

A woman with curly hair, wearing blue medical scrubs and a stethoscope, is looking intently at a screen. The screen displays several medical scans, likely CT or MRI images of a head, in a grid layout. The overall lighting is dim and blue-toned, creating a professional and focused atmosphere.

HOSPICE AND PALLIATIVE NURSES ASSOCIATION

RESEARCH AGENDA

2023-2026



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.

PRIORITY: EQUITABLE PALLIATIVE CARE

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“Health equity is social justice” (Reimer-Kirkham et al., 2016, p. 296). Health equity must be critically examined from moral, cultural, civic, and humanitarian perspectives (National Academies of Sciences, Engineering, and Medicine, 2019) and explored within the context of what is happening in society (Whitehead, 1992). Health equity encompasses access to services, equitable outcomes, and socioecological influences on multiple levels of care delivery. Braveman et al. (2017) define health equity as all persons having “a fair and just opportunity to be as healthy as possible” (para. 1). To achieve health equity, the structural and social barriers of poor housing, unsafe neighborhoods, minimum wage jobs, underperforming schools, and access to health care must be identified and eliminated (Braveman et al., 2017). However, access especially to healthcare services does not automatically equate to equity. Individuals may have access, yet, due to societal conditions including systemic racism, stigma, poverty, or homelessness, may not feel welcome accessing health care (Stajduhar, 2020), therefore contributing to health inequities.

Health inequities occur when populations are unable to achieve optimal health, often in relation to societal, economic, environmental, and structural inequities (National Academies of Sciences, Engineering, and Medicine, 2017). These inequities are influenced by a combination of complex, inter-reliant factors grouped into two root causes; each is profoundly influenced by power and resources (National Academies of Sciences, Engineering, and Medicine, 2017). The first root cause identifies how power and resources are distributed differently across demographic identifiers such as gender, race, citizenship, and class (Woolf, 2017) through “intrapersonal, interpersonal, institutional, and systemic mechanisms” (National Academies of Sciences, Engineering, and Medicine, 2017, p. 99). The second root cause is the unfair distribution of power and resources among societal groups,



producing inequitable conditions across the social determinants of health (National Academies of Sciences, Engineering, and Medicine, 2017). Deeply interwoven with these root causes are the societal macrostructures of public policy and community values (Woolf, 2017), which combined further exacerbate the health disparities experienced by structurally vulnerable, minoritized populations (National Academies of Sciences, Engineering, and Medicine, 2017; Ndugga & Artiga, 2021; Rajaram et al., 2020; Stajduhar et al., 2020).

Structural vulnerability exists when a person's or group's status (e.g., homelessness, poverty) in society places them at risk for greater health disparities, poorer health outcomes, and higher disease burden across the life span than the dominant population (Griggs, 2020; Rajaram et al., 2020; Stajduhar, 2020). Structural vulnerability and health inequity tend to have a global impact, as the financial implications of these inequities threaten the U.S. economy through the burden of excess medical costs, lost productivity, and economic loss due to premature death (Gilman, 2016). These inequities more often impact minoritized, historically marginalized, and disenfranchised populations, yet can be mitigated through engagement in hospice and palliative care services.

Palliative care, as envisioned, should be equitable, yet because it is grounded in white, Christian, middle-class values, it is often inequitable (Reimer-Kirkham et al., 2016). Minoritized is defined as a group that is actively oppressed regardless of intentionality; the power dynamics are unequal resulting in less resources for the minoritized group. (Harper, 2013). For minoritized populations, equitable palliative care is often elusive. Patients are either intentionally or unintentionally not approached about hospice and palliative care because of preconceived barriers to engaging the patient and their family with such services (Gazaway et al., 2021). When hospice and palliative care services are offered, they are either inaccessible or not provided in a culturally informed manner. Reasons for this vary and may be attributed to subconscious "othering" of minoritized populations, resulting in implicit bias, systemic racism, or interpersonal/organizational barriers (Nelson et al., 2021; Rosa et al., 2020).

Recent literature has suggested dissolving the use of labels or recognizing the patient's race and ethnicity as part of providing a fuller description of the patient (Dillard-Wright & Gazaway, 2021). This effort has merit insofar as attempting to limit healthcare providers' preconceived perception of the patient. Nursing textbooks, however, continue to identify stereotypical "cultural norms" (Dillard-Wright & Gazaway, 2021) and have the potential to lead the nurse to unintentional preconceived biases (Whitehead, 1992). While it is vital to recognize the unique needs of all patients, identifying the patient as part of a group in some circumstances is required. Many institutions require patients to be identified by their race and ethnicity for reimbursement efforts. Medicare, for example, requires hospitals to complete racial and ethnic profiles for each patient for payment. Nurses are ideal advocates for the merit of isolating race and ethnicity demographic information from cultural norms and values of the patient and their family.

Nurses, regardless of their scope of practice, are well positioned to address equitable end-of-life and palliative care issues in minoritized populations, as their foundational education and training centers on partnership and advocacy with patients and families. Yet, nursing education lacks cross-cultural exposure to the harmful effects of implicit bias and structural racism. In addition, nursing education is based on white, Christian, middle-class values and often does not consider the uniqueness of minoritized populations (Cain et al., 2018; Lee et al., 2016; Wicher & Meeker, 2012). Traditionally, the common narrative put forth by nursing textbooks to describe "minority" populations often reduces or overly simplifies risk factors within a group as fact without context. For example, LGBTQ+ populations are described as at risk for homelessness and increased risk of suicide, while religious and cultural risk factors are presented as nonmodifiable, and stress is identified as a modifiable risk factor (Whitehead, 1992). The structural factors that influence risk factors for "minority" populations are absent, thereby introducing nursing students to a narrow view of diversity. Many nursing textbooks



still employ the term “minority” when in fact populations are not a numerical minority, therefore, using the term “minority” implies inferior or deficient in some manner (Cooper, 2016). Thus, well-meaning new graduates enter the workforce ill-prepared to acknowledge and support value systems apart from their own.

To address these concerns, it is critical that nurses adopt a practice of cultural humility, which acknowledges societal and historical factors that influence patient access to and engagement in health care. Evidence suggests that practicing cultural humility demonstrates great potential in addressing health inequities and improving health equity. Yet, research is limited in how practicing cultural humility improves equity in palliative and end-of-life care. Moreover, few healthcare professional education programs incorporate the practice of cultural humility or include strategies to address implicit bias and systemic racism. Fewer organizations require regular education and reflection on cultural humility (Cain et al., 2018; Lee et al., 2016; National Academies of Sciences, Engineering, and Medicine, 2017).

An urgent need exists to fundamentally shift how equitable end-of-life and palliative care is approached and delivered. To redefine assumptions that disparities in care are caused by characteristics of the groups receiving the suboptimal care, research must focus on policy and education in efforts to change how the healthcare system views and interacts with the minoritized groups (National Academies of Sciences, Engineering, and Medicine, 2017). Further, it is critical that hospice and palliative care agencies examine how they approach minoritized groups. For example, are institutions employing harm reduction strategies or trauma-informed care to reduce barriers to access or continuation of services? (Rajaram et al., 2020; Randall et al., 2020). Evidence suggests minoritized populations are not approached and do not enroll in hospice and palliative care programs with the same frequency as white, CIS gendered, heterosexual, Christian populations. As a result, minoritized groups receive less goal-concordant care and typically endure more painful and costly procedures (Griggs, 2020; Nelson et al., 2021). It is difficult to address these concerns, as minoritized, historically marginalized, and disenfranchised communities are understudied in palliative and end-of-life care research. Therefore, it is vital to engage with and garner community input to ensure culturally informed research efforts to shape policy and nursing education. Achieving equitable palliative care services for minoritized groups requires a multifaceted research approach. Several models or frameworks exist to assist in providing this multifaceted approach. Brooks et al. (2017) described development and core components of the PETAL framework for addressing health equity within a learning health system. PETAL stands for Prioritize health equity; Engage the community; Target health disparities; Act on the data; and Learn and improve. This framework demonstrates great promise in addressing health disparities, yet more work is needed to align it with health equity principles (Brooks et al., 2017). Griggs’s (2020) framework provides healthcare professionals a way to easily identify the societal, health system, and patient–provider factors that may contribute to the structural racism and burden experienced by minoritized populations when seeking palliative care services.

Peterson et al.’s (2021) work illustrates a “science- and justice-based framework for promoting health equity” (p. 742). While not specific to palliative care, the health equity framework identifies the many intersecting and complex components needed to understand and achieve equity across populations. The model indicates spheres of influence, which may be risk or protective factors. The spheres are multilevel and include systems of power, relationships and networks, individual factors, and physiological pathways. Nelson et al. (2021) identify a conceptual framework toward addressing facilitators and barriers for palliative care. This framework takes the traditional biopsychosocial-spiritual palliative care model and interweaves it with ecological components. In addition, it assists healthcare professionals in understanding the complex micro-, meso-, and macro-level factors that facilitate or hinder palliative care access and delivery for minoritized groups. Similar to Nelson et al.



(2021), Chidiac et al. (2021) also address ways to improve palliative care for minoritized groups through a multilevel approach. Their model includes ways to identify barriers and facilitators for access, as well as shares recommendations to positively impact palliative care access and delivery. Thus, we provide recommendations at the individual, organizational, societal, and research levels to address barriers and facilitators toward improving equity in palliative and end-of-life care based on Chidiac et al.'s (2021) framework.

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.

References

- Braveman, P., Arkin, E., Orleans, T., Proctor, D. & Plough, A. (2017, May 1). What is health equity. Robert Wood Johnson Foundation. <https://www.rwjf.org/en/library/research/2017/05/what-is-health-equity-.html>
- Brooks, D., Douglas, M., Aggarwal, N., Prabhakaran, S., Holden, K., & Mack, D. (2017). Developing a framework for integrating health equity into the learning health system. *Learning Health Systems, 1*(3), e10029. <https://doi.org/10.1002/lrh2.10029>
- Cain, C. L., Surbone, A., Elk, R., & Kagawa-Singer, M. (2018). Culture and palliative care: Preferences, communication, meaning, and mutual decision making. *Journal of Pain and Symptom Management, 55*(5), 1408–1419. <https://doi.org/10.1016/j.jpainsymman.2018.01.007>
- Chidiac, C., El Zakhem, A., Osman, H., & Yamout, R. (2021). Recommendations to improve palliative care provision for marginalized populations: Summary of a roundtable discussion. *Journal of Palliative Medicine, 24*(8), 1132–1138. <https://doi.org/10.1089/jpm.2020.0548>
- Cooper, J. N. (2016). A call for a language shift: from covert oppression to overt empowerment. Retrieved from: [http://education.uconn.edu/2016/12/07/a-call-for-a-language-shift-from-covert-oppression-to-overt-empowerment/\(accessed July 1, 2020\)](http://education.uconn.edu/2016/12/07/a-call-for-a-language-shift-from-covert-oppression-to-overt-empowerment/(accessed%20July%201,%202020)).
- Dillard-Wright, J., & Gazaway, S. (2021). Drafting a diversity, equity, and inclusion textbook inventory: Assumptions, concepts, conceptual framework. *Teaching and Learning in Nursing, 16*(3), 247–253. <https://doi.org/10.1016/j.teln.2021.02.001>
- Gazaway, S. B., Barnett, M. D., Bowman, E. H., Ejem, D., Harrell, E. R., Brown, C. J., & Bakitas, M. (2021). Health professionals palliative care education for older adults: Overcoming ageism, racism, and gender bias. *Current Geriatrics Reports, 10*, 148–156. <https://doi.org/10.1007/s13670-021-00365-7>
- Gilman, M. E. (2016). En-gendering economic inequality. *Columbia Journal of Gender and Law, 32*.1. https://scholarworks.law.ubalt.edu/cgi/viewcontent.cgi?article=1950&context=all_fac



- Griggs, J. J. (2020). Disparities in palliative care in patients with cancer. *Journal of Clinical Oncology*, 38(9), 974–979. <https://doi.org/10.1200/JCO.19.02108>
- Harper, S. R. (2013). Am I my brother's teacher? Black undergraduates, racial socialization, and peer pedagogies in predominantly white postsecondary contexts. *Review of Research in Education*, 37(1), 183-211.
- Lee, J. J., Long, A. C., Curtis, J. R., & Engelberg, R. A. (2016). The influence of race/ethnicity and education on family ratings of the quality of dying in the ICU. *Journal of Pain and Symptom Management*, 51(1), 9–16. <https://doi.org/10.1016/j.jpainsymman.2015.08.008>
- National Academies of Sciences, Engineering, and Medicine. (2017). *Communities in action: Pathways to health equity*. National Academies Press. <https://doi.org/10.17226/24624>
- National Academies of Sciences, Engineering, and Medicine. (2019). *Improving access to and equity of care for people with serious illness: Proceedings of a workshop*. National Academies Press. <https://doi.org/10.17226/25530>
- Ndugga, N., & Artiga, S. (2021, May 11). *Disparities in health and health care: 5 key questions and answers*. Kaiser Family Foundation. <https://www.kff.org/report-section/disparities-in-health-and-health-care-5-key-questions-and-answers-issue-brief/>
- Nelson, K. E., Wright, R., Fisher, M., Koirala, B., Roberts, B., Sloan, D. H., Wu, D. S., & Davidson, P. M. (2021). A call to action to address disparities in palliative care access: A conceptual framework for individualizing care needs. *Journal of Palliative Medicine*, 24(2), 177–180. <https://doi.org/10.1089/jpm.2020.0435>
- Peterson, A., Charles, V., Yeung, D., & Coyle, K. (2021). The health equity framework: A science- and justice-based model for public health researchers and practitioners. *Health Promotion Practice*, 22(6), 741–746. <https://doi.org/10.1177/1524839920950730>
- Rajaram, A., Morey, T., Shah, S., Dosani, N., & Mamdani, M. (2020). Providing data-driven equitable palliative and end-of-life care for structurally vulnerable populations: A pilot survey of information management strategies. *American Journal of Hospice and Palliative Care*, 37(4), 244–249. <https://doi.org/10.1177/1049909119872756>
- Randall, J., Zametkin, E. M., & Mitchell, S. (2020). Using the design thinking process to target barriers to palliative care for socially vulnerable patients. *Journal of Palliative Medicine*, 23(5), 603–604. <https://doi.org/10.1089/jpm.2019.0526>
- Reimer-Kirkham, S., Stajduhar, K., Pauly, B., Giesbrecht, M., Mollison, A., McNeil, R., & Wallace, B. (2016). Death is a social justice issue: Perspectives on equity-informed palliative care. *Advances in Nursing Science*, 39(4), 293–307. <https://doi.org/10.1097/ANS.0000000000000146>
- Rosa, W. E., Shook, A., & Acquaviva, K. D. (2020). LGBTQ+ inclusive palliative care in the context of COVID-19: Pragmatic recommendations for clinicians. *Journal of Pain and Symptom Management*, 60(2), E44–E47. <https://doi.org/10.1016/j.jpainsymman.2020.04.155>
- Stajduhar, K. I. (2020). Provocations on privilege in palliative care: Are we meeting our core mandate? *Progress in Palliative Care*, 28(2), 89–93. <https://doi.org/10.1080/09699260.2019.1702334>
- Stajduhar, K. I., Giesbrecht, M., Mollison, A., & d'Archangelo, M. (2020). “Everybody in this community is at risk of dying”: An ethnographic exploration on the potential of integrating a palliative approach to care among workers in inner-city settings. *Palliative and Supportive Care*, 18(6), 670–675. <https://doi.org/10.1017/S1478951520000280>
- Whitehead, M. (1992). The concepts and principles of equity and health. *International Journal of Health Services*, 22(3), 429–445. <https://doi.org/10.2190/986L-LHQ6-2VTE-YRRN>
- Wicher, C. P., & Meeker, M. A. (2012). What influences African American end-of-life preferences? *Journal of Health Care for the Poor and Underserved*, 23(1), 28–58. <https://doi.org/10.1353/hpu.2012.0027>
- Woolf, S. H. (2017). Progress in achieving health equity requires attention to root causes. *Health Affairs*, 36(6), 984–991. <https://doi.org/10.1377/hlthaff.2017.0197>



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

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About 77% of natural disasters are attributable to climate and weather-related causes (International Federation of Red Cross and Red Crescent Societies, 2020). Globally, there were 127 documented floods, 59 storms, 25 landslides, 8 wildfires, 8 droughts, and 36 disease outbreaks among other natural disasters in 2019 alone, impacting 97.6 million people and leading to 24,396 deaths worldwide (International Federation of Red Cross and Red Crescent Societies, 2020). By 2050, deaths related to adverse climate events are anticipated to rise to 534,000 (Springmann et al., 2016). Perhaps the most alarming global disaster triggering a worldwide emergency response has been the COVID-19 pandemic, leading to more than 516 million cases and causing over 6.2 million deaths worldwide as of May 2022 (World Health Organization [WHO], 2022). While these numbers continue to grow, the true impact of COVID-19 is likely to be 2-4 times greater (Adam, 2022). These events impact the world's most vulnerable populations, such as the poor, incarcerated, medically frail, and other historically marginalized populations.

Although a number of nursing recommendations (International Council of Nurses, 2019; Veenema et al., 2017) call for increased nurse involvement in disaster response, palliative care is often overlooked as a critical component. WHO (2018) has provided guidelines to integrate palliative care into humanitarian crisis response that include roles for palliative nurse specialists. Although universal access to palliative care is considered part of the right to highest standard of mental and physical health (WHO, 2014), the serious illness care needs of many historically marginalized, minoritized, and at-risk populations go unaddressed. For example, per the World Bank's estimates in 2021, COVID-19 had pushed an additional 97 million people into extreme poverty in 2020 alone, bringing the global total of the extreme poor to roughly 711 million in 2021 (Mahler et al., 2021). In addition, while digital health is one of the major healthcare innovations utilized during the pandemic, there are growing concerns about digital health equity. There are many factors that contribute to digital health inequity, including poverty, lack of access to technology, poor engagement with digital health technology for some communities, and barriers to digital health literacy (Crawford & Serhal, 2020). However, digital inequity is also a global issue. According to a recent review, of more than 500 articles published on



telehealth from January to July 2021, the majority of authors (86.6%) are from high-income countries (Doraiswamy et al., 2020). This finding suggests that digital disparities within and across national borders may be widened by financial inequalities.

Palliative nurses must work with disaster management agencies during times of crisis to streamline public health messaging, strategize care delivery, and readily identify persons in need (Charney et al., 2018). However, there are a number of barriers to integrating palliative care into disaster response initiatives, including utilitarian, lifesaving priorities of humanitarian organizations; resource allocation amid scarcity; insufficient palliative care program funding; lack of palliative specialist preparation; poor access to controlled essential medicines, including opioids for injuries, surgeries, and moderate to severe symptoms at end of life; deficient mechanisms to address mass bereavement; ethical dilemmas to support care of the dying; and cultural variation related to dying and death (Charney et al., 2018; Harrop et al., 2020; Waldman & Glass, 2019; Wynne et al., 2020, Rosa et al., 2022). The pandemic has demonstrated the need for generalists to be trained in principles of palliative care, including symptom management and communication (Chidiac et al., 2020). However, a lack of symptom assessment tools and of training and mentorship in palliative care exacerbates the ability of healthcare providers to provide palliative care without prior training (Powell & Silveira, 2020). Research has demonstrated that disaster-related training increases preparedness for disaster response (Labrague et al., 2018), and an emerging body of work in disaster-related curriculum development (McDermott-Levy et al., 2019; Shannon, 2019; Williams & Downes, 2017), simulation development and evaluation (Evans et al., 2019; Gandhi et al., 2021; Greco et al., 2019; Strout et al., 2017), and instrument development (Siemon et al., 2019; Wang et al., 2020) reflects the growing urgency and awareness of the essential role of hospice and palliative care in the context of social, climate, and health crises.

Since the emergence of the COVID-19 pandemic, there has been a rapidly growing body of literature related to the response of hospice and palliative nurses to the pandemic. Palliative nurses' expertise in advance care planning, pain and symptom management, communication, and end-of-life care filled a critical gap in this pandemic (Rosa et al., 2020). The sudden and overwhelming nature of the global pandemic has challenged hospice agencies and the hospice and palliative care workforce in ways never experienced, including the substantial strains that the pandemic has added to hospice agencies' census, staffing, and resource availability (Baker Rogers et al., 2021; Costantini et al., 2020; Kates et al., 2021).

Additionally, the emotional toll of the pandemic is pervasive—at its peak, over 4 in 10 adults reported anxiety or depression between April 2020 and April 2021, a fourfold increase compared with rates before the pandemic (Kaiser Family Foundation, 2021). A rapidly growing body of evidence suggests the existence of a high burden of moral distress among long-term care providers (Bolt et al., 2021), the hospice and palliative workforce (Baker Rogers et al., 2021; Costantini et al., 2020; Kates et al., 2021; Wiener et al., 2021), and frontline workers providing palliative care (Cheng & Li Ping Wah-Pun Sin, 2020), as well as the heightened psychological and emotional impact on patients and caregivers navigating illness and bereavement (Brown et al., 2020). As such, there is an urgent need to assess, support, and mitigate the immediate and long-lasting mental health and well-being implications of the pandemic on populations as well as the providers who serve them (Duncan, 2020; Fernandez et al., 2020; Pai et al., 2020; Rosa et al., 2020, Schlak et al. 2022). Therefore, the recommendations of the workgroup have identified five key areas of research priority pertaining to disaster and emergency hospice and palliative care:

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.

References

- Adam, D. (2022). The pandemic's true death toll: millions more than official counts. *Nature*, *601*(7893), 312-315.
- Baker Rogers, J. E., Constantine, L. A., Thompson, J. M., Mupamombe, C. T., Vanin, J. M., & Navia, R. O. (2021). COVID-19 pandemic impacts on U.S. hospice agencies: A national survey of hospice nurses and physicians. *American Journal of Hospice and Palliative Care*, *38*(5), 521–527. <https://doi.org/10.1177/1049909121989987>
- Bolt, S. R., van der Steen, J. T., Mujezinović, I., Janssen, D. J. A., Schols, J. M. G. A., Zwakhalen, S. M. G., Khemai, C., Knapen, E. P. A. G. M., Dijkstra, L., & Meijers, J. M. M. (2021). Practical nursing recommendations for palliative care for people with dementia living in long-term care facilities during the COVID-19 pandemic: A rapid scoping review. *International Journal of Nursing Studies*, *113*, 103781. <https://doi.org/10.1016/j.ijnurstu.2020.103781>
- Brown, C., Peck, S., Humphreys, J., Schoenherr, L., Saks, N. T., Sumser, B., & Elia, G. (2020). COVID-19 lessons: The alignment of palliative medicine and trauma-informed care. *Journal of Pain and Symptom Management*, *60*(2), E26–E30. <https://doi.org/10.1016/j.jpainsymman.2020.05.014>
- Charney, R. L., Rebmann, T., Endrizal, A., & Dalawari, P. (2018). The general public's attitudes and beliefs regarding resource management, collaboration, and community assistance centers during disasters. *Disaster Medicine and Public Health Preparedness*, *12*(4), 446–449. <https://doi.org/10.1017/dmp.2017.108>
- Cheng, J. O. S., & Li Ping Wah-Pun Sin, E. (2020). The effects of nonconventional palliative and end-of-life care during COVID-19 pandemic on mental health—Junior doctors' perspective. *Psychological Trauma: Theory, Research, Practice, and Policy*, *12*(Suppl. 1), S146–S147. <https://doi.org/10.1037/tra0000628>
- Chidiac, C., Feuer, D., Flatley, M., Rodgerson, A., Grayson, K., & Preston, N. (2020). The need for early referral to palliative care especially for Black, Asian and minority ethnic groups in a COVID-19 pandemic: Findings from a service evaluation. *Palliative Medicine*, *34*(9), 1241–1248. <https://doi.org/10.1177/0269216320946688>



- Costantini, M., Sleeman, K. E., Peruselli, C., & Higginson, I. J. (2020). Response and role of palliative care during the COVID-19 pandemic: A national telephone survey of hospices in Italy. *Palliative Medicine*, 34(7), 889–895. <https://doi.org/10.1177/0269216320920780>
- Crawford, A., & Serhal, E. (2020). Digital health equity and COVID-19: The innovation curve cannot reinforce the social gradient of health. *Journal of Medical Internet Research*, 22(6), e19361. <https://doi.org/10.2196/19361>
- Doraiswamy, S., Abraham, A., Mamtani, R., & Cheema, S. (2020). Use of telehealth during the COVID-19 pandemic: Scoping review. *Journal of Medical Internet Research*, 22(12), e24087. <https://doi.org/10.2196/24087>
- Duncan, D. L. (2020). What the COVID-19 pandemic tells us about the need to develop resilience in the nursing workforce. *Nursing Management*, 27(3), 22–27. <https://doi.org/10.7748/nm.2020.e1933>
- Evans, C. A., Baumberger-Henry, M., Schwartz, R., & Veenema, T. (2019). Nursing students' transfer of learning during a disaster tabletop exercise. *Nurse Educator*, 44(5), 278–283. <https://doi.org/10.1097/NNE.0000000000000602>
- Fernandez, R., Lord, H., Halcomb, E., Moxham, L., Middleton, R., Alananzeh, I., & Ellwood, L. (2020). Implications for COVID-19: A systematic review of nurses' experiences of working in acute care hospital settings during a respiratory pandemic. *International Journal of Nursing Studies*, 111, 103637. <https://doi.org/10.1016/j.ijnurstu.2020.103637>
- Gandhi, S., Yeager, J., & Glaman, R. (2021). Implementation and evaluation of a pandemic simulation exercise among undergraduate public health and nursing students: A mixed-methods study. *Nurse Education Today*, 98, 104654. <https://doi.org/10.1016/j.nedt.2020.104654>
- Greco, S., Lewis, E. J., Sanford, J., Sawin, E. M., & Ames, A. (2019). Ethical reasoning debriefing in disaster simulations. *Journal of Professional Nursing*, 35(2), 124–132. <https://doi.org/10.1016/j.profnurs.2018.09.004>
- Harrop, E., Mann, M., Semedo, L., Chao, D., Selman, L. E., & Byrne, A. (2020). What elements of a systems' approach to bereavement are most effective in times of mass bereavement? A narrative systematic review with lessons for COVID-19. *Palliative Medicine*, 34(9), 1165–1181. <https://doi.org/10.1177/0269216320946273>
- International Council of Nurses. (2019). *Core competencies in disaster nursing version 2.0*. https://www.icn.ch/sites/default/files/inline-files/ICN_Disaster-Comp-Report_WEB.pdf
- International Federation of Red Cross and Red Crescent Societies. (2020). *World disasters report 2020*. https://www.ifrc.org/sites/default/files/2021-05/20201116_WorldDisasters_Full.pdf
- Kaiser Family Foundation. (2021). *Adults reporting symptoms of anxiety or depressive disorder during COVID-19 pandemic*. <https://www.kff.org/other/state-indicator/adults-reporting-symptoms-of-anxiety-or-depressive-disorder-during-covid-19-pandemic/?currentTimeframe=25&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>
- Kates, J., Gerolamo, A., & Pogorzelska-Maziarz, M. (2021). The impact of COVID-19 on the hospice and palliative care workforce. *Public Health Nursing*, 38(3), 459–463. <https://doi.org/10.1111/phn.12827>
- Labrague, L. J., Hammad, K., Gloe, D. S., McEnroe-Petitte, D. M., Fronda, D. C., Obeidat, A. A., Leocadio, M. C., Cayaban, A. R., & Mirafuentes, E. C. (2018). Disaster preparedness among nurses: A systematic review of literature. *International Nursing Review*, 65(1), 41–53. <https://doi.org/10.1111/inr.12369>
- Mahler, D. G., Yonzan, N., Lakner, C., Aguilar, R. A. C., & Wu, H. (2021). Updated Estimates of the Impact of COVID-19 on Global Poverty: Turning the Corner on the Pandemic in 2021?. *World Bank*, 24.



- McDermott-Levy, R., Jackman-Murphy, K. P., Leffers, J. M., & Jordan, L. (2019). Integrating climate change into nursing curricula. *Nurse Educator*, 44(1), 43–47. <https://doi.org/10.1097/NNE.0000000000000525>
- Pai, R. R., Nayak, M. G., & Sangeetha, N. (2020). Palliative care challenges and strategies for the management amid COVID-19 pandemic in India: Perspectives of palliative care nurses, cancer patients, and caregivers. *Indian Journal of Palliative Care*, 26(Suppl. 1), S121–S125.
- Powell, V. D., & Silveira, M. J. (2020). What should palliative care's response be to the COVID-19 pandemic? *Journal of Pain and Symptom Management*, 60(1), E1–E3. <https://doi.org/10.1016/j.jpainsymman.2020.03.013>
- Rosa WE, Grant L, Knaul FM, et al. The value of alleviating suffering and dignifying death in war and humanitarian crises [published online ahead of print, 2022 Mar 21]. *Lancet*. 2022;S0140-6736(22)00534-7. doi:10.1016/S0140-6736(22)00534-7.
- Rosa, W. E., Gray, T. F., Chow, K., Davidson, P. M., Dionne-Odom, J. N., Karanja, V., Khanyola, J., Kpoeh, J. D. N., Lusaka, J., Matula, S. T., Mazanec, P., Moreland, P. J., Pandey, S., Parekh de Campos, A., & Meghani, S. H. (2020). Recommendations to leverage the palliative nursing role during COVID-19 and future public health crises. *Journal of Hospice and Palliative Nursing*, 22(4), 260–269. <https://doi.org/10.1097/NJH.0000000000000665>
- Schlak AE, Rosa WE, Rushton CH, Poghosyan L, Root MC, McHugh MD. An expanded institutional- and national-level blueprint to address nurse burnout and moral suffering amid the evolving pandemic. *Nurs Manage*. 2022;53(1):16-27. doi:10.1097/01.NUMA.0000805032.15402.b3
- Shannon, C. (2019). Improving student engagement in community disaster preparedness. *Nurse Educator*, 44(6), 304–307. <https://doi.org/10.1097/NNE.0000000000000645>
- Siemon, M., Hackwith, J., & Monson, K. (2019). Development of a disaster nursing competencies assessment instrument for baccalaureate nursing education. *Journal of Nursing Education*, 58(4), 229–233. <https://doi.org/10.3928/01484834-20190321-08>
- Springmann, M., Mason-D'Croz, D., Robinson, S., Garnett, T., Godfray, H. C. J., Gollin, D., Rayner, M., Ballon, P., & Scarborough, P. (2016). Global and regional health effects of future food production under climate change: A modelling study. *Lancet*, 387(10031), 1937–1946. [https://doi.org/10.1016/S0140-6736\(15\)01156-3](https://doi.org/10.1016/S0140-6736(15)01156-3)
- Strout, K., Saber, D. A., Caruso, L. S., Ingwell-Spolan, C., Koplovsky, A., Caron, E. M., Federico, J., Hulst, C., & Etro, I. (2017). Interprofessional mass casualty incident simulation design protocol to prepare prelicensure nursing students to respond to a disaster. *Nurse Educator*, 42(5), E1–E4. <https://doi.org/10.1097/NNE.0000000000000365>
- Veenema, T. G., Lavin, R. P., Griffin, A., Gable, A. R., Couig, M. P., & Dobalian, A. (2017). Call to action: The case for advancing disaster nursing education in the United States. *Journal of Nursing Scholarship*, 49(6), 688–696. <https://doi.org/10.1111/jnu.12338>
- Waldman, E., & Glass, M. (Eds.). (2019). *A field manual for palliative care in humanitarian crises*. Oxford University Press.
- Wang, J., Li, C., Zou, S., Chen, H., Xiang, J., Hu, Y., Huang, H., & Tan, Y. (2020). Psychometric evaluation of undergraduate student nurses' learning perceived needs in disaster nursing: Two cross-sectional studies. *Nurse Education Today*, 84, 104208. <https://doi.org/10.1016/j.nedt.2019.104208>
- Wiener, L., Rosenberg, A. R., Pennarola, B., Fry, A., & Weaver, M. (2021). Navigating the terrain of moral distress: Experiences of pediatric end-of-life care and bereavement during COVID-19. *Palliative and Supportive Care*, 19(2), 129–134. <https://doi.org/10.1017/s1478951521000225>
- Williams, H., & Downes, E. (2017). Development of a course on complex humanitarian emergencies: Preparation for the impact of climate change. *Journal of Nursing Scholarship*, 49(6), 661–669. <https://doi.org/10.1111/jnu.12339>
- World Health Organization. (2014, May 24). *Sixty-seventh world health assembly: Agenda item 15.5*. https://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf?ua=1



World Health Organization. (2018). *Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises: A WHO guide*.

<https://apps.who.int/iris/handle/10665/274565>

World Health Organization. (2022). *WHO coronavirus (COVID-19) dashboard*. Retrieved May 12, 2022, from <https://covid19.who.int/>

Wynne, K. J., Petrova, M., & Coghlan, R. (2020). Dying individuals and suffering populations: Applying a population-level bioethics lens to palliative care in humanitarian contexts: Before, during and after the COVID-19 pandemic. *Journal of Medical Ethics*, 46(8), 514–525.

<https://doi.org/10.1136/medethics-2019-105943>

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

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A scoping review of literature related to burnout among hospice and palliative care nurses (HPCNs) revealed that nurse burnout in hospice and palliative care is influenced by intrinsic characteristics, the work environment, and nursing professional development. Intrinsic factors that contribute to burnout include emotional exhaustion, depersonalization, lack of personal achievement, lack of commitment to the workplace, self-care deficit, and lack of meaning (Barnett et al., 2019; Diehl et al., 2020; Payne, 2001; Rizo-Baeza et al., 2018). Extrinsic factors that contribute to burnout among HPCNs include work stress, work demands, work setting, workload, poor professional quality of life, and working more than eight hours a day.

Mediators of burnout can also be intrinsic to the nurse, such as having a sense of meaning in life, resilience, openness to new experiences, a sense of humor, and tolerance of failures, and treating life as a challenge (Barnett et al., 2019; Ogińska-Bulik & Michalska, 2020). Other mediators may not be intrinsic but can be learned through ongoing professional development. For example, programs such as resilience training and inoculation training that are aimed toward facilitating growth in self-efficacy, self-confidence, assertiveness, and appropriate coping skills may protect against job burnout (Ogińska-Bulik & Michalska, 2020; Payne, 2001). Extrinsic mediators that are squarely the responsibility of the manager and/or organization include fostering strong coworker support systems and team dynamics, recognizing employees for their contributions, and ensuring effective communication (Clayton et al., 2019; Diehl et al., 2020; Lowe et al., 2020; Payne, 2001). Specifically, managers should take the time to inquire about what brings meaning to nurses' lives and work; support participation in religious, cultural, and personal traditions that foster meaning; and connect nurses with resources to cope with the existential demands of providing end-of-life care (Barnett et al., 2019). Managers should also screen staff for signs of burnout, offering training on effective coping skills as needed (Ogińska-Bulik & Michalska, 2020; Payne, 2001; Rizo-Baeza et al., 2018). Organizational efforts are needed to ensure adequate payment; improve communication; foster self-care; strengthen teamwork among employees; and promulgate policies related to shifts, overtime, and appropriate caseloads (Diehl et al., 2020; Lowe et al., 2020; Ogińska-Bulik & Michalska, 2020; Rizo-Baeza et al., 2018).



The findings derived from the extant literature are intuitive and are based on the findings of quantitative research studies. However, no intervention studies were identified that directly tested the actions of nurses, managers, or organizational changes on burnout. What's more, the preparation of nurse managers to implement the recommendations given their own heavy workload and risk for burnout has not been considered. Other areas that have not been fully explored include changes in nurse burnout related to the COVID-19 pandemic, especially within specific practice settings. Published studies do not offer insight into the experiences of home hospice nurses versus home palliative care nurses, versus hospital-based palliative care nurses versus inpatient hospice nurses. Yet, numerous studies indicate that the work setting has bearing on whether or not individuals experience burnout (Kavalieratos et al., 2017). In terms of research approach, all of the published studies on burnout in hospice and palliative care nursing in our scoping review were quantitative in nature, and many used the Maslach Burnout Inventory to measure dimensions of burnout. Since no qualitative research studies were identified, it is reasonable to conclude that the nuanced experiences of this unique population of nurses may not yet be fully captured.

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.

References

- Barnett, M. D., Moore, J. M., & Garza, C. J. (2019). Meaning in life and self-esteem help hospice nurses withstand prolonged exposure to death. *Journal of Nursing Management*, 27(4), 775–780. <https://doi.org/10.1111/jonm.12737>
- Clayton, M. F., Iacob, E., Reblin, M., & Ellington, L. (2019). Hospice nurse identification of comfortable and difficult discussion topics: Associations among self-perceived communication effectiveness, nursing stress, life events, and burnout. *Patient Education and Counseling*, 102(10), 1793–1801. <https://doi.org/10.1016/j.pec.2019.06.013>
- Diehl, E., Rieger, S., Letzel, S., Schablon, A., Nienhaus, A., Pinzon, L. C. E., & Dietz, P. (2020). Health and intention to leave the profession of nursing—Which individual, social and organisational resources buffer the impact of quantitative demands? A cross-sectional study. *BMC Palliative Care*, 19(1), 83. <https://doi.org/10.1186/s12904-020-00589-y>
- Kavalieratos, D., Siconolfi, D. E., Steinhauer, K. E., Bull, J., Arnold, R. M., Swetz, K. M., & Kamal, A. H. (2017). “It is like heart failure. It is chronic ... and it will kill you”: A qualitative analysis of burnout among hospice and palliative care clinicians. *Journal of Pain and Symptom Management*, 53(5), 901–910.e1. <https://doi.org/10.1016/j.jpainsymman.2016.12.337>



- Lowe, M. A., Prapanjaroensin, A., Bakitas, M. A., Hites, L., Loan, L. A., Raju, D., & Patrician, P. A. (2020). An exploratory study of the influence of perceived organizational support, coworker social support, the nursing practice environment, and nurse demographics on burnout in palliative care nurses. *Journal of Hospice and Palliative Nursing*, 22(6), 465–472. <https://doi.org/10.1097/NJH.0000000000000686>
- Ogińska-Bulik, N., & Michalska, P. (2020). Psychological resilience and secondary traumatic stress in nurses working with terminally ill patients—The mediating role of job burnout. *Psychological Services*, 18(3), 398–405. <https://doi.org/10.1037/ser0000421>
- Payne, N. (2001). Occupational stressors and coping as determinants of burnout in female hospice nurses. *Journal of Advanced Nursing*, 33(3), 396–405. <https://doi.org/10.1046/j.1365-2648.2001.01677.x>
- Rizo-Baeza, M., Mendiola-Infante, S. V., Sepehri, A., Palazón-Bru, A., Gil-Guillén, V. F., & Cortés-Castell, E. (2018). Burnout syndrome in nurses working in palliative care units: An analysis of associated factors. *Journal of Nursing Management*, 26(1), 19–25. <https://doi.org/10.1111/jonm.1250>

PRIORITY: PEDIATRIC PALLIATIVE AND HOSPICE RESEARCH PRIORITIES

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When developing the research agenda for the field of pediatric palliative and hospice nursing, we must first consider the words and requests of children and parents themselves. In response to a previous research prioritization in pediatric palliative and hospice medicine (Feudtner et al., 2019), a group of parents of children with serious illness noted that while they appreciated the care and commitment of pediatric palliative and hospice care (PPHC) researchers, families' voices were missing. They offered three recommended areas from which we can build: (a) implementation and dissemination of best communication practices across disciplines, specialties, settings, and stages of training; (b) interventions to manage their children's symptoms and enhance quality of life; and (c) an increased understanding of family impact in order to facilitate or improve family adaptation and coping (Lord, 2019). These parents' words are our call to action, and we, as PPHC nurses and researchers, are particularly well positioned to study and work to build a system of PPHC that not only is inclusive of, but also that amplifies, children's and families' voices.

Second, we, as pediatric nurses, are deeply aware of our social responsibility (Tyer-Viola et al., 2009) to advocate for the needs of children, their families, and their communities. As a piece of this advocacy, nurses are charged with promoting "equitable access to health care and health information" (National Institute of Nursing Research [NINR], 2021, p.3) through cultivating trust with the communities we serve; ensuring equity in research; and supporting, implementing, and effectively communicating evidence-based research, especially for minoritized and historically marginalized people and populations. (National Academies of Sciences, Engineering, and Medicine, 2021; NINR, 2021). In response to this call to action and in alignment with our nursing social responsibility, we focused on identifying research gaps and priorities for the field of PPHC. Our first step was to review research priorities previously identified by PPHC leaders and experts, as well as by parents (Feudtner et al., 2019; Lord et al., 2019). We then explored where we have been as a field over the previous five years and where we need to go next. Using these previous priorities to guide our literature search, we conducted comprehensive reviews of the literature in four key areas: communication, systems of care, symptom management, and family impact. This directed yet comprehensive review of the literature helped us identify critical gaps in the science of PPHC nursing, which informed the development of our suggested overall research priorities and subpriorities for the field of PPHC for 2023–2026, described in detail below:

First, we should employ a holistic socioecological approach to studying child, family, and community outcomes associated with PPHC and the factors that affect these outcomes.

Pediatric palliative care researchers should prioritize a biopsychosocial-spiritual model of symptom assessment and management. Challenges in assessing and managing the diversity of symptoms in children requiring pediatric palliative care persist. There is a growing body of literature that suggests that interventions to improve mental health have a positive impact on physical symptoms (Thrane et al. 2016; Greenfield et al., 2020; Namisango et al., 2019). Previous systematic reviews of the physiologic (e.g., respiratory distress, sleep disturbance, fatigue), mental (e.g., anxiety, depression, stress), and social (e.g., family, friendships, romantic) health impacts of serious illness have been limited by heterogeneous outcome measurement. The manner in which PPHC is integrated and how it impacts seriously ill children's symptom experience also requires further evaluation (Brock et al., 2018; Morrison et al., 2018). Undertaking a biopsychosocial-spiritual model of symptom assessment and management could lead to improved understanding of the relationships between different constellations of symptoms and help identify mechanisms to reduce overall symptom burden.



Researchers should also explore and measure family-level outcomes associated with pediatric serious illness. A child's serious illness impacts family well-being. The child's family members are also recipients of palliative care, through psychosocial support, screening, and coaching to guide them in how to best support their child and care for themselves, and the family's well-being also significantly impacts the child. The impact of palliative care on children and families (both on individual members and at the family level), however, has been historically challenging to evaluate because outcomes associated with family impact are complex. Much of the current literature focuses on anxiety, depression, stress, caregiver burden, health-related quality of life, communication with providers, and satisfaction with care at the individual patient or individual family member level (Rosenberg et al., 2016; Bally et al., 2018; Boyden et al., 2020; Boyden and Hill et al., 2021; Feudtner et al., 2021; Kaye et al., 2021; Broden et al., 2022). Such outcomes are important to examine as they impact other family members and add a cumulative impact to family life; however, we see less research attention on family processes, such as family functioning, family management, family communication, and family hardiness (Weaver et al., 2018; Mooney-Doyle et al., 2017). Attention to family processes also provides an opportunity to advance the science by asking family-focused research questions and using innovative family research approaches to answer them. The relationship between child physical and/or emotional health and family member well-being should be more comprehensively explored and measured using a holistic socioecological model.

We must also advance our understanding of the social determinants of pediatric serious illness (Mendola et al., 2021). Understanding the ordinary and extraordinary impact of juggling competing demands of caring for seriously ill children is critical to better supporting families (Mooney-Doyle et al., 2016). As families care for their ill child and deal with the other responsibilities (e.g., medical bills, copays, insurance) and costs associated with medical care (e.g., hospital parking fees, meals, transportation to and from medical appointments), they also contend with the daily strains of their own healthcare needs and the healthcare needs of their other family members; employment; and schooling and childcare for siblings (Mooney-Doyle et al., 2016; Mooney-Doyle et al., 2018). As parents deal with these seemingly ordinary challenges on top of the life-sustaining care they provide to their seriously ill child, accumulation of stressors threatens to overwhelm parents on a daily basis (Mooney-Doyle et al., 2016). Yet, our current system offers little in terms of screening, support, and connection to community resources for these important social determinants of family and child health. Thus, researchers need to more closely explore and measure family life strains (such as time cost, financial stressors, material hardship, and employment challenges) and family life resources (such as social and psychological resources of individual family members and the family unit) (Bona et al., 2016; Ilowite et al., 2018; Mooney-Doyle & Lindley, 2019; Roeland et al., 2020; Boyden, Hill, et al., 2022; Mendola et al., 2021). This is especially important for families of medically complex children (Boyden, Hill, et al., 2022). While we have a growing evidence base on how families of children with cancer manage (Bona & Wolfe, 2017; Mack et al., 2020), we know less about the impact of serious illness on families of children who have lifelong medically complex serious illnesses. By assessing these challenges and resources from a holistic socioecological perspective, we can more readily partner with important stakeholders to address these multipronged challenges by building on family and community strengths.

Researchers should explore outcomes related to the system of PPHC. Significant variability in how care is provided has been documented across the system of PPHC, including in access, funding, policies, and practice across providers, institutions, regions, states, and countries, leading to significant variation in PPHC-associated child and family outcomes (Chong et al., 2017; Rajeshuni et al., 2017; Johnston et al., 2017; Boyden et al., 2018; Lindley et al., 2018; Kaye et al., 2019). More research is necessary to first develop a greater understanding of what neonatal, young child, adolescent, and young adult patients and families need from the PPHC system so that researchers, clinicians, administrators, and policymakers know where to prioritize funding and interventions.



Second, researchers, clinicians, administrators, and policymakers should work together to identify optimal models of PPHC that currently exist to more effectively serve the needs of neonates, infants, children, adolescents, and young adults and their families, wherever they may seek care. Third, more work is needed to increase our understanding of funding and regulatory models that can expand and sustain PPHC services for future generations of patients and families. For example, Quinn et al. (2020) note that we have limited systemic ways to support families earlier in the illness trajectory because the child, and not their family, is considered the patient for whom an institution can bill for services. To address the impact of PPHC on families, we should explore the relationships between institutional and governmental health/social policy on PPHC provision and child- and family-level outcomes.

Second, we should advance research surrounding bioethical issues and the social responsibility of nursing in PPHC. Nurses share in the social responsibility of advocating for the needs of our seriously ill patients, their families, and their communities. A piece of this advocacy, particularly in the age of COVID-19, should come in the form of increasing our efforts to cultivate trust with the communities we serve, focusing on increasing access to high-quality, evidence-based nursing research about PPHC and ensuring the trustworthy communication of this evidence to the public. Few studies in PPHC have investigated this understudied yet critically important area of research, allowing for opportunities for misinformation among providers and the general public about the role and importance of PPHC in promoting the health and well-being of seriously ill children and their families (Bogetz et al., 2019). More research is also needed to better understand strategies to increase health literacy surrounding PPHC (particularly in minoritized and historically marginalized people and populations [NINR, 2021]); strategies to increase stakeholder engagement throughout the PPHC research process (Weaver et al., 2019); and methods to ensure trustworthy, effective public health communication regarding PPHC.

Quality PPHC should also be grounded in bioethical principles, yet the bioethical challenges faced by PPHC patients, families, and providers are not well studied. Research surrounding bioethical issues in PPHC—including issues around consent and assent, futility of care, “potentially inappropriate” interventions, and parent–child conflicts and family–provider conflicts concerning decision-making—is growing (Feudtner and Nathanson, 2018); however, current published literature typically include ethics roundtables, expert opinions, and case reports (Rapoport & Morrison, 2016; Thieleman et al., 2016; Mendes et al., 2017; Feudtner and Nathanson, 2018; Chrastek et al., 2019; Sisk et al., 2019). Few empirical studies on bioethical issues in PPHC exist; the few empirical studies that exist focus on descriptive qualitative interviews of providers’ and family members’ perspectives on conflicts in the PPHC setting (Birchley et al., 2017; Cicero-Oneto et al., 2017). More work is needed to advance empirical research into the field of bioethics when caring for seriously ill children and their families.

Third, we should improve our understanding of the experiences of understudied populations and settings of care within PPHC. A better understanding of understudied groups who access, or lack access to, PPHC is imperative. Clinical, social, and other inequities impact communication, symptom management, family experiences, and systems issues, but they are not well understood within PPHC. We need to explore symptom assessment and management within understudied age-, diagnostic-, demographic- and location-based perspectives. Most systematic reviews of pediatric palliative symptom management practices focus on similar perspectives and experiences of serious illness and symptom management (Pinheiro et al., 2018; Snaman et al., 2020), particularly older children with oncologic diseases. It is therefore necessary to gather more diverse perspectives to better understand and tend to seriously ill children’s symptoms. Specifically, very little research on symptom assessment or management focuses on populations with developmental and/or neurologic characteristics that challenge usual assessment techniques, including younger children (neonates and 1- to 5-year-olds) and children with medically complex serious illnesses. Additionally, limited



research has examined the intersection of PPHC and mental illness, and, in particular, the assessment and treatment of mental illness in pediatric patients who receive or who could benefit from both palliative and psychiatric care (Lindley et al., 2021; Muriel et al., 2016; Svyrenko et al., 2021). Further, as pediatric chronic illness management and palliative/hospice care shifts more heavily into the home setting and as treatment options become increasingly sophisticated, research that aims to understand patients', parents', home care nurses', and palliative and hospice providers' experiences of symptom assessment and management in the home is necessary (Greenfield et al., 2020; Boyden et al., 2021; Thrane et al., 2021).

Similarly, we must also improve symptom assessment and management for minoritized, historically marginalized communities. While evidence exists that disparities in care, systemic racism, discrimination, and low English proficiency may significantly impact the quality of care and care outcomes (Johnston et al., 2017; Munoz-Blanco et al., 2017; Mack et al., 2020; DeGroote et al., 2022; Umaretiya et al., 2022), the impact of such disparities on the symptom experience for children and families remains largely unknown. Significantly more research is needed to improve symptom assessment and management in these populations in particular.

Researchers should also investigate communication and decision-making in the many settings where pediatric patients receive care. Existing research has often focused on communication and decision-making in the pediatric oncology setting (Badarau et al., 2017; Odeniyi et al., 2017; Sisk et al., 2018; Snaman et al., 2020; Sisk et al., 2021), with significantly fewer studies focused on children with medically complex chronic conditions (Bogetz et al., 2020; Jonas et al., 2022). These children may live for years with significant medical needs and receive care from many different subspecialties and institutions, resulting in many opportunities for decision-making over the course of often-fluctuating and prognostically uncertain disease trajectories. Improving communication, therefore, between these children and families and their care network (e.g., subspecialists, primary care physicians, home care nurses, adult hospice providers, school nurses, emergency medical personnel) is imperative. Research should focus on continuity of communication, such as information and documentation shared across specialists, settings, and institutions, as well as on decision-making as an iterative process that occurs over time as children's conditions fluctuate over the course of years. Finally, multilevel systems research should study the structures and systems necessary for supporting decision-making and advance care planning across care settings and across transitions of care (e.g., from pediatric to adult services, from hospital to home) for children with medically complex serious illnesses and their families.

We also need to investigate communication and decision-making in the perinatal and neonatal population. Communication and decision-making pertaining to palliative and hospice care may look different in the perinatal and neonatal settings due to differences in family life stage; provider knowledge and skills; and availability of palliative and hospice supports for pregnant mothers, neonates, new parents, and young siblings (Boss et al., 2016; Shaw et al., 2016; Wool et al., 2016; Fortney et al., 2020). More research is needed to optimize support for communication and decision-making for parents of seriously ill fetuses and newborns.

Finally, we need to develop and test interventions to strengthen equitable palliative and hospice care provided to children and families in minoritized and historically marginalized communities. Intervention research is needed to reduce variability in, increase continuity of, and improve equitability of PPHC services for all children and families who require PPHC. More specifically, we need to improve the system of PPHC provided in minoritized and historically marginalized communities. Increasingly, research has found significant gaps in the care of children with serious illnesses and their families in low-income, resource-constrained communities (Bona et al., 2016; Ilowite et al., 2018; Mooney-Doyle & Lindley, 2019; Roeland et al., 2020; Boyden, Hill, et



al., 2022). These children and their families may travel significant distances to access appropriate care, and many do not have adequate access in their home communities to the more robust inpatient and community-based palliative and hospice services found in resource-rich settings. More research is needed to build and test optimal PPHC systems, which include the healthcare workforce, pharmaceuticals, medical devices, policy, and funding, that can best support children and families in minoritized and historically marginalized communities. Borrowing from other areas of health care, public health approaches like utilizing community health workers to supplement existing palliative care provider networks may be particularly important in lower-resourced communities (Rhee et al., 2018; Philip et al., 2019; Sedhom et al., 2021). Other areas of further research include increasing primary palliative provider training and expanding the use of digital technologies (e.g., videoconferencing, telehealth) within and across geographic areas to support the care of children and families who may not have adequate access to care due to geography, socioeconomic challenges, transportation needs, or other family circumstances (Winegard et al., 2017; Weaver et al., 2020; Weaver et al., 2021). For example, in a low-resource setting, where broadband may be less or not available, the effectiveness of other digital technologies (e.g., phone technologies) may be particularly important. Interdisciplinary research teams that transcend institutions and communities should be developed and expanded to support these critical research efforts.

Relatedly, interventions are needed to improve communication and decision-making across cultures and languages for minoritized and historically marginalized people and populations. A growing number of studies are examining communication and decision-making across cultures and languages. Several recent studies from Middle Eastern, African, and Latin American organizations have observed unique cultural values and beliefs that impact communication styles and decision-making preferences (Cochran et al., 2017; Rosenberg et al., 2017; Thorvilson et al., 2019; de Arruda-Colli et al., 2018; Al Mutair et al., 2019; Chrastek et al., 2019; Rosenberg et al., 2019), but the actual decision-making experience relative to preferences may differ for non-white families compared to white families (Sisk et al., 2020). More research is also warranted on the effectiveness of translators and translation services, as well as on patient advocates in supporting families from different cultural, racial and ethnic, and linguistic backgrounds in communication and decision-making within pediatric palliative care. Fewer studies have examined the impact of health literacy, resource constraints, and socioeconomic barriers on communication and decision-making in PPHC. Some studies provide evidence that communication and decision-making may face particular challenges in resource-constrained settings (Munoz-Blanco et al., 2017; Rosenberg et al., 2019; Lau et al., 2020; Umaretiya et al., 2022). Interventions are needed to improve support for communication and decision-making in minoritized and historically marginalized communities.

Finally, it is critical that we explore the impact of systematic biases, racism, and other forms of discrimination on the experience of families caring for a seriously ill child. As families negotiate healthcare and social care systems, they may also encounter, personally or toward their family, implicit or explicit biases, racism, sexism, ethnocentrism, homophobia, ableism, and inadequate language services (Munoz-Blanco et al., 2017; Rosenberg et al., 2019; Lau et al., 2020; DeGroot et al., 2022; Umaretiya et al., 2022). There is limited research about the impact of these systemic factors on a family's experience when their child is seriously ill. Centering nursing research on the perspectives of these understudied populations can help better guide the interdisciplinary team's support of patients and their families.

In conclusion, we have proposed four research recommendations that will help to advance the science of PPHC nursing. By employing a holistic socioecological approach, advancing research into bioethical issues and nursing social responsibility in PPHC, improving our understanding of PPHC for understudied groups, and developing interventions to strengthen the equitable provision of PPHC for



children and families across communities and cultures, we as PPHC nurses and researchers will help move the field of PPHC toward an inclusive, equitable, and high-quality system of PPHC for all children with serious illnesses and their families that is centered on the child's and family's voice.

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.

References

- Al Mutair, A., Al Ammary, M., Brooks, L.A., & Bloomer, M.J. (2019). Supporting Muslim families before and after a death in neonatal and paediatric intensive care units. *Nursing in Critical Care*, 24(4), 192–200. <https://doi.org/10.1111/nicc.12434>
- Badarau, D.O., Ruhe, K., Kühne, T., De Clercq, E., Colita, A., Elger, B.S., & Wangmo, T. (2017). Decision making in pediatric oncology: Views of parents and physicians in two European countries. *AJOB Empirical Bioethics*, 8(1), 21-31.
- Bally, J.M.G, Smith, N.R., Holtslander, L., Duncan, V., Hodgson-Viden, H., Mpofu, C., & Zimmer, M. (2018). A metasynthesis: Uncovering what is known about the experiences of families with children who have life-limiting and life-threatening illnesses. *Journal of Pediatric Nursing*, 38, 88-98.
- Birchley, G., Gooberman-Hill, R., Deans, Z., Fraser, J., & Huxtable, R. (2017). 'Best interests' in paediatric intensive care: an empirical ethics study. *Archives of Disease in Childhood*, 102, 930-935.
- Bogetz, J. F., Root, M. C., Purser, L., & Torkildson, C. (2019). Comparing health care provider-perceived barriers to pediatric palliative care fifteen years ago and today. *Journal of Palliative Medicine*, 22(2), 145–151. <https://doi.org/10.1089/jpm.2018.0367>
- Bogetz, J.F., Revette, A., Rosenberg, A.R., & DeCoursey, D. (2020). "I Could Never Prepare for Something Like the Death of My Own Child": Parental perspectives on preparedness at end of life for children with complex chronic conditions. *Journal of Pain and Symptom Management*, 60(6), 1154-1162.
- Bona K, London WB, Guo D, Frank DA, Wolfe J. Trajectory of material hardship and income poverty in families of children undergoing chemotherapy: A prospective cohort study. *Pediatr Blood Cancer*. 2016;63(1):105-11.
- Bona, K., & Wolfe, J. (2017). Disparities in pediatric palliative care: An opportunity to strive for equity. *Pediatrics*, 140(4), e20171662. <https://doi.org/10.1542/peds.2017-1662>
- Boss, R.D., Donohue, P.K., Larson, S.M., Arnold, R.M., & Roter, D.L. (2016). Family conferences in the neonatal ICU. *Pediatric Critical Care Medicine*, 17(3), 223-230 doi: 10.1097/PCC.0000000000000617
- Boyden, J.Y., Curley, M.A.Q., Deatrick, J.A., & Ersek, M. (2018). Factors associated with the use of U.S. community-based palliative care for children with life-limiting or life-threatening illnesses and their families: An integrative review. *Journal of Pain and Symptom Management*, 55(1), 117-131.
- Boyden, J.Y., Hill, D.L., Carroll, K.W., Morrison, W.E., Miller, V.A., & Feudtner, C. (2020). The association of perceived social support with anxiety over time in parents of children with serious illnesses. *Journal of Palliative Medicine*, 23(4), 529-534.



- Boyden, J., Feudtner, C., Deatrck, J., Widger, K., Laragione, G., Lord, B., & Ersek, M. (2021). Developing a parent-reported measure of experiences with home-based pediatric palliative and hospice care: A multi-method, multi-stakeholder approach. *BMC Palliative Care*, 20(17).
- Boyden,* J., Hill,* D., Nye, R., Bona, K., Johnston, E., Hinds, P., Friebert, S., Kang, T.I., Hays, R., Hall, M., Wolfe, J., & Feudtner, C. (2022). Pediatric palliative care parents' distress, financial difficulty, and child symptoms. *Journal of Pain and Symptom Management*, 63(2), 271-282.
- Brock, K. E., Wolfe, J., & Ullrich, C. (2018). From the child's word to clinical intervention: Novel, new, and innovative approaches to symptoms in pediatric palliative care. *Children*, 5(4), 45. <https://doi.org/10.3390/children5040045>
- Broden, E.G., Hinds, P.S., Werner-Lin, A., Quinn, R., Asaro, L.A., & Curley, M.A.Q. (2022). Nursing care at end of life in pediatric intensive care unit patients requiring mechanical ventilation. *American Journal of Critical Care*, 31(3), 230-239. doi: 10.4037/ajcc2022294.
- Chong, P.H., Hamsah, E., & Goh, C. (2017). Paediatric palliative care in the Asia Pacific region: where are we now? *BMJ Supportive & Palliative Care*, 7(1), 17-22.
- Chrastek JJR, Goloff N, Moore T. A case study in cross-cultural health care and ethics: Who decides what is in the child's "best interest"? *J Hosp Palliat Nurs*, 2019;21:8-13.
- Cicero-Oneto, C.E., Valdez-Martinez, E. & Bedolla, M. (2017). Decision-making on therapeutic futility in Mexican adolescents with cancer: a qualitative study. *BMC Med Ethics*,18(74). <https://doi.org/10.1186/s12910-017-0231-8>
- Cochran, D., Saleem, S., Khawaja-Punjwani, S., & Lantos, J. (2017). Cross-cultural differences in communication about a dying child. *Pediatrics*, 140(5), e20170690.
- de Arruda-Colli, M.N.F., Sansom-Daly, U., dos Santos, M.A., & Wiener, L. (2018). Considerations for the cross-cultural adaptation of an advance care planning guide for youth with cancer. *Clinical Practice in Pediatric Psychology*, 6(4), 341-354.
- DeGroot, N.P., Allen, K.E., Falk, E.E., Velozzi-Averhoff, C., Wasilewski-Masker, K., Johnson, K., & Brock, KE. (2022). Relationship of race and ethnicity on access, timing, and disparities in pediatric palliative care for children with cancer. *Supportive Care in Cancer*, 30(1), 923-930.
- Feudtner, C., & Nathanson, P. G. (2018). Futility, inappropriateness, conflict, and the complexity of medical decision-making. *Perspectives in Biology and Medicine*, 60(3), 345–357. <https://doi.org/10.1353/pbm.2018.0008>
- Feudtner, C., Rosenberg, A. R., Boss, R. D., Wiener, L., Lyon, M. E., Hinds, P. S., Bluebond-Langner, M., & Wolfe, J. (2019). Challenges and priorities for pediatric palliative care research in the U.S. and similar practice settings: Report from a Pediatric Palliative Care Research Network workshop. *Journal of Pain and Symptom Management*, 58(5), 909–917.e3. <https://doi.org/10.1016/j.jpainsymman.2019.08.011>
- Feudtner, C., Nye, R., Hill, D.L., Hall, M., Hinds, P., Johnston, E.E., Friebert, S., Hays, R., Kang, T.I., & Wolfe, J. (2021). Poly-symptomatology in pediatric palliative care patients based on parent-reported data. *JAMA Network Open*, 4(8), e2119730.
- Feudtner, C., Nye, R.T., Boyden, J.Y., Schwartz, K.E., Korn, E.R., Dewitt, A.G., Waldman, A.T., Schwartz, L.A., Shen, Y.A., Manocchia, M., Xiao, R., Lord, B.T., & Hill, D.L. (2021). Association between children with life-threatening conditions and their parents' and siblings' mental and physical health. *JAMA Network Open*, 4(12), e2137250.
- Fortney, C.A., Baughcum, A.E., Moscato, E.L., & Winning, A.M. (2020). Bereaved parents' perceptions of infant suffering in the NICU. *Journal of Pain and Symptom Management*, 59(5), 1001-1008.
- Goloff, N., & Moore, T. (2019). A Case Study in Cross-cultural Health Care and Ethics: Who Decides What Is in the Child's "Best Interest"?. *Journal of Hospice & Palliative Nursing*, 21(1), 8-13.
- Greenfield, K., Holley, S., Schoth, D. E., Harrop, E., Howard, R. F., Bayliss, J., Brook, L., Jassal, S. S., Johnson, M., Wong, I., & Liossi, C. (2020). A mixed-methods systematic review and meta-analysis of barriers and facilitators to paediatric symptom management at end of life. *Palliative Medicine*, 34(6), 689–707. <https://doi.org/10.1177/0269216320907065>



- Ilowite, M. F., Al-Sayegh, H., Ma, C., Dussel, V., Rosenberg, A. R., Feudtner, C., Kang, T. I., Wolfe, J., & Bona, K. (2018). The relationship between household income and patient-reported symptom distress and quality of life in children with advanced cancer: A report from the PediQUEST study. *Cancer, 124*(19), 3934–3941. <https://doi.org/10.1002/cncr.31668>
- Ilowite, M. F., Cronin, A. M., Kang, T. I., & Mack, J. W. (2017). Disparities in prognosis communication among parents of children with cancer: The impact of race and ethnicity. *Cancer, 123*(20), 3995–4003. <https://doi.org/10.1002/cncr.30960>
- Johnston, E.E., Alvarez, E., Saynina, O., Sanders, L., Bhatia, S., & Chamberlain, L.J. Disparities in the intensity of end-of-life care for children with cancer. (2017). *Pediatrics, 140*(4), e20170671. doi: 10.1542/peds.2017-0671. PMID: 28963112.
- Jonas, D., Scanlon, C., & Bogetz, J. F. (2022). Parental decision-making for children with medical complexity: An integrated literature review. *Journal of Pain and Symptom Management, 63*(1), e111–e123. <https://doi.org/10.1016/j.jpainsymman.2021.07.029>
- Kaye, E.C., Gattas, M., Kiefer, A., Reynolds, J., Zalud, K., Li, C., Lu, Z., & Baker, J.N. (2019). Provision of palliative and hospice care to children in the community: A population study of hospice nurses. *Journal of Pain and Symptom Management, 57*(2), 241-250.
- Kaye, E. C., Weaver, M. S., DeWitt, L. H., Byers, E., Stevens, S. E., Lukowski, J., Shih, B., Zalud, K., Applegarth, J., Wong, H.-N., Baker, J. N., & Ullrich, C. K. (2021). The impact of specialty palliative care in pediatric oncology: A systematic review. *Journal of Pain and Symptom Management, 61*(5), 1060–1079.e2. <https://doi.org/10.1016/j.jpainsymman.2020.12.003>
- Lau, N., Bradford, M.C., Steineck, A., Scott, S., Bona, K., Yi-Frazier, J.P., McCauley, E., & Rosenberg, A.R. (2020). Examining key sociodemographic characteristics of adolescents and young adults with cancer: A post hoc analysis of the Promoting Resilience in Stress Management randomized clinical trial. *Palliative Medicine, 34*(3), 336-348.
- Lindley, L.C., & Edwards, S.L. (2018). Geographic variation in California pediatric hospice care for children and adolescents: 2007-2010. *American Journal of Hospice and Palliative Care, 35*(1), 15-20.
- Lindley, L. C., Svyarenko, R., & Beebe, L. H. (2021). Mental health and developmental disabilities in US children admitted in hospice care. *International Journal of Palliative Nursing, 27*(3), 124–130. <https://doi.org/10.12968/ijpn.2021.27.3.124>
- Lord, B. (2019). Parent perspective and response to challenges and priorities for pediatric palliative care research. *Journal of Pain and Symptom Management, 58*(5), e9–e10. <https://doi.org/10.1016/j.jpainsymman.2019.08.007>
- Mack, J. W., Uno, H., Twist, C. J., Bagatell, R., Rosenberg, A. R., Marachelian, A., Granger, M. M., Bender, J. G., Baker, J. N., Park, J. R., Cohn, S. L., Fernandez, J. H., Diller, L. R., & Shusterman, S. (2020). Racial and ethnic differences in communication and care for children with advanced cancer. *Journal of Pain and Symptom Management, 60*(4), 782–789. <https://doi.org/10.1016/j.jpainsymman.2020.04.020>
- Mendes, J., Wool, J., & Wool, C. (2017). Ethical Considerations in Perinatal Palliative Care. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 46*(3), 367-377. <https://doi.org/10.1016/j.jogn.2017.01.011>
- Mendola, A., Naumann, W. C., Mooney-Doyle, K., & Lindley, L. C. (2021). Social determinants of comfort: A new term for end-of-life care. *Journal of Palliative Medicine, 24*(8), 1130–1131. <https://doi.org/10.1089/jpm.2021.0209>
- Mooney-Doyle, K., & Deatrck, J.A. (2016). Parenting in the face of childhood life-threatening conditions: The ordinary in the context of the extraordinary. *Palliative & Supportive Care, 14*(3), 187-198.
- Mooney-Doyle, K., Dos Santos, M.R., Szylit, R., & Deatrck, J.A. (2017). Parental expectations of support from healthcare providers during pediatric life-threatening illness: A secondary, qualitative analysis. *Journal of Pediatric Nursing, 36*, 163-172.



- Mooney-Doyle, K., Deatrck, J.A., Ulrich, C.M., Meghani, S.H., & Feudtner, C. (2018). Parenting in childhood life-threatening illness: A mixed-methods study. *Journal of Palliative Medicine, 21*(2), 208-215.
- Mooney-Doyle, K., & Lindley, L.C. (2019). The association between poverty and family financial challenges of caring for medically complex children. *Nursing Economics, 37*(4), 198.
- Morrison, W. E., Gauvin, F., Johnson, E., & Hwang, J. (2018). Integrating palliative care into the ICU: From core competency to consultative expertise. *Pediatric Critical Care Medicine, 19*(8S, Suppl. 2), S86–S91. <https://doi.org/10.1097/PCC.0000000000001465>
- Muriel, A. C., Wolfe, J., & Block, S. D. (2016). Pediatric palliative care and child psychiatry: A model for enhancing practice and collaboration. *Journal of Palliative Medicine, 19*(10), 1032–1038. <https://doi.org/10.1089/jpm.2015.0354>
- Munoz-Blanco, S., Raisanen, J.C., Donohue, P.K., & Boss, R.D. Enhancing pediatric palliative care for Latino children and their families: A review of the literature and recommendations for research and practice in the United States. *Children, 5*(1).
- Namisango, E., Bristowe, K., Allsop, M. J., Murtagh, F. E. M., Abas, M., Higginson, I. J., Downing, J., & Harding, R. (2019). Symptoms and concerns among children and young people with life-limiting and life-threatening conditions: A systematic review highlighting meaningful health outcomes. *Patient, 12*(1), 15–55. <https://doi.org/10.1007/s40271-018-0333-5>
- National Academies of Sciences, Engineering, and Medicine. (2021). *The future of nursing 2020–2030: Charting a path to achieve health equity*. National Academies Press. <https://doi.org/10.17226/25982>
- National Institute of Nursing Research. (2021). *Strategic plan working group draft framework for 2022-2026*. https://www.ninr.nih.gov/sites/files/docs/strategic_planning_working_group_framework_report_051021_v1_508c.pdf
- Odeniyi, F., Nathanson, P.G., Schall, T.E., & Walter, J.K. (2017). Communication challenges of oncologists and intensivists caring for pediatric oncology patients: A qualitative study. *Journal of Pain and Symptom Management, 54*(6), 909-915.
- Quinn, M., Weiss, A. B., & Crist, J. D. (2020). Early for everyone: Reconceptualizing palliative care in the neonatal intensive care unit. *Advances in Neonatal Care, 20*(2), 109–117. <https://doi.org/10.1097/ANC.0000000000000707>
- Rosenberg, A.R., Orellana, L., Ullrich, C., Kang, T., Geyer, J.R., Feudtner, C., Dussel, V., & Wolfe, J. (2016). Quality of life in children with advanced cancer: A report from the PediQUEST Study. *Journal of Pain and Symptom Management, 52*(2), 243-253.
- Rosenberg, A.R., Starks, H., Unguru, Y., Feudtner, C., & Diekema, D. (2017). Truth telling in the setting of cultural differences and incurable pediatric illness: A review. *JAMA Pediatrics, 171*(11), 1113–1119. doi:10.1001/jamapediatrics.2017.2568
- Rosenberg, A.R., Bona, K., Coker, T., Feudtner, C., Houston, K., Ibrahim, A., Macauley, R., Wolfe, J., & Hays, R. (2019). Pediatric palliative care in the multicultural context: Findings from a workshop conference. *Journal of Pain & Symptom Management, 57*(4), 846-855.
- Philip, R.R., Venables, E., Manima, A., Tripathy, J.P., & Philip, S. (2019). "Small small interventions, big big roles"- a qualitative study of patient, care-giver and health-care worker experiences of a palliative care programme in Kerala, India. *BMC Palliative Care, 18*(1), 16.
- Pinheiro, L. C., McFatrigh, M., Lucas, N., Walker, J. S., Withycombe, J. S., Hinds, P. S., Sung, L., Tomlinson, D., Freyer, D. R., Mack, J. W., Baker, J. N., & Reeve, B. B. (2018). Child and adolescent self-report symptom measurement in pediatric oncology research: A systematic literature review. *Quality of Life Research, 27*(2), 291–319. <https://doi.org/10.1007/s11136-017-1692-4>
- Rajeshuni, N., Johnston, E.E., Saynina, O., Sanders, L.M., & Chamberlain, L.J. (2017). Disparities in location of death of adolescents and young adults with cancer: A longitudinal, population study in California. *Cancer, 123*(21), 4178-84.



- Rapoport, A., & Morrison, W. (2016). No child is an island: ethical considerations in end-of-life care for children and their families. *Current Opinion in Supportive and Palliative Care*, 10(3), 196-200. doi: 10.1097/SPC.0000000000000226
- Rhee, J.Y., Garralda, E., Namisango, E., Luyirika, E., de Lima, L., Powell, R.A., Robinson, C.A., & Centeno, C. (2018). Factors affecting palliative care development in Africa: In-country experts' perceptions in seven countries. *Journal of Pain and Symptom Management*, 55(5), 1313-1320.
- Roeland, E. J., Lindley, L. C., Gilbertson-White, S., Saeidzadeh, S., Currie, E. R., Friedman, S., Bakitas, M., & Mack, J. W. (2020). End-of-life care among adolescent and young adult patients with cancer living in poverty. *Cancer*, 126(4), 886–893. <https://doi.org/10.1002/cncr.32609>
- Sedhom, R., Nudotor, R., Freund, K., Smith, T., Cooper, L., Owczarzak, J., & Johnston, F.M. (2021). Can community health workers increase palliative care use for African American patients? A pilot study. *JCO Oncology Practice*, 17(2), e158-e67.
- Shaw, C., Stokoe, E., Gallagher, K., Aladangady, N. & Marlow, N. (2016). Parental involvement in neonatal critical care decision-making. *Sociology of Health & Illness*, 38, 1217-1242. <https://doi.org/10.1111/1467-9566.12455>
- Sisk, B.A., Mack, J.W., Ashworth, R., & DuBois, J. (2018). Communication in pediatric oncology: State of the field and research agenda. *Pediatric Blood & Cancer*, 65(1), e26727.
- Sisk, B.A., Canavera, K., Sharma, A., Baker, J.N., & Johnson, L.-M. (2019). Ethical issues in the care of adolescent and young adult oncology patients. *Pediatric Blood & Cancer*, 66, e27608. <https://doi.org/10.1002/pbc.27608>
- Sisk, B.A., Kang, T.I., & Mack, J.W. (2020). Racial and ethnic differences in parental decision-making roles in pediatric oncology. *Journal of Palliative Medicine*, 23(2), 192-7.
- Sisk, B.A., Friedrich, A.B., Kaye, E.C., Baker, J.N., Mack, J.W., DuBois, J.M. (2021). Multilevel barriers to communication in pediatric oncology: Clinicians' perspectives. *Cancer*, 127(12), 2130-2138.
- Snaman, J., McCarthy, S., Wiener, L., & Wolfe, J. (2020). Pediatric palliative care in oncology. *Journal of Clinical Oncology*, 38(9), 954-962.
- Svynarenko, R., Beebe, L. H., & Lindley, L. C. (2021). Identifying patterns of pediatric mental and behavioral health at end of life: A national study. *Journal of Hospice and Palliative Nursing*, 23(6), 571–578. <https://doi.org/10.1097/NJH.0000000000000800>
- Thieleman, K.J., Wallace, C., Cimino, A.N., & Rueda, H.A. (2016) Exhaust all measures: Ethical issues in pediatric end-of-life care. *Journal of Social Work in End-of-Life & Palliative Care*, 12(3), 289-306. doi: 10.1080/15524256.2016.1200518
- Thrane, S.E., Maurer, S.H., Ren, D., Danford, C.A., & Cohen, S.M. (2017). Reiki therapy for symptom management in children receiving palliative care: A pilot study. *American Journal of Hospice and Palliative Medicine*, 34(4), 373-379. doi:10.1177/1049909116630973
- Thrane, S.E., Maurer, S.H., & Danford, C.A. (2021). Feasibility and acceptability of reiki therapy for children receiving palliative care in the home. *Journal of Hospice and Palliative Nursing*, 23(1), 52-58.
- Thorvilson, M.J., Manahan, A.J., Schiltz, B.M., & Collura, C.A. (2018). Homeward bound: A case series of cross-cultural care at end of life, enhanced by pediatric palliative transport. *Journal of Palliative Medicine*, 22(4):464-467.
- Tyer-Viola, L., Nicholas, P. K., Corless, I. B., Barry, D. M., Hoyt, P., Fitzpatrick, J. J., & Davis, S. M. (2009). Social responsibility of nursing: A global perspective. *Policy, Politics, and Nursing Practice*, 10(2), 110–118. <https://doi.org/10.1177/1527154409339528>
- Umaretiya, P., Wolfe, J., & Bona, K. (2022). Naming the problem: A structural racism framework to examine disparities in palliative care. *Journal of Pain and Symptom Management*, 63(5), e461-e463.
- Weaver, M., Wichman, C., Darnall, C., Bace, S., Vail, C., & MacFadyen, A. (2017). Proxy-reported quality of life and family impact for children followed longitudinally by a pediatric palliative care team. *Journal of Palliative Medicine*, 21(2), 241-244.



- Weaver, M.S., Mooney-Doyle, K., Kelly, K.P., Montgomery, K., Newman, A.R., Fortney, C.A., Bell, C.J., Spruit, J.L., Kurtz Uveges, M., Wiener, L., Schmidt, C.M., Madrigal, V.N., & Hinds, P.S. (2019). The benefits and burdens of pediatric palliative care and end-of-life research: A systematic review. *Journal of Palliative Medicine*, 22(8), 915-926.
- Weaver, M.S., Robinson, J.E., Shostrom, V.K., & Hinds, P.S. (2020). Telehealth acceptability for children, family, and adult hospice nurses when integrating the pediatric palliative inpatient provider during sequential rural home hospice visits. *Journal of Palliative Medicine*, 23(5), 641-649.
- Weaver, M.S., Shostrom, V.K., Neumann, M.L., Robinson, J.E., & Hinds, P.S. (2021). Homestead together: Pediatric palliative care telehealth support for rural children with cancer during home-based end-of-life care. *Pediatric Blood & Cancer*, 68(4), e28921.
- Winegard, B., Miller, E.G., & Slamon, N.B. (2017). Use of telehealth in pediatric palliative care. *Telemedicine and E-Health*, 23(11), 938-940.
- Wool, C., Côté-Arsenault, D., Perry Black, B., Denney-Koelsch, E., Kim, S., & Kavanaugh, K. (2016). Provision of services in perinatal palliative care: A multicenter survey in the United States. *Journal of Palliative Medicine*, 19(3), 279-285.

PRIORITY: TRANSITIONS IN CARE

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Transitions in hospice and palliative care occur across multiple settings, including hospitals, home health, skilled nursing facilities, long-term care organizations, and ambulatory settings. Information and communication technologies play a vital role in transitions of care for patients with serious illness, families, and the hospice and palliative care team members (Ostherr et al., 2016). Care transitions are “anticipated, planned, and coordinated to ensure patient goals are achieved” (National Consensus Project for Quality Palliative Care, 2018, p. 7). Prior to the COVID-19 pandemic, the Public Health Institute Center for Connected Health Policy (2019) noted that despite the growth and benefits associated with telehealth, Medicare and Medicaid policies cause provider, service, and payment restrictions, which causes lags in technological advancements.

Electronic medical records can potentially enhance continuity during transitions in care (World Health Organization [WHO], 2021) in patients with serious illnesses and should be used to document both medical and nonmedical preferences of patients at end of life. WHO (2021) recommends the



development of an “interoperable digital health ecosystem” (p. 11), which would enhance continuity of care, quality, and communication between providers, patients, researchers, and the public health sector (p. 5). Most of the existing literature focuses on transitions in care from hospice and palliative services to hospitals, and there is a need to explore transitions between types of care; provider, patient, and family experiences; and outcomes after transition back to the community. The use of digital technologies can enhance access to care in communities where there are physician shortages, but digital readiness among consumers and providers requires further assessment due to access, connectivity, and security risks (Mills, 2019; WHO, 2021).

In hospice and palliative care settings, digital technology has been used for years, particularly for pain management. In response to the COVID-19 pandemic, healthcare systems have had to develop and adapt to innovative ways of providing patient care services, including mobile technology (Kaye et al., 2020), remote monitoring, virtual consults, telehealth, and telemedicine, which Tahan (2020) posits has increased collaboration across all levels of care. However, in their retrospective analysis study, Wang et al. (2016) reported that about 7% to 21% of Medicare hospice patients have had at least one transition in care, primarily to the emergency department or intensive care unit (ICU). Transitions in care can place patients at risk for medical errors, decreased quality of life, and poor outcomes due to communication issues. One of the challenges in transitions in care is the continuity of patient care preferences at end of life, specifically those related to nonmedical choices and preference for place of death (Williams et al., 2020). Williams et al. (2020) audited 50 electronic and paper records of deceased patients from hospitals, long-term care facilities, and community-based palliative care organizations and found that documentation of preferred place of death was lacking in 70% of the records. In addition, 63% of preferences for preferred place of death were obtained from family members in the last week of the patient’s life. Having conversations about end-of-life wishes during a crisis situation may account for last-minute referrals to hospices. Care coordination must include the management of transitions designed to improve quality of care and positive patient and caregiver outcomes.

It is well appreciated that shared decision-making (SDM), one of the six pillars of healthcare quality defined by the Institute of Medicine (IOM, 2015), places the patient’s and caregiver’s wishes into the management of transitions for quality care in clinical practice. In 2018, the WHO discussed multiple drivers that impact quality care, including a collaborative plan of care that includes the patient as a key person in the SDM process. Thus, supporting person-centered, goal-oriented plans of care and coaching individuals, families, and informal caregivers to be fully involved in assessment and decisions about care is an important factor of successful care coordination (WHO, 2018). The COVID-19 pandemic highlights the importance of SDM in palliative care and has changed how we deliver care while allowing us to reevaluate common practices and enhance effectiveness of our decision-making strategies (Abrams et al., 2020).

The National Consensus Project for Quality Palliative Care’s (2018) [*Clinical Practice Guidelines for Quality Palliative Care*](#) defined SDM as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options to achieve informed preferences. The use of SDM processes in palliative care creates a primed area for study application in the alignment of the patient’s goals and values with the best available evidence. Belanger (2017) identified that challenges remain in aligning care decisions with the patient’s and caregiver’s values and goals throughout the healthcare continuum. Baik et al. (2019) stated that “the effects of the SDM intervention on patient outcomes were inconsistent, highlighting the need for further SDM intervention studies among diverse patient populations using consistent measures” (p. 76). Recommendations, based on identified research gaps, include aligning the goals and values of patients with serious illnesses and their informal care partners with decisions that are supportive, and based on patient preferences and the best available clinical evidence.



Although caregiving is often conceptualized as family caregiving (i.e., family members caring for each other), the literature also includes studies with healthcare providers who are professional caregivers (e.g., nurses, physicians). There is also a focus on the last days of life or transitions during advanced illness (Meeker et al., 2019), rather than on transitions early in the illness trajectory when palliative care may be appropriate. The emphasis on end of life may explain why studies primarily capture family caregiver and provider perspectives, rather than patient perspectives. Despite the sheer volume of studies, most studies in the past five years have utilized qualitative or chart review designs (Carpenter, 2017; Killackey et al., 2020; Meeker et al., 2019; Saunders et al., 2019), limiting the conclusions that can be drawn from the literature. Main topics of study include discharge planning when transitioning from the hospital to the community, transitions from the nursing home to the hospital and vice versa, and transitions to palliative or hospice care (Carpenter, 2017; Killackey et al., 2020; Meeker et al., 2019; Saunders et al., 2019). Additional research is needed to better understand transitions in the community. Outcomes of interest include healthcare utilization variables, such as length of stay and hospital readmissions (Saunders et al., 2019), and use of palliative care services (Carpenter, 2017) and code status (Bhangu et al., 2020). The major challenges that exist include communication/coordination between providers, communication/coordination between providers–patients–family caregivers, lack of understanding about the roles of different individuals during transitions, and lack of preparedness to make transitions decisions (Carpenter, 2017; Killackey et al., 2020; Meeker et al., 2019; Saunders et al., 2019). Future work is needed to examine the transitions experience earlier in the illness trajectory, in a quantitative manner, and by measuring outcomes that are patient and family centered (e.g., quality of transitions). Opportunities exist to examine outcomes after a transition occurs, as most studies examine only the immediate transitions period; determine how to measure the quality of a transition toward the end of life; and investigate the factors (e.g., family caregiver’s level of involvement) that predict a positive transition experience between types of care (e.g., palliative to hospice) and location of care.

While the proportion of hospital deaths, ICU use, and care transitions during the final days of life has declined in recent years (Teno et al., 2018), there is a need to pursue innovative research designs to continue this trend for people with serious illness and their caregivers. Such approaches should consider the variety of factors driving care transitions at the individual, community, health system, and policy levels. One way to promote palliative care transitions and avoid nonbeneficial transitions in care is to design community-based participatory research projects. By involving community members, it may be possible to illuminate previously unknown barriers to accessing comfort-focused care (Bazargan & Bazargan-Hejazi, 2021; Paramanandam et al., 2020; Yosik et al., 2019). This is particularly necessary for ensuring the delivery of culturally sensitive equitable care to overcome barriers posed by the social determinants of health of high-need individuals.

Secondary data analysis using machine-learning and artificial intelligence (AI) research methods may uniquely contribute to understanding care transition trajectories and outcomes outside of the hospital setting (Hirschman et al., 2020; Makaroun et al., 2018). These cutting-edge methods make it possible to present information to clinicians in an easy-to-interpret format to support personalized clinical decision-making (Morin & Onwuteaka-Philipsen, 2021). Moreover, machine-learning and AI may potentiate the development of dynamic, data-driven algorithms for identifying and communicating care transition risk using technology such as smartphone apps (e.g., mHealth), wearable devices (e.g., gait analysis for fall risk), and the interoperable exchange of shared care plans across the continuum of care using health information exchanges.

Future research should also focus on the development of novel educational approaches for augmenting the competencies of all nurses in delivering palliative care to expand access to supportive care services, potentially reducing nonbeneficial care transitions (IOM, 2015; Mann & Sullivan, 2021). The COVID-19 pandemic brought forth new challenges and opportunities for using technology to facilitate end-of-life communication and expand the reach of telehealth, presenting



many opportunities to investigate how technology may help mitigate nonbeneficial transitions of care. In a rapidly changing healthcare environment, innovative research methodologies are necessary for the timely identification of care transition risk so nurses and other providers may personalize care and develop upstream interventions to support individuals with serious illness and their families in planning and preparing for palliative and end-of-life care.

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.

References

- Abrams, E. M., Shaker, M., Oppenheimer, J., Davis, R. S., Bukstein, D. A., & Greenhawt, M. (2020). The challenges and opportunities for shared decision making highlighted by COVID-19. *Journal of Allergy and Clinical Immunology: In Practice*, 8(8), 2474–2480.E1. <https://doi.org/10.1016/j.jaip.2020.07.003>
- Baik, D., Cho, H., & Masterson Creber, R. M. (2019). Examining interventions designed to support shared decision making and subsequent patient outcomes in palliative care: A systematic review of the literature. *American Journal of Hospice and Palliative Care*, 36(1), 76–88. <https://doi.org/10.1177/1049909118783688>
- Bazargan, M., & Bazargan-Hejazi, S. (2021). Disparities in palliative and hospice care and completion of advance care planning and directives among non-Hispanic Blacks: A scoping review of recent literature. *American Journal of Hospice and Palliative Care*, 38(6), 688–718. <https://doi.org/10.1177/1049909120966585>
- Belanger, E. (2017). Shared decision-making in palliative care: Research priorities to align care with patients' values. *Palliative Medicine*, 31(7), 585–586. <https://doi.org/10.1177/0269216317713864>
- Bhangu, J. K., Young, B. T., Posillico, S., Ladhani, H. A., Zolin, S. J., Claridge, J. A., & Ho, V. P. (2020). Goals of care discussions for the imminently dying trauma patient. *Journal of Surgical Research*, 246, 269–273. <https://doi.org/10.1016/j.jss.2019.07.046>
- Carpenter, J. G. (2017). Hospital palliative care teams and post-acute care in nursing facilities: An integrative review. *Research in Gerontological Nursing*, 10(1), 25–34. <https://doi.org/10.3928/19404921-20161209-02>
- Hirschman, K. B., Toles, M. P., Hanlon, A. L., Huang, L., & Naylor, M. D. (2020). What predicts health care transitions for older adults following introduction of LTSS? *Journal of Applied Gerontology*, 39(7), 702–711. <https://doi.org/10.1177/0733464819833565>
- Institute of Medicine. (2015). *Dying in America: Improving quality and honoring individual preferences near the end of life*. National Academies Press. <https://doi.org/10.17226/18748>
- Kaye, R., Rosen-zvi, M., & Ron, R. (2020). Digitally-enabled remote care for cancer patients: Here to stay. *Seminars in Oncology Nursing*, 36(6), 151091. <https://doi.org/10.1016/j.soncn.2020.151091>
- Killackey, T., Lovrics, E., Saunders, S., & Isenberg, S. R. (2020). Palliative care transitions from acute care to community-based care: A qualitative systematic review of the experiences and perspectives of health care providers. *Palliative Medicine*, 34(10), 1316–1331. <https://doi.org/10.1177/0269216320947601>



- Makaroun, L. K., Teno, J. M., Freedman, V. A., Kasper, J. D., Gozalo, P., & Mor, V. (2018). Late transitions and bereaved family member perceptions of quality of end-of-life care. *Journal of the American Geriatrics Society*, 66(9), 1730–1736. <https://doi.org/10.1111/jgs.15455>
- Mann, C. M., & Sullivan, S. S. (2021). Promoting evidence-based practice in clinical education at a hospice designated education unit. *Journal of Hospice and Palliative Nursing*, 23(4), 354–359. <https://doi.org/10.1097/NJH.0000000000000764>
- Meeker, M. A., McGinley, J. M., & Jezewski, M. A. (2019). Metasynthesis: Dying adults' transition process from cure-focused to comfort-focused care. *Journal of Advanced Nursing*, 75(10), 2059–2071. <https://doi.org/10.1111/jan.13970>
- Mills, S. (2019). Digital health technology in palliative care: Friend or foe? *Progress in Palliative Care*, 27(4), 145–146. <https://doi.org/10.1080/09699260.2019.1650420>
- Morin, L., & Onwuteaka-Philipsen, B. D. (2021). The promise of big data for palliative and end-of-life care research. *Palliative Medicine*, 35(9), 1638–1640. <https://doi.org/10.1177/02692163211048307>
- National Consensus Project for Quality Palliative Care. (2018). [*Clinical Practice Guidelines for Quality Palliative Care*](#) (4th ed.). National Coalition for Hospice and Palliative Care. <https://www.nationalcoalitionhpc.org/ncp/>
- Ostherr, K., Killoran, P., Shegog, R., & Bruera, E. (2016). Death in the digital age: A systematic review of information and communication technologies in end-of-life care. *Journal of Palliative Medicine*, 19(4), 408–420. <https://doi.org/10.1089/jpm.2015.0341>
- Paramanandam, G., Volk-Craft, B. E., Brueckner, R. M., O'Sullivan, T. M., & Waters, E. (2020). Avoided hospitalization criteria: Validating the impact of a community-based palliative care program. *Palliative Medicine Reports*, 1(1), 246–250. <https://doi.org/10.1089/pmr.2020.0077>
- Public Health Institute Center for Connected Health Policy. (2019). *Federally designated National Telehealth Policy Resource Center*. <https://www.telehealthpolicy.us/sites/default/files/2019-03/TELEHEALTH%20REIMBURSEMENT%202019%20FINAL.pdf>
- Saunders, S., Killackey, T., Kurahashi, A., Walsh, C., Wentlandt, K., Lovrics, E., Scott, M., Mahtani, R., Bernstein, M., Howard, M., Tanuseputro, P., Goldman, R., Zimmermann, C., Aslakson, R. A., & Isenberg, S. R. (2019). Palliative care transitions from acute care to community-based care—A systematic review. *Journal of Pain and Symptom Management*, 58(4), 721–734.E1. <https://doi.org/10.1016/j.jpainsymman.2019.06.005>
- Tahan, H. M. (2020). Essential case management practices amidst the novel coronavirus disease 2019 (COVID-19) crisis: Part 2: End-of-life care, workers' compensation case management, legal and ethical obligations, remote practice, and resilience. *Professional Case Management*, 25(5), 267–284. <https://doi.org/10.1097/NCM.0000000000000455>
- Teno, J. M., Gozalo, P., Trivedi, A. N., Bunker, J., Lima, J., Ogarek, J., & Mor, V. (2018). Site of death, place of care, and health care transitions among US Medicare beneficiaries, 2000–2015. *JAMA*, 320(3), 264–271. <https://doi.org/10.1001/jama.2018.8981>
- Wang, S.-Y., Aldridge, M. D., Gross, C. P., Canavan, M., Cherlin, E., Johnson-Hurzeler, R., & Bradley, E. (2016). Transitions between healthcare settings of hospice enrollees at the end of life. *Journal of the American Geriatrics Society*, 64(2), 314–322. <https://doi.org/10.1111/jgs.13939>
- Williams, S., Hwang, K., Watt, J., Batchelor, F., Gerber, K., Hayes, B., & Brijnath, B. (2020). How are older people's care preferences documented towards the end of life? *Collegian*, 27(3), 313–318. <https://doi.org/10.1016/j.colegn.2019.09.008>
- World Health Organization. (2018). *Continuity and coordination of care: A practice brief to support implementation of the WHO Framework on integrated people-centered health services*.
- World Health Organization. (2021). *Global strategy on digital health 2020-2025*.



Yosick, L., Crook, R. E., Gatto, M., Maxwell, T. L., Duncan, I., Ahmed, T., & Mackenzie, A. (2019). Effects of a population health community-based palliative care program on cost and utilization. *Journal of Palliative Medicine*, 22(9), 1075–1081. <https://doi.org/10.1089/jpm.2018.0489>



APPENDIX 1

Steps of the Process for Generation of the HPNA Research Agenda

2023-2026 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 2023-2026 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



APPENDIX 2

Priority Recommendation and NCP Guidelines Crosswalk Table

Crosswalk Table

The NCP [Clinical Practice Guidelines for Quality Palliative Care](#) describe essential elements of high-quality, evidence-based palliative and hospice nursing practice. This table maps the HPNA priorities to the NCP guidelines. The [Clinical Practice Guidelines for Quality Palliative Care](#) delineate eight domains:

Domain 1: Structure and Processes of Care

Palliative care principles and practices can be integrated into any health care setting, delivered by all clinicians and supported by palliative care specialists who are part of an interdisciplinary team (IDT) with the professional qualifications, education, training, and support needed to deliver optimal patient- and family-centered care. Palliative care begins with a comprehensive assessment and emphasizes patient and family engagement, communication, care coordination, and continuity of care across health care settings. (NCP, pg. 1)

Domain 2: Physical Aspects of Care

Physical care of seriously ill patients begins with an understanding of the patient goals in the context of their physical, functional, emotional, and spiritual well-being. The assessment and care plan focus on relieving symptoms and improving or maintaining functional status and quality of life. The management of symptoms encompasses pharmacological, non-pharmacological, interventional, behavioral, and complementary treatments. Physical care, acute and chronic symptom management across all care settings is accomplished through communication, collaboration, and coordination between all professionals involved in the patients' care, including primary and specialty care providers. (NCP, pg.13).

Domain 3: Psychological and Psychiatric Aspects of Care

The palliative care interdisciplinary team (IDT) systematically addresses psychological and psychiatric aspects of care in the context of serious illness. The IDT conducts comprehensive developmentally and culturally sensitive mental status screenings of seriously ill patients. The social worker facilitates mental health assessment and treatment in all care settings, either directly, in consultation, or through referral to specialist level psychological and/or psychiatric care. The IDT communicates to the patient and family the implications of psychological and psychiatric aspects of care in establishing goals of care and developing a treatment plan, addressing family conflict, delivering grief support and resources from the point of diagnosis onward, and providing referrals for patients or family members who require additional support (NCP, pg. 20).

Domain 4: Social Aspects of Care

Social determinants of health, hereafter encompassed in the term "social factors," have a strong and sometimes overriding influence on patients with a serious illness. Palliative care addresses environmental and social factors that affect patient and family functioning and quality of life. The palliative care interdisciplinary team (IDT) partners with the patient and family to identify and support their strengths and to address areas of need. The IDT includes a social worker to maximize patient functional capacity and achieve patient and family goals. (NCP, pg.26).

Domain 5: Spiritual, Religious, and Existential Aspects of Care

Spirituality is recognized as a fundamental aspect of compassionate, patient and family-centered palliative care. It is a dynamic and intrinsic aspect of humanity through which individuals seek meaning, purpose, and transcendence, and experience relationship to self, family, others, community,



society, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices. Palliative care interdisciplinary teams (IDT) serve each patient and family in a manner that respects their spiritual beliefs and practices. Teams are also respectful when patients and families decline to discuss their beliefs or accept spiritual support. (NCP, pg. 32)

Domain 6: Cultural Aspects of Care

Assessing and respecting values, beliefs and traditions related to health, illness, family caregiver roles and decision-making are the first step in providing culturally sensitive palliative care. Palliative care interdisciplinary team (IDT) members continually expand awareness of their own biases and perceptions about race, ethnicity, gender identity and gender expression, sexual orientation, immigration and refugee status, social class, religion, spirituality, physical appearance, and abilities. Information gathered through a comprehensive assessment is used to develop a care plan that incorporates culturally sensitive resources and strategies to meet the needs of patients and family members. Respectful acknowledgment of and culturally sensitive support for patient and family grieving practices is provided. (NCP, pg. 38)

Domain 7: Care of the Patient Nearing the End of Life

This domain highlights the care provided to patients and their families near the end of life, with a particular emphasis on the days leading up to and just after the death of the patient. The meticulous and comprehensive assessment and management of pain and other physical symptoms, as well as social, spiritual, psychological, and cultural aspects of care, are critically important as the patient nears death. It is essential that the interdisciplinary team (IDT) ensures reliable access and attention in the days before death, and provides developmentally appropriate education to the patient, family and/or other caregivers about what to expect near death, as well as immediately following the patient's death. (NCP, pg. 45).

Domain 8: Ethical and Legal Aspects of Care

The palliative care interdisciplinary team (IDT) applies ethical principles to the care of patients with serious illness, including honoring patient preferences, as well as decisions made by legal proxies or surrogate decision-makers. It is important to note that in all cases surrogates' obligations are to represent the patient's preferences or best interests. Familiarity with local and state laws is needed relating to advance care planning, decisions regarding life-sustaining treatments, and evolving treatments with legal ramifications (eg, medical marijuana), especially when caring for vulnerable populations, such as minors, prisoners, or those with developmental disability or psychiatric illness. (NCP, pg. 52).

Reference: National Consensus Project for Quality Palliative Care. [Clinical Practice Guidelines for Quality Palliative Care](https://www.nationalcoalitionhpc.org/nc), 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. <https://www.nationalcoalitionhpc.org/nc>



| HPNA Research Recommendations | Associated NCP Guideline Domains | | | | | | | |
|--|----------------------------------|---|---|--------------------------|--------------------------|--------------------------|---|--------------------------|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| Priority: Equitable Palliative Care | | | | | | | | |
| 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. | <input type="checkbox"/> | | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | <input type="checkbox"/> |
| 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. | <input type="checkbox"/> | | | <input type="checkbox"/> | | | | <input type="checkbox"/> |
| 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. | <input type="checkbox"/> | | | <input type="checkbox"/> | | | | |
| Recommendation 4. (Societal) Recognize and support the unique challenges of rurality for research teams conducting community-based participatory research with minoritized population groups. | <input type="checkbox"/> | | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | <input type="checkbox"/> |
| Recommendation 5. (Individual/educational) Explore healthcare professionals' perspectives and educational needs for developing a practice of cultural humility. | | | | | <input type="checkbox"/> | <input type="checkbox"/> | | <input type="checkbox"/> |
| 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. | | | | <input type="checkbox"/> | | | | <input type="checkbox"/> |
| Priority: Local, National, and Global Disaster/Emergency Response in Palliative and Hospice Care | | | | | | | | |
| 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. | <input type="checkbox"/> | | | | | | | <input type="checkbox"/> |



| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| <p>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.</p> | □ | | | | | | | □ |
| <p>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.</p> | | □ | □ | □ | □ | □ | □ | □ |
| <p>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.</p> | | | □ | □ | | | | □ |
| <p>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.</p> | □ | | | | | | | |
| Priority: Well-Being of Palliative Care and Hospice Clinicians: Self-Care and Workforce Development | | | | | | | | |
| <p>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.</p> | □ | | | □ | | | | |
| <p>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.</p> | □ | | | | | | | □ |
| <p>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.</p> | □ | | | □ | | | | □ |



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| <p>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.</p> | □ | | | | □ | | □ |
| <p>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.</p> | | | | | | | |
| <p>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.</p> | □ | | | | □ | | |
| Priority: Pediatric Palliative and Hospice Research Priorities | | | | | | | |
| <p>Recommendation 1. Employ a holistic socioecological approach to studying child, family, and community outcomes associated with PPHC and the factors that affect these outcomes.</p> | □ | □ | □ | □ | □ | □ | □ |
| <p>Recommendation 2. Advance research surrounding bioethical issues and the social responsibility of nursing in PPHC.</p> | □ | | □ | □ | □ | | □ |
| <p>Recommendation 3. Improve our understanding of understudied populations and settings of care within PPHC.</p> | □ | □ | □ | □ | □ | □ | □ |
| <p>Recommendation 4. Develop and test interventions to strengthen equitable palliative and hospice care provided to children and families in minoritized and historically marginalized communities.</p> | □ | | □ | □ | □ | □ | □ |
| Priority: Transitions in Care | | | | | | | |
| <p>Recommendation 1. Examine transitions with quantitative study designs that measure patient- and family-centered outcomes, not just hospitalization data.</p> | □ | | □ | □ | | □ | □ |
| <p>Recommendation 2. Engage in studies that consider a broader understanding of transitions beyond the actual transition and the period immediately after transitions occur.</p> | □ | □ | □ | □ | □ | □ | □ |
| <p>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.</p> | □ | | | | | | |