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Abstract

Palliative care is an approach that focuses on optimizing quality of life for patients and families affected by serious illness, regardless of prognosis. It comprises pain and symptom management; psychological, spiritual, and social support; assistance with treatment decision-making; and complex care coordination. Mounting evidence indicates that palliative care reduces symptom burden, improves mood, decreases healthcare utilization, and improves quality of life for both patients with end-stage heart disease and their caregivers. Indeed, there is a consensus among major clinical guidelines of the importance of early integration of palliative care as an essential component of high quality care for patients with heart failure, a growing use of palliative care in patients with end-stage heart disease, and a clear desire of patients for such care.

Disciplines

Medical Humanities | Medicine and Health Sciences | Nursing | Palliative Care

Palliative Care: Is Now the Time?

Barbara Riegel, PhD, RN, FAAN and Stephen E. Kimmel, MD, MSCE

Palliative care is an approach that focuses on optimizing quality of life for patients and families affected by serious illness, regardless of prognosis.¹ It comprises pain and symptom management; psychological, spiritual, and social support; assistance with treatment decision-making; and complex care coordination.² Mounting evidence indicates that palliative care reduces symptom burden,³⁻⁵ improves mood,^{3,6} decreases healthcare utilization,^{4,7} and improves quality of life for both patients with end-stage heart disease and their caregivers.⁸ Indeed, there is a consensus among major clinical guidelines of the importance of early integration of palliative care as an essential component of high quality care for patients with heart failure,⁹⁻¹¹ a growing use of palliative care in patients with end-stage heart disease,¹² and a clear desire of patients for such care.¹³⁻¹⁶

In spite of this clear impetus, palliative care is not yet routinely provided for patients with end-stage cardiac disease.¹⁷ In 2002, Jaarsma and Leventhal published a Special Paper on end-of-life issues in cardiac patients and their families in *EJCN*.¹⁸ In this article, the authors made the point that delaying discussions of palliative care until death is imminent excludes patients who may benefit from early palliative care. They argued for a model that considers both cure and symptom relief. In a later Editorial, Ohlen¹⁹ described remarkable inequities in the circumstances surrounding death, the quality of care before death, and support for family members throughout the world. These issues were revisited by Beattie in a 2014 Editorial in *EJCN* arguing for the importance of advance care planning. Beattie articulately argued for “acknowledging uncertainty” in patients with heart failure.²⁰ Yet, clearly, in the 12 years since the original call for a change in care practices until these two Editorials in 2014 and now in 2018, little has changed.

The European Journal of Cardiovascular Nursing has been a leader in publishing research on palliative care in end-stage cardiac disease. In total, 26 articles on some element of palliative care have been published in EJCN. As shown in the list of articles below, EJCN authors have addressed symptoms^{21,22} and the lived experience²³⁻²⁶ of cardiac patients late in the disease trajectory. Many of the published articles have described effective approaches to care for end-stage cardiac patients.²⁷⁻³⁰ Several articles described the value that nurses bring to palliative care,³¹⁻³⁴ emphasizing nurses' knowledge, skills, and abilities to communicate prognosis and care for patients late in the illness trajectory.^{35,36}

In spite of the rich resources devoted by EJCN to palliative care, topics that have been addressed only briefly include the needs of those who care for patients at the end of life,³⁷ the importance of deactivating implantable cardioverter defibrillators at the end of life,³⁸ and the challenges of conducting research in populations with advanced illness.³⁹ Important gaps in the general cardiac literature exist around the question of who should deliver palliative care and how it should be delivered.⁴⁰⁻⁴²

As advocated by Ohlen,¹⁹ clearly this is the time for “creative collaboration between practitioners and researchers for the development of modes, approaches and models for end-of-life care responding to palliative care needs of individuals of all ages, independent of diagnosis and living circumstances”. Nurses are uniquely poised to lead such initiatives because of our focus on the symptom experience, our holistic approach, and our insights into the experiences of family caregivers.⁴³

[INSERT EJCN ARTICLES HERE]

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