx">http://www.nationalacademies.org/hmd/Reports/2016/families-caring-for-an-aging-america.aspx</a></p> <p><i>Dying in America: Improving quality and honoring individual preferences near the end of life</i>. (2014). Washington, DC: The National Academies Press.  <a href="http://www.nationalacademies.org/hmd/Reports/2014/">http://www.nationalacademies.org/hmd/Reports/2014/</a></p>

	<p><a href="http://www.nationalacademies.org/hmd/Reports/2013/Delivering-High-Quality-Cancer-Care-Charting-a-New-Course-for-a-System-in-Crisis.aspx">Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx</a></p> <p><i>Delivering high-quality cancer care: Charting a new course for a system in crisis.</i> (2013). Washington, DC: The National Academies Press.  <a href="http://www.nationalacademies.org/hmd/Reports/2013/Delivering-High-Quality-Cancer-Care-Charting-a-New-Course-for-a-System-in-Crisis.aspx">http://www.nationalacademies.org/hmd/Reports/2013/Delivering-High-Quality-Cancer-Care-Charting-a-New-Course-for-a-System-in-Crisis.aspx</a></p> <p>Committee on palliative and end-of-life care for children and their families. (2003). In M. J. Field &amp; R. E. Behrman (Eds.), <i>When children die: Improving palliative and end of life care for children and their families</i>. Washington, DC: The National Academies Press.  <a href="https://www.nap.edu/catalog/10390/when-children-die-improving-palliative-and-end-of-life-care">https://www.nap.edu/catalog/10390/when-children-die-improving-palliative-and-end-of-life-care</a></p> <p><i>Crossing the quality chasm: A new health system for the 21<sup>st</sup> century.</i> (2001). Washington, DC: The National Academies Press.  <a href="http://www.nationalacademies.org/hmd/Reports/2001/Crossing-the-Quality-Chasm-A-New-Health-System-for-the-21st-Century.aspx">http://www.nationalacademies.org/hmd/Reports/2001/Crossing-the-Quality-Chasm-A-New-Health-System-for-the-21st-Century.aspx</a></p> <p><i>To err is human: Building a safer health system.</i> (2000). Washington, DC: The National Academies Press.  <a href="https://www.nap.edu/catalog/9728/to-err-is-human-building-a-safer-health-system">https://www.nap.edu/catalog/9728/to-err-is-human-building-a-safer-health-system</a></p>
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<p>National Quality Forum.</p>	<p><i>Issue brief: Strategies for change – A collaborative journey to transform advanced illness care.</i> (2016). Washington, DC: Author.  <a href="http://www.qualityforum.org/Publications/2016/11/Strategies-for-change">http://www.qualityforum.org/Publications/2016/11/Strategies-for-change</a></p>

	<p><a href="#">Strategies for Change - A Collaborative Journey to Transform Advanced Illness Care.aspx</a></p> <p><i>National voluntary consensus standards: Palliative care and end of life care – A consensus report.</i> (2012). Washington, DC: Author.  <a href="http://www.qualityforum.org/Publications/2012/04/Palliative_Care_and_End-of-Life_Care%E2%80%9494A_Consensus_Report.aspx">http://www.qualityforum.org/Publications/2012/04/Palliative_Care_and_End-of-Life_Care%E2%80%9494A_Consensus_Report.aspx</a></p>
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Wittenberg-Lyles, E., Goldsmith, J., Ferrell, B., & Ragan, S. L. (2013).	<i>Communication in palliative nursing.</i> New York: Oxford University Press.
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**Advance Care Planning, Respecting Choices, Crucial Conversations**

AARP	<p><i>Advance directive: Creating a living will and health care power of attorney.</i> (2010).  <a href="http://www.aarp.org/relationships/caregiving-resource-center/info-11-2010/lfm_living_will_and_health_care_power_of_attorney.html">http://www.aarp.org/relationships/caregiving-resource-center/info-11-2010/lfm_living_will_and_health_care_power_of_attorney.html</a></p>
Advance Care Planning Decisions	<p>Resources for both healthcare providers, patients and families on what palliative care is, and the beginning steps of the process</p> <ul style="list-style-type: none"> <li>• Checklists for patients and families on preparing for palliative care in many languages</li> <li>• Video resources for patients and families</li> </ul>

	<p>on what palliative care is</p> <ul style="list-style-type: none"> <li>• Video resources for health care providers on a variety of different conditions</li> </ul> <p><a href="https://www.acpdecisions.org">https://www.acpdecisions.org</a></p>
Aging with Dignity (Five Wishes)	<a href="https://www.agingwithdignity.org/about-us">https://www.agingwithdignity.org/about-us</a>
American Cancer Society	<p><i>How to set up an advance directive so that it works when you need it</i></p> <p><a href="http://www.cancer.org/treatment/findingandpavingfortreatment/understandingfinancialandlegal matters/advancedirectives/advance-directives-setting-up-a-good-adv-health-care-directive">http://www.cancer.org/treatment/findingandpavingfortreatment/understandingfinancialandlegal matters/advancedirectives/advance-directives-setting-up-a-good-adv-health-care-directive</a></p>
Center to Advance Palliative Care	<p>For clinicians: <a href="https://getpalliativecare.org/resources/clinicians/">https://getpalliativecare.org/resources/clinicians/</a></p> <p>For patients: <a href="https://getpalliativecare.org/whatis/">https://getpalliativecare.org/whatis/</a></p>
The Conversation Project	<p><i>The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.</i></p> <p><a href="http://www.theconversationproject.org/">www.theconversationproject.org/</a></p>
Gundersen Health System	<p><i>Respecting Choices<sup>®</sup>: Transforming person-centered care.</i></p> <p><a href="http://www.gundersenhealth.org/respecting-choices">http://www.gundersenhealth.org/respecting-choices</a></p>
National Hospice and Palliative Care Organization <a href="http://www.caringinfo.org">www.caringinfo.org</a>	<p>Download your state's advance directives. <i>CaringInfo</i> (formerly Caring Connections) lists each state's advance directives and necessary forms.</p> <p><a href="http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289">http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289</a></p>
National POLST Paradigm	<p>Out-of-hospital life-sustaining treatment orders – physician orders for life-sustaining treatment (also known as POLST, MOLST)</p> <p><a href="http://www.polst.org/">http://www.polst.org/</a></p>
Planetree Patient-Centered Care	<p>Patient-centered care</p> <p><a href="http://planetree.org/">http://planetree.org/</a></p>

U.S. Department of Veterans Affairs	<p><i>Geriatrics and extended care: Shared decision making – Overview</i>                  Patient information for family discussion, planning chronic illness care, and transitioning to palliative and hospice care.  <a href="http://www.va.gov/geriatrics/Guide/LongTermCare/Shared_Decision_Making.asp">http://www.va.gov/geriatrics/Guide/LongTermCare/Shared_Decision_Making.asp</a></p>
U.S. Living Will Registry	<p>Site at which people can register their advance directives; allows the document to be accessed by providers or hospitals in the event that access becomes necessary.  <a href="https://www.uslivingwillregistry.com/">https://www.uslivingwillregistry.com/</a></p> <p><i>Advance directive forms</i>  <a href="http://uslwr.com/formslst.shtm">http://uslwr.com/formslst.shtm</a></p>

### Organizations

American Association of Critical Care Nurses (AACN)	<p><i>Clinical resources</i>  <a href="https://www.aacn.org/clinical-resources">https://www.aacn.org/clinical-resources</a></p> <p>CSI project – Bridging the gap: Improving care through understanding  <a href="https://www.aacn.org/clinical-resources/csi-projects/bridging-the-gap-improving-care-through-understanding">https://www.aacn.org/clinical-resources/csi-projects/bridging-the-gap-improving-care-through-understanding</a></p> <p>Palliative care in the ICU: Critical communication skills (free webinar)  <a href="https://www.aacn.org/education/webinar-series/wb0032/palliative-care-in-the-icu-critical-communication-skills">https://www.aacn.org/education/webinar-series/wb0032/palliative-care-in-the-icu-critical-communication-skills</a></p> <p><i>Resources for palliative/end of life</i>  <a href="http://www.aacn.org/wd/practice/content/palliative-and-end-of-life-care.pcms?menu=practice">http://www.aacn.org/wd/practice/content/palliative-and-end-of-life-care.pcms?menu=practice</a></p>
Ariadne Labs	<p>Serious illness care  <a href="https://www.ariadnelabs.org/areas-of-work/serious-illness-care">https://www.ariadnelabs.org/areas-of-work/serious-illness-care</a></p>
Center to Advance Palliative Care™ (CAPC)	<p>National organization dedicated to increasing the availability of tools, training, technical</p>

	<p>assistance, and metrics to support successful implementation and integration of quality palliative care services for people facing serious illness.</p> <p><i>Overview</i>  <a href="https://www.capc.org/policymakers/overview/">https://www.capc.org/policymakers/overview/</a></p> <p><i>About the Center to Advance Palliative Care (CAPC)</i>  <a href="https://www.capc.org/about/capc/">https://www.capc.org/about/capc/</a></p> <p><i>For clinicians: Ten steps for what to day and do</i>  <a href="https://getpalliativecare.org/resources/clinicians/">https://getpalliativecare.org/resources/clinicians/</a></p> <p><i>What is palliative care?</i>  <a href="https://getpalliativecare.org/whatis/">https://getpalliativecare.org/whatis/</a></p>
<p>City of Hope Pain &amp; Palliative Care Resource Center</p>	<p>Resources for pain, palliative care, quality of life, and cancer survivorship</p> <p>Key resources</p> <ul style="list-style-type: none"> <li>• Pain management card</li> <li>• Symptoms management card</li> <li>• Knowledge and attitudes survey regarding pain</li> <li>• Quality of life instruments</li> </ul> <p>Categories of materials</p> <ul style="list-style-type: none"> <li>• Quality of life and cancer survivorship</li> <li>• Spirituality</li> <li>• Palliative care</li> <li>• Pain and symptom management</li> <li>• Special populations</li> <li>• Education</li> <li>• Quality improvement</li> <li>• Ethical and legal issues</li> <li>• Research instruments and resources</li> </ul> <p><a href="http://prc.coh.org/">http://prc.coh.org/</a></p>
<p>Coalition to Transform Advanced Care (C-TAC)</p>	<p>Nonprofit, nonpartisan organization based in Washington, D.C., funded by grants and the support of members</p> <p><a href="http://www.thectac.org/">http://www.thectac.org/</a></p>

	<p>Novelli, B., &amp; Koutsoumpas, T.; Workman, B. (Ed.). (2015). <i>A roadmap for success: Transforming advanced illness care in America</i>. Washington, DC: C-TAC.  <a href="https://issuu.com/ctac5/docs/a_roadmap_for_success">https://issuu.com/ctac5/docs/a_roadmap_for_success</a></p>
ConsultGeri	<p>The Hartford Institute for Geriatric Nursing clinical website. Classic assessment tools commonly used in the geriatric population. Includes <i>Nursing Standard of Practice Protocol: Palliative Care</i> and other related topics.  <a href="https://consultgeri.org/">https://consultgeri.org/</a></p>
Critical Care Societies Collaborative: Choosing Wisely	<p><i>Five Things Physicians and Patients Should Question</i> (n.d.)  <a href="http://ccsconline.org/images/CCSC-Choosing-Wisely.pdf">http://ccsconline.org/images/CCSC-Choosing-Wisely.pdf</a></p>
Eldercare Workforce Alliance	<p>31 national organizations representing patients, family caregivers, the direct-care workforce, and healthcare professionals, joined together to propose practical solutions to strengthen our eldercare workforce and improve the quality of care.  <a href="http://www.eldercareworkforce.org/">http://www.eldercareworkforce.org/</a></p>
Emergency Nurses Association (ENA)	<p>Position statement: Access to quality care. (2016). Des Plaines, IL: Author.  <a href="https://www.ena.org/practice-research/Practice/Position/Pages/AccessToQualityHealthcare.aspx">https://www.ena.org/practice-research/Practice/Position/Pages/AccessToQualityHealthcare.aspx</a></p>
Hospice and Palliative Nurses Association (HPNA) position statements	<p>Website for the Hospice and Palliative Care Nurses Association (<a href="http://hpna.advancingexpertcare.org/">http://hpna.advancingexpertcare.org/</a>) with free and member-only resources in the areas of education, certification, advocacy, leadership, research, and careers.</p> <p>Position statements on the following topics may be found at  <a href="http://advancingexpertcare.org/position-statements/">http://advancingexpertcare.org/position-statements/</a></p>



	<p><a href="#"><u>Artificial Nutrition and Hydration in Advanced Illness</u></a></p> <p><a href="#"><u>Assuring High Quality in Palliative Nursing</u></a></p> <p><a href="#"><u>Complementary Therapies in Palliative Care Nursing Practice</u></a></p> <p><a href="#"><u>Evidence-Based Practice</u></a></p> <p><a href="#"><u>Medication Error Reporting in the Home Setting</u></a></p> <p><a href="#"><u>Pain Management</u></a></p> <p><a href="#"><u>Palliative Sedation</u></a></p> <p><a href="#"><u>Role of Hospice and Palliative Nurses in Research</u></a></p> <p><a href="#"><u>Role of Palliative Care in Organ and Tissue Donation</u></a></p> <p><a href="#"><u>Role of the Nurse when Hastened Death is Requested</u></a></p> <p><a href="#"><u>Shortage of Registered Nurses</u></a></p> <p><a href="#"><u>Spiritual Care</u></a></p> <p><a href="#"><u>The Ethics of Opioid Use at End of Life</u></a></p> <p><a href="#"><u>The Nurse's Role in Advance Care Planning</u></a></p> <p><a href="#"><u>The Use of Medical Marijuana</u></a></p> <p><a href="#"><u>Value of the Advanced Practice Registered Nurse in Palliative Care</u></a></p> <p><a href="#"><u>Value of the Licensed Practical/Vocational Nurse in Palliative Care</u></a></p> <p><a href="#"><u>Value of the Nursing Assistant in Palliative Care</u></a></p> <p><a href="#"><u>Value of the Professional Nurse in Palliative Care</u></a></p> <p><a href="#"><u>Withholding and/or Withdrawing Life Sustaining Therapies</u></a></p> <p><a href="#"><u>Definition of Terms for Position Statements</u></a></p>
<p>The Integrating Multidisciplinary Palliative Care into the ICU (IMPACT-ICU) Project</p>	<p>Led by University of California San Francisco and taught in all UC hospitals</p> <p>Milic, M. M., Puntillo, K., Turner, K., Joseph, D., Peters, N., Ryan, R., ... Anderson, W. G. (2015). Communicating with patients' families and physicians about prognosis and goals of care. <i>American Journal of Critical Care</i>, 24: e56–e64.</p> <p>Anderson, W. G., Puntillo, K., Cimino, J., Noort, J., Pearson, D., Boyle, D., ... Pantilat, S.</p>

	<p>Z. (in press). IMPACT-ICU: Multi-center implementation of a palliative care professional development program for bedside critical care nurses. <i>American Journal of Critical Care</i>.</p> <p>Anderson, W. G. , Puntillo, K., Barbour, S., Turner, K., Cimino, J., Moore, E., ... Pantilat, S. <i>The Integrating multidisciplinary palliative care into the ICU (IMPACT-ICU) project guide</i>, 2015.  <a href="https://ucsf.box.com/ImpactICUProjectGuide">https://ucsf.box.com/ImpactICUProjectGuide</a></p>
International Children's Palliative Care Network	<p>Worldwide network of individuals and agencies working to improve the lives of children with life-limiting conditions through communication, advocacy, research, education and strategic development of services  <a href="http://www.icpcn.org">http://www.icpcn.org</a></p>
International Council of Nurses (ICN)	<p>Position statement on nurses' role in providing care to dying patients and their families  <a href="http://www.icn.ch/images/stories/documents/publications/position_statements/A12_Nurses_Role_Care_Dying_Patients.pdf">http://www.icn.ch/images/stories/documents/publications/position_statements/A12_Nurses_Role_Care_Dying_Patients.pdf</a></p>
Interventions to Reduce Acute Care Transfers (INTERACT)	<p>Quality improvement, communications, decision support, advance planning tools from Florida Atlantic University  <a href="https://interact2.net/tools_v4.html">https://interact2.net/tools_v4.html</a></p>
Johns Hopkins: The Only Metastatic Cancer Survivor Retreat of its Kind	<p>Video describing Johns Hopkins Breast Center retreats for stage IV breast cancer survivors  <a href="https://www.youtube.com/watch?v=Bg02G2a7uHo">https://www.youtube.com/watch?v=Bg02G2a7uHo</a></p>
National Association of Pediatric Nurse Practitioners (NAPNAP)	<p><i>Position statement: Precepts of palliative care for children and adolescents and their families</i>  <a href="https://www.napnap.org/sites/default/files/userfiles/about/PalliativecarePS_support.pdf">https://www.napnap.org/sites/default/files/userfiles/about/PalliativecarePS_support.pdf</a></p>
National Hospice and Palliative Care Organization (NHPCO)	<p>Community practice models, webinars and courses  <a href="http://www.nhpc.org/palliative-care-4">http://www.nhpc.org/palliative-care-4</a>  <a href="http://www.nhpc.org/resources">http://www.nhpc.org/resources</a></p> <p>Information on quality and performance</p>

	<p>measures  <a href="http://www.nhpc.org/qualitypartners">http://www.nhpc.org/qualitypartners</a></p> <p>Information about ChiPPS (Children’s Project on Palliative/Hospice Services), NHPCO’s pediatric advisory council, including standards of practice, educational programs, patient and family teaching materials, and information on Concurrent Care for Children Requirement of Patient Protection and Affordable Care Act (PPACA)  <a href="http://www.nhpc.org/pediatric">http://www.nhpc.org/pediatric</a></p> <p>List of links for multiple resources related to palliative care for patients and families and healthcare providers  <a href="http://www.nhpc.org/resources/end-life-care--resources">http://www.nhpc.org/resources/end-life-care--resources</a></p>
<p>National Institute of Nursing Research (NINR)</p>	<p>Palliative care resources  <a href="https://www.ninr.nih.gov/newsandinformation/newsandnotes/category/Palliative%20Care#.Vz6ta_krLio">https://www.ninr.nih.gov/newsandinformation/newsandnotes/category/Palliative%20Care#.Vz6ta_krLio</a></p>
<p>National Institute on Aging (NIA)</p>	<p>Health &amp; aging: Palliative care  <a href="https://www.nia.nih.gov/health/topics/palliative-care">https://www.nia.nih.gov/health/topics/palliative-care</a></p>
<p>National Library of Medicine (NLM)</p>	<p>Medline Plus: Palliative care  <a href="https://www.nlm.nih.gov/medlineplus/palliativecare.html">https://www.nlm.nih.gov/medlineplus/palliativecare.html</a></p>
<p>National Palliative Care Research Center (NPCRC)</p>	<p>Promotes and funds research on improving care for seriously ill patients and their families  <a href="http://www.npcrc.org">http://www.npcrc.org</a></p>
<p>Oncology Nurses Society (ONS)</p>	<p><i>Palliative care for people with cancer.</i> (reviewed 2016).  <a href="https://www.ons.org/advocacy-policy/positions/practice/palliative-care">https://www.ons.org/advocacy-policy/positions/practice/palliative-care</a></p> <p><i>Cancer pain management.</i> (2016).  <a href="https://www.ons.org/advocacy-policy/positions/practice/pain-management">https://www.ons.org/advocacy-policy/positions/practice/pain-management</a></p>

	<p>Colwell, J. ONS: Start palliative care at diagnosis for all cancer patients. <i>CancerNetwork</i>, 2015.  <a href="http://www.cancernetwork.com/oncology-nursing/ons-start-palliative-care-diagnosis-all-cancer-patients">http://www.cancernetwork.com/oncology-nursing/ons-start-palliative-care-diagnosis-all-cancer-patients</a></p>
Palliative Care Network of Wisconsin (PC NOW)	<p>Home of “Fast Facts”  <a href="http://www.mypcnw.org/">http://www.mypcnw.org/</a></p>
UCLA Health	<p><i>Palliative care services: For health care professionals – Resources and educational materials</i> (n.d.)</p> <ul style="list-style-type: none"> <li>• Advance directive planning resources</li> <li>• Resources on pain assessment and management</li> <li>• Education modules regarding various palliative care topics</li> <li>• Current research discussions/resources</li> </ul> <p><a href="https://www.uclahealth.org/palliative-care/resources-and-educational-material#general">https://www.uclahealth.org/palliative-care/resources-and-educational-material#general</a></p>

### Education

American Academy of Hospice and Palliative Medicine. (2014)	<p><i>Primer of Palliative Care</i>, 6<sup>th</sup> Edition. Chicago: Author.</p> <p>Favorite educational tool used by fellowship programs and teaching institutions to introduce the core, essential concepts in high-quality care for patients facing serious or life-threatening illnesses and their families. Available for purchase at <a href="http://aahpm.org/self-study/primer">http://aahpm.org/self-study/primer</a></p>
American Association of Colleges of Nursing (AACN)	<p><i>CARES: Competencies and recommendations for educating undergraduate nursing students – Preparing nurses to care for the seriously ill and their families.</i> (n.d.)  <a href="http://www.aacn.nche.edu/el nec/New-Palliative-Care-Competencies.pdf">http://www.aacn.nche.edu/el nec/New-Palliative-Care-Competencies.pdf</a>          (Appendix I and II are especially helpful)</p> <p>Guides for academic faculty for curriculum content evaluated during accreditation processes:</p>

	<p>(2006). <i>The essentials of doctoral education for advanced nursing practice</i>. Washington, DC: Author.</p> <p>(2008). <i>The essentials of baccalaureate education for professional nursing practice</i>. Washington, DC: Author.</p> <p>(2011). <i>The essentials of master's education for advanced practice nursing education</i>. Washington, DC: Author.</p>
Benner, P., Benner, P. E., Sutphen, M., & Leonard, V. (2009)	<i>Educating nurses: A call for radical transformation</i> . San Francisco, CA: Jossey--Bass.
Bradshaw, M. J., & Lowenstein, A. J. (Eds.). (2014)	<i>Innovative teaching strategies in nursing and related health professions</i> . Sudbury, MA: Jones & Bartlett.
Education in Palliative and End-of-Life Care (EPEC)	<a href="http://bioethics.northwestern.edu/programs/epec/">http://bioethics.northwestern.edu/programs/epec/</a>
End-of-Life Nursing Education Consortium (ELNEC), American Association of Colleges of Nursing	<p>Online learning modules</p> <ul style="list-style-type: none"> <li>• ELNEC-Core</li> <li>• ELNEC-Pediatric Palliative Care</li> <li>• ELNEC-Geriatric</li> <li>• ELNEC-Critical Care</li> <li>• ELNEC-APRN</li> <li>• ELNEC Online for Undergraduate Nursing Students</li> </ul> <p><a href="http://www.aacn.nche.edu/elnec">http://www.aacn.nche.edu/elnec</a></p>
Hospice and Palliative Nurses Association	<p>Graduate Program Listing: Hospice and Palliative Master's Education Programs updated July 2013</p> <p><a href="http://hpna.advancingexpertcare.org/education/graduate-program-listing/">http://hpna.advancingexpertcare.org/education/graduate-program-listing/</a></p>
Hospice & Palliative Credentialing Center (HPCC); 20110	<p>Statement on continuing competence for nursing: A call to action. Pittsburgh: Author.</p> <p><a href="http://hpcc.advancingexpertcare.org/wp-content/uploads/2015/02/Statement-on-Continuing-Competence-for-Nursing.pdf">http://hpcc.advancingexpertcare.org/wp-content/uploads/2015/02/Statement-on-Continuing-Competence-for-Nursing.pdf</a></p>

<p>Interprofessional Education Collaborative Expert Panel. (2016)</p>	<p><i>Core competencies for interprofessional collaborative practice: 2016 update.</i> Washington, DC: Interprofessional Education Collaborative.  <a href="https://ipecollaborative.org/uploads/IPEC-2016-Updated-Core-Competencies-Report_final_release_.PDF">https://ipecollaborative.org/uploads/IPEC-2016-Updated-Core-Competencies-Report_final_release_.PDF</a></p>
<p>Knowles, M. S., Holton, E. F., &amp; Swanson, R. A. (2015)</p>	<p><i>The adult learner: The definitive classic in adult education and human resource development.</i> New York: Routledge.</p>
<p>National Council of State Boards of Nursing (NCSBN)</p>	<p>(2015). 2014 RN practice analysis: Linking the NCLEX-RN<sup>®</sup> examination to practice – U.S. and Canada. <i>NCSBN Research Brief</i>, 62.  <a href="https://www.ncsbn.org/15_RN_Practice_Analysis_Vo_l62_web.pdf">https://www.ncsbn.org/15_RN_Practice_Analysis_Vo_l62_web.pdf</a></p> <p>(2016). 2016 environmental scan. <i>Journal of Nursing Regulation</i>, 6(4).  <a href="https://www.ncsbn.org/6212.htm">https://www.ncsbn.org/6212.htm</a></p>
<p>National League for Nursing (NLN; n.d.)</p>	<p>Advancing Care Excellence for Seniors (ACES) and Advancing Care Excellence for Alzheimer's Patients and Caregivers (ACEZ) Projects advance the care of older adults through innovations in nursing education  <a href="http://www.nln.org/professional-development-programs/teaching-resources/aging">http://www.nln.org/professional-development-programs/teaching-resources/aging</a></p>

**Cultural Diversity**

<p>American Association of Colleges of Nursing</p>	<p><i>Tool kit of resources for cultural competent education for baccalaureate nurses.</i> (2008)  <a href="http://www.aacn.nche.edu/education-resources/toolkit.pdf">http://www.aacn.nche.edu/education-resources/toolkit.pdf</a></p> <p><i>Tool kit for cultural competence in master's and doctoral nursing education.</i> (2011)  <a href="http://www.aacn.nche.edu/education-resources/Cultural_Competency_Toolkit_Grad.pdf">http://www.aacn.nche.edu/education-resources/Cultural_Competency_Toolkit_Grad.pdf</a></p>
<p>Betancourt, J., Green, A. R., &amp; Carrillo, J. E.</p>	<p><i>Cultural competence in health care: Emerging frameworks and practical approaches.</i> (2002). New York: The Commonwealth Fund.</p>
<p>Betancourt, J. R.</p>	<p><i>Improving quality and achieving equity: The role of cultural competence in reducing racial and ethnic</i></p>

	<i>disparities in health care.</i> (2006). New York: The Commonwealth Fund.
Fadia, S.	The case for cultural competence in health professions education. (2006). <i>American Journal of Pharmacy Education</i> , 70(6): 124.
Giger, J., Davidhizar, R., Purnell, L., Harden, T., Phillips, J., & Strickland, O.	American Academy of Nursing expert panel report: Developing cultural competencies to eliminate health disparities in ethnic minorities and other vulnerable populations. (2007). <i>Journal of Transcultural Nursing</i> , 18(2), 100.
Growthhouse.org	Provides resources for patient and healthcare professionals <a href="http://www.growthhouse.org/">http://www.growthhouse.org/</a>
Health Evidence Network, World Health Organization Regional Office for Europe.	<i>What is the evidence on effectiveness of empowerment to improve health?</i> (2006). <a href="http://www.euro.who.int/__data/assets/pdf_file/0010/74656/E88086.pdf">http://www.euro.who.int/__data/assets/pdf_file/0010/74656/E88086.pdf</a>
Implementing culturally competent care.	(2015). <i>Nursing Outlook</i> , 63, 227–229.
Institute of Medicine (IOM).	<i>Unequal treatment: What healthcare providers need to know about racial and ethnic disparities in health care.</i> (2002). <a href="http://www.nationalacademies.org/hmd/Reports/2002/Unequal-Treatment-Confronting-Racial-and-Ethnic-Disparities-in-Health-Care.aspx">http://www.nationalacademies.org/hmd/Reports/2002/Unequal-Treatment-Confronting-Racial-and-Ethnic-Disparities-in-Health-Care.aspx</a>
Leininger, M. M., & McFarland, M. R.	<i>Culture care diversity and universality: A worldwide nursing theory.</i> (2006). Boston: Jones and Bartlett Publishers.
Lurie, N., Fremont, A., Somers, S. A., Coltin, K., Geltzer, A., Johnson, R., ... Zimmerman, D.	The national health plan collaborative to reduce disparities and improve quality. (2008). <i>Joint Commission Journal on Quality and Patient Safety</i> , 34(5), 256–265.
Rosenkoetter, M. M., & Nardi, D. A.	American Academy of Nursing Expert Panel on Global Nursing and Health: White paper on global nursing and health. [Academia Americana de Enfermería, Panel de Expertos en Enfermería Global y Salud: Documento de opinión en

	enfermería global y salud]. (2007). <i>Journal of Transcultural Nursing</i> , 18(4), 305–315.
The Sullivan Commission	<i>Missing person: Minorities in the health professions – A report of the Sullivan Commission on Diversity in the Healthcare Workforce</i> . (2004). <a href="http://www.aacn.nche.edu/media-relations/SullivanReport.pdf">http://www.aacn.nche.edu/media-relations/SullivanReport.pdf</a>
United Nations	Office of the High Commissioner for Human Rights. <i>universal declaration of human rights: Dignity and justice for all of us</i> . (2008). <a href="http://www.un.org/en/universal-declaration-human-rights/">http://www.un.org/en/universal-declaration-human-rights/</a>
U.S. Department of Health and Human Services Administration, Health Resources and Services Administration (HRSA)	<i>Culture, language, and health literacy resources: General</i> <a href="http://www.hrsa.gov/culturalcompetence/general.html">http://www.hrsa.gov/culturalcompetence/general.html</a>
U.S. Department of Health and Human Services Administration, Health Resources and Services Administration (HRSA)	<i>Indicators of cultural competence in health care delivery organizations: An organizational cultural competence assessment profile</i> . (2002). <a href="http://www.hrsa.gov/culturalcompetence/healthdlvr.pdf">http://www.hrsa.gov/culturalcompetence/healthdlvr.pdf</a>

## Research

National Institute of Nursing Research (NINR)	<a href="https://www.ninr.nih.gov">https://www.ninr.nih.gov</a>  <i>The NINR strategic plan: Advancing science, improving lives</i> (page 31) <a href="https://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/NINR_StratPlan2016_reduced.pdf">https://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/NINR_StratPlan2016_reduced.pdf</a>
National Palliative Care Research Center	<a href="http://www.npcrc.org/">http://www.npcrc.org/</a>
Palliative Care Research Cooperative Group (PCRC)	<a href="http://www.npcrc.org/">http://www.npcrc.org/</a>

## Administration

American Association of Critical-Care Nurses	<i>Resources for palliative/end-of-life</i> <a href="http://www.aacn.org/wd/practice/content/palliative-and-end-of-life-care.pcms?menu=practice">http://www.aacn.org/wd/practice/content/palliative-and-end-of-life-care.pcms?menu=practice</a>
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<p>Hospice &amp; Palliative Nurses Association</p>	<p><i>Position statement: Palliative nursing leadership</i></p> <p><a href="http://hpna.advancingexpertcare.org/wp-content/uploads/2015/02/Position-Statement-on-Palliative-Nursing-Leadership.pdf">http://hpna.advancingexpertcare.org/wp-content/uploads/2015/02/Position-Statement-on-Palliative-Nursing-Leadership.pdf</a></p>
<p>Husaini, A.</p>	<p>The role of nurses in providing palliative care for dying cancer patients: A meta-ethnographic synthesis. (2014). <i>BMJ Supportive &amp; Palliative Care</i>, 4(Suppl 1), A1–A110.</p> <p><a href="http://spcare.bmj.com/content/4/Suppl_1/A1.3.abstract">http://spcare.bmj.com/content/4/Suppl_1/A1.3.abstract</a></p>
<p>The Joint Commission</p>	<p><i>Certification for palliative care programs</i> (information about advanced certification program for palliative care, implemented in 2011 to recognize hospital inpatient programs that demonstrate family-centered care excellence and provide optimal care for pediatric and adult patients with serious illness)</p> <p><a href="https://www.jointcommission.org/certification/palliative_care.aspx">https://www.jointcommission.org/certification/palliative_care.aspx</a></p>
<p>Pallimed</p>	<p><i>Nursing leadership in palliative care: Challenges and opportunities</i></p> <p><a href="http://www.pallimed.org/2015/05/nursing-leadership-in-palliative-care.html">http://www.pallimed.org/2015/05/nursing-leadership-in-palliative-care.html</a></p>
<p>Robert Wood Johnson Foundation</p>	<p><i>Advocates call on nurses to take leading role in palliative care</i></p> <p><a href="http://www.rwjf.org/en/library/articles-and-news/2012/09/advocates-call-on-nurses-to-take-leading-role-in-palliative-care.html">http://www.rwjf.org/en/library/articles-and-news/2012/09/advocates-call-on-nurses-to-take-leading-role-in-palliative-care.html</a></p>
<p>Santa Clara University Markkula Center for Applied Ethics</p>	<p><i>Palliative care: An ethical obligation</i></p> <p><a href="https://www.scu.edu/ethics/focus-areas/bioethics/resources/palliative-care-an-ethical-obligation/">https://www.scu.edu/ethics/focus-areas/bioethics/resources/palliative-care-an-ethical-obligation/</a></p>

## **Appendix B. Additional Opportunities for Actions**

The Steering Committee compiled an extensive list of opportunities for action that were revisited and refined during the development of the final recommendations. These opportunities are offered as additional initiatives for nurses to lead and transform palliative care.

### **Practice**

- Develop palliative care experts within an organization.
  - Establish and maintain an evidence-based practice (EBP) mentorship program to develop and mentor palliative care nurses; perhaps partner with the Daisy Foundation or others to promote more EBP projects in palliative care.
  - Consider incorporating palliative care content when establishing council structure.
  - Develop goals to have a delineated percentage of ELNEC-prepared staff.
- Establish an organizational objective that all nurses working with seriously ill and injured patients, families, and communities will provide quality primary palliative nursing.

### **Education**

- Curriculum content must include didactic content and practicum care of patients who are acutely ill, chronically ill, or terminally ill, with a focus on caring and treatment de-escalation characteristic of palliative care.
- Reinforce accreditation mandates for inclusion of palliative care concepts and the standardized ELNEC modules in all levels of educational preparation, pre-licensure to doctoral level (new online ELNEC undergraduate content available in 2017).
- Issue call for all faculty to be prepared to teach ELNEC content.
- Convene think tank to address best practices, models, and next steps to create specialty palliative care professionals across populations—look at innovative certificate models to create expanded number of APRN experts, as well as RN level.

- Create collaborative education centers to leverage best practices, innovations, and resources, moving from state-based to interstate programs. Leverage and fast-track by building on those already in place.
- Bring faculty together for synergistic development of innovative palliative care solutions, models, and common approaches in conjunction with HPNA, AACN, ONS, and other conferences.
- Integrate the science of palliative care into nursing education and practice building on expanded and enhanced palliative care research.
- Promote interprofessional palliative education programs with nursing leading the collaborative model.
  - Include medical and other professional stakeholders.
  - Build on the characteristics and competencies of interprofessional teams.
- Develop culturally sensitive patient-focused palliative care educational and information resources for patients, families, and caregivers.

## **Research**

- Conduct systematic examinations of the current palliative care nursing workforce, including those practicing primary palliative care nursing, frontline nursing staff (including CNAs and LPNs), and palliative care nurse specialists.
- Clarify the scope of primary and specialty palliative nursing practice.
- Identify effective approaches to standardize palliative care nursing education and evaluate its impact on the competencies of nurses practicing primary palliative care nursing, and ultimately its impact on patient and family outcomes.
- Examine the complex interplay of individual and environmental factors that can contribute to compassion fatigue and burnout of nurses and other palliative workforce members.

## **Administration**

- Address workforce and staffing issues to assure sufficient time to identify and then complete primary palliative care and needed palliative care consult requests.

- Value and support the staff nurse who advocates for palliative care services and necessary resources.
- Develop palliative care champions within organizations.
- Integrate AACN's Healthy Work Environments standards into the practice setting (<http://www.aacn.org/wd/hwe/content/resources.content?lastmenu=>).
- Establish RN and APRN mentoring programs to reduce the incidence of and reliance on palliative training by physicians.
- Ensure that patients and clinicians are knowledgeable about the characteristics and value of palliative nursing.
- Promote standardization of palliative care terms and definitions.
- Develop initiatives with the American (and state) Hospital Associations and other stakeholders to promote the role of the nurse in leading and transforming palliative care.
- Establish upper-level administrative commitment to provide budget support to address the limited resources of community agencies providing palliative care.

## **Policy**

- Education
  - Learn about and track current federal and state bills and regulatory initiatives regarding palliative care.
  - Access state board of nursing and NCSBN website resources to become familiar with state-level palliative care bills and the effect of their outcomes on patients, families, caregivers, and interprofessional teams and members.
  - Join webinars or visit online resources provided by the ANA, HPNA, and other professional organizations addressing palliative care and associated policies.
  - Provide palliative care educational resources to patients, families, communities, and populations.
- Engagement
  - Contribute to state board of nursing palliative care policy initiatives.

- o Become an active member of ANA, HPNA, and other professional associations advocating on behalf of palliative care and volunteer to help in such efforts.
- Advocacy
  - o Join other local stakeholders on common issues related to palliative care in the community and advocate for action and solutions by contacting local government leaders and legislators.
  - o Contribute to expanded palliative care advocacy actions through individual communications and joining other stakeholders in contacting state-level legislators, governmental leaders, and stakeholders on common issues related to palliative care.
  - o Advocate about palliative care issues and concerns at the national level by contacting Congressional members, governmental leaders, and other stakeholders.