



Executive Summary

Introduction

The Hospice and Palliative Nursing Association (HPNA) is the professional organization for nurses working in the field of palliative and hospice care. Aligning with the *National Consensus Project Clinical Practice Guidelines for Quality Palliative Care*, we define palliative care as care that focuses on the relief of pain and other symptoms for those with serious illness. It also supports their caregivers. Palliative nursing, which includes hospice, is practiced in all healthcare settings, such as hospitals, nursing homes, outpatient clinics, assisted-living facilities, personal homes, and others—at all stages of serious illnesses and for people of all ages. Through this grounding definition, we provide the next HPNA Research Agenda priorities.

In 2009, HPNA established the triannual research agenda to (a) provide focus for researchers to conduct meaningful scientific and quality improvement initiatives and inform evidence-based practice; (b) guide organizational funding; and (c) illustrate to other stakeholders the importance of nursing research foci. Therefore, the HPNA Research Agendas are developed to give direction for future research to continue advancing expert care in serious illness and ensure equitable delivery of hospice and palliative care.

Steps of the Process for Generation of the HPNA Research Agenda 2023-2036

Summer 2020

1. Open forum comments on research topics of importance were received from attendees of the June 2020 HPNA Virtual Research Meeting.
2. Over summer 2020, Research Committee members used the open forum comments to create a prioritized list of 10 topics.

Fall 2020

3. A membership survey was sent to all HPNA members in September 2020 to rank order the 10 topics by order of importance from one to ten.
4. The survey results were reviewed by the HPNA Director of Research and HPNA Research Committee members to finalize the top five research agenda priorities based on the top five highest rankings from the membership survey.
5. The draft top five research priorities were approved by the HPNA Board.
6. Research Committee members self-identified their interest in joining one of the five priority topic writing groups.

Spring 2021-Fall 2021

7. From spring 2021 to summer 2021, priority topic writing groups met to create content for each of their assigned priority topics. As needed, Research Committee members identified additional HPNA nursing experts to join their writing groups.
8. From fall 2021 to spring 2022, the HPNA Director of Research and the Research Committee led writing groups that worked on collating and creating drafts of the final document.

Spring 2022-Summer 2022

9. Completed draft iterations and copy editing revisions.



10. Each writing group completed National Consensus Guideline Mapping to their priority topic area recommendations.

Fall 2022

11. HPNA Marketing department formatted to create the Final version of the *HPNA Research Agenda 2023-2026* and *HPNA Research Agenda 2023-2036 Executive Summary*.
12. The HPNA board approved the *HPNA Research Agenda 2023–2026 Executive Summary*.
13. Dissemination of *HPNA Research Agenda 2023–2026* via marketing, website and publications

PRIORITY: EQUITABLE PALLIATIVE CARE

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Recommendation 1. (Research/societal) Design and conduct more intervention studies founded on community-based participatory research principles, where the community is in equal partnership with the research team in identifying their needs and best approaches.

Recommendation 2. (Societal/organizational) Identify structural vulnerabilities (e.g., social and structural forces that constrain decision-making, frame choices, and limit life options) that limit equitable palliative care access and delivery, and develop policies and harm reduction approaches toward more equitable care.

Recommendation 3. (Research) Allow inclusion of smaller sample size requirements that parallel the minoritized group’s representation in the population at large to ensure inclusion of underrepresented populations.

Recommendation 4. (Societal) Recognize and support the unique challenges of rurality for research teams conducting community-based participatory research with minoritized population groups.

Recommendation 5. (Individual/educational) Explore healthcare professionals’ perspectives and educational needs for developing a practice of cultural humility.

Recommendation 6. (Societal) Identify the multiple points of impact that financial hardship affects patients with chronic illnesses and their families, and explore strategies to mitigate economic burden across the illness trajectory.

PRIORITY: LOCAL, NATIONAL, AND GLOBAL DISASTER/EMERGENCY RESPONSE IN PALLIATIVE AND HOSPICE CARE

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Recommendation 1. Mental health and moral suffering of hospice and palliative workforce. Generate an empirical needs assessment of mental health needs and moral suffering (e.g., moral distress, moral injury) amid disaster and emergency response among hospice and palliative clinicians across care settings with the goal of identifying protective and risk factors, as well as future interventions to improve and sustain workforce health and well-being.

Recommendation 2. Nursing education. Identify and address barriers to integrating hospice and palliative nursing education (e.g., primary and specialist training) at all levels of formal and continuing education to ensure evidence-based integration of hospice and palliative care delivery through enhanced communication, symptom management, psychosocial support, and spiritual care in the context of disaster management and emergency response.

Recommendation 3. Patient, families of choice, and caregiver support across the care continuum. Evaluate hospice and palliative nurse-led interventions that seek to alleviate patient suffering, family and caregiver burden, and grief and bereavement throughout serious illness and at end of life while considering the distress associated with disasters and emergencies.

Recommendation 4. Minoritized and historically marginalized people and populations. Explore the experiences of seriously ill minoritized and historically marginalized people and populations requiring palliative care to promote equitable, inclusive access to people-centered hospice and palliative care services during natural and humanitarian crises.

Recommendation 5. Digital integration of hospice and palliative care. Test the feasibility, accessibility, and efficacy of telehealth interventions to promote continuity of care during disaster management and emergency response, particularly for resource-poor settings and among impoverished populations.

PRIORITY: WELL-BEING OF PALLIATIVE CARE AND HOSPICE CLINICIANS: SELF-CARE AND WORKFORCE DEVELOPMENT

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Recommendation 1. Identify the unique needs of HPCNs (across nurse training levels) within the spectrum of settings and patient-specific populations where hospice and palliative nursing is practiced and delivered.

Recommendation 2. Examine, identify, and develop nursing professional development resources to integrate self-care and well-being as integral components of personal and team-based practice in hospice and palliative nursing.

Recommendation 3. Gain a better understanding of the unique challenges and opportunities that hospice and palliative care organizations face in cultivating a culture focused on well-being.

Recommendation 4. Explore the role of hospice and palliative nurse managers and leaders to identify their impact and influence on burnout, self-care, and well-being.

Recommendation 5. Research methods: Exploratory (qualitative) studies are needed within hospice and palliative nursing. Conduct studies using implementation science principles and frameworks to facilitate the successful translation of research into the clinical practice of hospice and palliative nursing. There are opportunities for methodologically rigorous research designs, including interventional and longitudinal designs.

Recommendation 6. COVID-19: Explore and examine the effects of COVID-19 on the hospice and palliative nursing workforce with a focus on development, retention, and resilience.

PRIORITY: PEDIATRIC PALLIATIVE AND HOSPICE RESEARCH PRIORITIES

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Recommendation 1. Employ a holistic socioecological approach to studying child, family, and community outcomes associated with PPHC and the factors that affect these outcomes.

Recommendation 2. Advance research surrounding bioethical issues and the social responsibility of nursing in PPHC.

Recommendation 3. Improve our understanding of understudied populations and settings of care within PPHC.

Recommendation 4. Develop and test interventions to strengthen equitable palliative and hospice care provided to children and families in minoritized and historically marginalized communities.

PRIORITY: TRANSITIONS IN CARE

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Recommendation 1. Examine transitions with quantitative study designs that measure patient- and family-centered outcomes, not just hospitalization data.

Recommendation 2. Engage in studies that consider a broader understanding of transitions beyond the actual transition and the period immediately after transitions occur.

Recommendation 3. Traditional approaches, combined with cutting-edge research designs, are necessary for understanding the constellation of factors impacting care transitions, ranging from community-based participatory research through the linking and analysis of population-level data sets.