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Advancing palliative and end-of-life science in cardiorespiratory populations: The contributions of nursing science

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ABSTRACT

Nursing science has a critical role to inform practice, promote health, and improve the lives of individuals across the lifespan who face the challenges of advanced cardiorespiratory disease. Since 1997, the National Institute of Nursing Research (NINR) has focused attention on the importance of palliative and end-of-life care for advanced heart failure and advanced pulmonary disease through the publication of multiple funding opportunity announcements and by supporting a cadre of nurse scientists that will continue to address new priorities and future directions for advancing palliative and end-of-life science in cardiorespiratory populations.

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Introduction

Cardiorespiratory disease remains a leading cause of death in the United States.[1] While, advances in science and technology have resulted in a range of new interventions, treatment options and medical supports that are contributing to increased patient survival, the progressive symptomatic nature of cardiorespiratory disease results in high morbidity and mortality and substantial burden on patients, caregivers and health care systems.[2–4] Palliative care, including hospice care, is increasingly recognized as an important component of quality care for cardiorespiratory disease due to its focus on symptom management and emphasis on individual and family-oriented goals of care.[5,6] A growing evidence base is demonstrating that comprehensive palliative care delivered throughout the trajectory of a cardiorespiratory disease significantly improves quality of life. Results from palliative care research are identifying the unique challenges and barriers in optimizing cardiorespiratory symptom relief and reducing illness burden.[7–10] Research results are also demonstrating the benefits of palliative care in areas such as advance care planning, shared decision making and communication of preferences for end-of-life care.[11–17]

Cardiorespiratory research that addresses the need for palliative care throughout the trajectory of an advanced illness is important and cannot be overlooked. At the National Institute of Nursing Research (NINR), principal research priorities in end-of-life and palliative care science focus on high-quality research to advance new knowledge to assist individuals, their families, and their health care providers in managing the complex experiences of advanced symptoms, to mitigate the effects of symptom burden on their health and well-being, and to optimize informed health care decisions (NINR End-of-Life and Palliative Care Research, http://www.ninr.nih.gov/eolpc-theme). Many of the health-related needs of the cardiorespiratory disease population lend themselves to a synergy for palliative care research in the critical care environment to understand the health care utilization demands of cardiorespiratory disease on recurrent hospitalizations, increasing frailty, or functional disability.[2,8,10,18] At the same time, the therapeutic management and support of many advanced heart or respiratory conditions pose numerous and unique challenges in research to understand the nature, prognosis, severity and pattern of cardiorespiratory symptoms and concomitant overlying complex conditions. These include, among others, on-going research that substantiates best practices and outcome metrics related to pain, fatigue, dyspnea, depression and other symptom management; patient and family-oriented needs; models of care that eliminate multiple transitions and delayed referral to hospice; use of innovative technologies; and, attention to variations in palliative services across multiple health systems and diverse populations.

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The NINR has an extensive history of end-of-life and palliative care research that has demonstrated the key role of nursing science in developing and testing interventions to reduce symptoms and distress, facilitate communication and informed choices, and improve the quality of care to individuals and their families. In 1997, the Institute of Medicine called upon the National Institutes of Health (NIH) for leadership in building research in end-of-life care and to address research priorities through fostering expansion and development of end-of-life science across NIH Institutes and Centers. The NINR, along with a number of other Institutes and the Office of Alternative Medicine (now the National Center for Complementary and Integrative Health, or NCCIH) sponsored a workshop on the symptoms of terminal illness. A series of subsequent funding opportunity announcements emanated from NINR to address these research priorities and to expand efforts to focus studies on advanced symptom management and support advance care planning and decision making. As a result, in 1997, the Director of the NIH designated NINR as the lead Institute for end-of-life research to lead these efforts, and as such the NINR continued to call for research focusing on the management of "symptoms and syndromes associated with life-limiting illness" and specifically, symptoms of end-stage heart disease. As the evidence base developed, NINR called upon experts from across the field of end-of-life and palliative care research to participate in a 2004 State-of-the-Science conference focused on issues pertinent to cardiorespiratory care and acute and critical care delivery. These issues included: symptoms affecting cardiorespiratory populations such as dyspnea, fatigue, and pain; challenging issues of withdrawal of life-sustaining treatments in critical care settings; enhanced communication surrounding advance care planning; and, support of caregivers.[19] NINR continued its leadership through by collaborating at the State-of-the-Science with the Centers for Disease Control and Prevention, the Centers for Medicare and Medicaid Services, the National Cancer Institute, the then National Center for Complementary and Alternative Medicine, the National Institute of Mental Health, and the National Institute on Aging.[19,20] Several NINR-led requests for research applications emanated over the next decade that looked to build the science of palliative care in advanced heart failure, acute life threatening conditions, decision making, and advanced symptom management. NINR continued to address knowledge gaps and research needs[21] as exemplified in the 2011 national science summit, *The Science of Compassion: Future Directions in End-of-Life and Palliative Care* (https://www.ninr.nih.gov/researchandfunding/scienceofcompassion)[22] and later in the expansion of NINR's leadership in the field by establishing in 2013 an Office of End-of-Life and Palliative Care Research (OEPCR) to coordinate and support ongoing efforts in the science of end-of-life and palliative care.

NINR-supported scientists continue to make significant contributions to an evidence-base that supports the integration of palliative care as part of the health services provided in cardiorespiratory conditions, particularly in symptom recognition and management, advance care planning, and in addressing the needs of this population in the acute critical care setting. The next sections highlight some of the advances made through this research and several challenges for end-of-life and palliative care science in the future.

Advances in cardiorespiratory end-of-life and palliative care research

Palliative care science and advanced cardiorespiratory symptoms

For individuals with advanced cardiorespiratory conditions, knowledge has increased about symptom intensity and distress for those in intensive care units[23,24] and the range of symptoms experienced in advanced heart failure, including lack of energy, dry mouth, dyspnea, numbness or tingling of extremities, pain, and sleep-disorders.[25] While it has long be known that there are affective components affecting the experience of dyspnea,[26] recent research has described the physiologic changes in advanced dyspnea[27] and the appropriate cut points for dyspnea assessment in non-verbal patients.[28] The role of affective components such as fear and anxiety that individuals and their family caregivers may experience concerning symptoms has also been confirmed.[29] We have learned that individuals with heart failure are more likely to experience higher symptom severity and lower quality of life than those with other advanced illnesses such as cancer.[30] New scientific findings are shaping innovative methods of managing symptoms, such as the effects of a nutritional intervention on advanced heart failure symptoms[31] or the use of specialized programs that incorporate palliative care as a critical component of heart failure care.[32] Other researchers have found tested nurse-led psycho-educational interventions of individuals with heart failure and their family caregivers to improve symptom management and overall quality of life.[33,34]

Palliative care communication in critical care and other settings

Over the past 20 years, nursing science has fostered the awareness of the foundational role of communication in critical care settings and the effects of these conversations on a family's ability to participate in decision-making, their satisfaction with care and perceptions of family member's illness and death.[35–43] Palliative care in these settings is framed by larger issues related to the context of care in ICUs and PICUs, the stressors experienced by families, and the challenges to palliative care philosophy within this environment.[44] The receipt of palliative care must be integrated into intensive care cultures, particularly surrounding end-of-life decision making.[45–48] Improved communication outcomes have also extended to non-English speaking populations with attention to ethnic, cultural and health literacy needs.[49]

Addressing the importance of communication structures as a mainstay of palliative and end-of-life care been examined in all settings.[32,44,50,51] Positive outcomes related to improved patient-family communication in patients with advanced heart failure include reduced mortality, increased health status, less distress, and lower caregiver burden.[52]

Improving quality of life through palliative care

Optimizing treatments to maximize quality of life, which may include discontinuation of certain treatments which may no longer have benefit is an important aspect of palliative care. While there is compelling evidence to begin statin treatment to prevent cardiovascular disease, there also is a need for data that guides decisions about whether to continue this treatment in patients with advanced illness. In a recent multicenter pragmatic trial, researchers in the NINR-supported Palliative Care Research Cooperative (PCRC) Group examined the safety of discontinuing statin therapy in patients with advanced, life-limiting illness by a randomized controlled trial comparing the outcomes of continuing versus discontinuing statin therapy. Their findings suggest that discontinuing statin treatment in patients with advanced illness is safe and does not increase risk of death within 60 days, and may be associated with improved quality of life and other benefits, contributing to the evidence base needed to inform decision making about statin therapy at the end of life.[53]

Nursing science continues to contribute to a deeper understanding of the causes and impact of transitions into and out of