Living with Heart Failure: Meanings of Illness and Implications for End-of-Life Care Policies and Advance Care Planning

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Abstract

Heart failure is a progressive, life-limiting condition often associated with functional decline, recurrent hospitalizations, and complex long-term care demands. Understanding the meanings attributed by patients to living with the disease can inform palliative care and end-of-life care policies. To analyze the meanings attributed by patients to living with heart failure and discuss implications for palliative care and end-of-life care policies. This exploratory, cross-sectional qualitative study included 209 Brazilian adults with heart failure, who completed a sociodemographic questionnaire and a Free Word Association Test (FWAT), using "Heart Failure" as the inducing stimulus. Lexical analysis was performed using IRaMuTeQ (word cloud, Descending Hierarchical Classification, and Correspondence Factor Analysis). The results were organized into five classes that expressed distinct meaning cores: Class 1 – Heart failure as rupture and functional loss, emphasizing limitations, dependence, and disruption of daily routines; Class 2 – Psychological distress and uncertainty, highlighting fear, sadness, anxiety, and perceived threat; Class 3 – Anticipation of death and a life-limiting trajectory, encompassing contents related to finitude, vulnerability, and anticipatory concerns about dying; Class 4 – Treatment, hospitalization, and biomedical coping, centered on medication, clinical follow-up, and hospital experiences; and Class 5 – Faith, hope, and resilience, describing spirituality and optimism as coping resources. Meanings of living with heart failure extend beyond biomedical symptoms and include anticipatory end-of-life concerns. Findings support integrating psychosocial assessment, prognosis communication, caregiver support, spiritual care, and advance care planning within long-term and palliative care pathways.

Keywords

Heart failure, palliative care, end-of-life care policies, advance care planning, IRaMuTeQ.