

Paper Session B3: Pain Control and Palliative Care

The Work of Spousal Caregiving in Heart Failure

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Purpose: The purpose of this study was to define the types of work manifested across 12-14 months of spousal caregiving for older adult patients with heart failure.

Background: The number of individuals with heart failure is at epidemic proportions. Heart failure significantly changes and impacts life for the patient and family. Heart failure requires complex home medical management, typically done by a spouse. Yet, little is known about the actual work of caregiving over time in the context of the unpredictable trajectory of heart failure or when this work should be assessed and supported by health care providers.

Methods: This was a qualitative secondary analysis of a larger longitudinal study of the palliative care needs of older patients with heart failure and their spouses. The in-depth serial interview data of 20 spousal caregivers of patients greater than or equal to 62, collected monthly over 12-14 months, were analyzed utilizing the tenets of grounded theory methodology.

Results: The work of spousal caregiving impacted all aspects of the lives of spouses. This work was constant across the trajectory of heart failure. Varying types of work were manifested not only during times of heart failure exacerbation but also during times when the patient was considered medically stable. Seven themes, which encompassed the competing demands of life in the midst of caregiving were identified. These included: living with the illness, providing care, vigilance, preserving normalcy, navigating complex systems, managing the household, and maintaining self. The demands varied in intensity across the trajectory. The core variable, committed obligation, was the unifying theme.

Conclusions: The work of caregiving was evident in times of heart failure exacerbation and in times of medical stability. Thus, caregivers should be supported with the work of caregiving across the whole heart failure illness trajectory. These caregivers will benefit from targeted interventions that address the changing needs of both the caregivers and patients with models of care that reflect reimbursements for palliative care interventions across the course of heart failure. The present policy conceptualization of palliative care as a service model of care needs to change and health care providers need to envision palliative care as a philosophy of care with reimbursements for early palliative care interventions for heart failure patients and caregivers.