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The state of palliative care and heart failure

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It is estimated that over 6.6 million Americans over the age of 18 have heart failure. Deaths attributed to heart failure remain high and the numbers are virtually unchanged from 15 years ago; with the 5-year mortality rate still hovering around 50%.¹ Despite these alarming numbers, support services for heart failure patients continue to remain disproportionately low. Services, such as palliative care and hospice, have been recommended to meet the complex needs of patient–caregiver dyads throughout the end-of-life heart failure trajectory. Although the percent of end-stage HF patients referred to hospice has significantly increased since 2000 according to the most recent CDC statistics,² heart disease accounted for only 11% of hospice admissions with 6.4% for heart failure. For other services, which include a wide range of medical and therapeutic services aimed at promoting, restoring, maintaining health with the goal of maximizing the level of independence for a patient, only 4.3% of admissions were for heart failure.² These services (which can be classified as palliative care) extend care beyond the traditional medical model’s focus on patients’ physiologic symptoms but also may include spiritual needs, emotional health, decision-making, loss, grief, and coping for both patients and their family caregivers.³

For over a decade, the need for palliative care for heart failure has been recognized. Initially, this was conceptualized as a service line or designated team, similar to hospice, which would be offered in the terminal phase of the disease. More recently, the goals of palliative care have been expanded and the models have evolved that envision palliative care as a philosophy of care delivered to all heart failure patients along with other treatments from initial diagnosis to end of life.⁴ As a philosophy, all healthcare providers who care for the patient and family would provide pieces of these services or refer the patient–caregiver dyad, as needed. This would also include referrals to hospice during the terminal phase of the trajectory. Thus, the goal of palliative care is to improve quality of life for both patients and their families throughout the course of heart failure, whether it follows a chronic disease course or a more rapid terminal trajectory.³

Why is palliative care still lacking in this population? There is evidence that both patients and healthcare providers do not see the need for palliative care early in the disease trajectory because for most patients, there are still many treatment options available. Later in the trajectory, the inability to accurately predict end of life, even using established models, is used as an excuse for not offering these services.⁵ However, there are many clues that should

be obvious to healthcare providers and patients and/or families that the patient is moving toward end of life.⁶ Yet at the point when recognizable signs of decline are apparent, services still may not be offered even after multiple admissions for acute heart failure exacerbations. And, if offered, patients and their family many times refuse to accept these services or when accepted, it is within days of the patient's death.

The state of palliative care in heart failure remains dismal. There is reluctance on the part of both healthcare providers and patient–caregiver dyads to utilize these services. For healthcare providers, who do not want to take away “hope” until all treatment options are exhausted, palliative care is at times confused with hospice. For many, there is a lack of knowledge of the services available for patients and family earlier in the disease trajectory. On the patient–caregiver side, there is a lack of true acceptance of the terminal course of heart failure, thus advance care planning and other services beyond medical management are not accepted. Once the concept of palliative care is understood and embraced by healthcare providers as a philosophy of care where the holistic needs of the patient and family are addressed, services can be consistently offered to patients and families as needs arise. The ultimate goal is to improve the quality of life throughout the heart failure trajectory, including the end-of-life course of the disease for both the patient and the family.

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