Illness trajectory in heart failure: narratives of family caregivers

Carlos Sampaio¹, Isabel Renaud², Paula Ponce-Leão³

¹Instituto de Bioética – Universidade Católica Portuguesa, Portugal. casampaio1509@gmail.com
²Instituto de Bioética – Universidade Católica Portuguesa, Portugal. icr.renaud@gmail.com
³CECH – Universidade de Coimbra, Portugal. paulaponceleao@gmail.com

Abstract. Approximately 26 million people live with heart failure (HF) worldwide (Ambrosy et al., 2014). The overall estimated prevalence of HF in Portugal was 4.4%, with prevalence varying between 1.36% among ages 25 to 50 years and 16% above 80 years (Ceia et al., 2002). Experiencing a chronic illness has devastating psychological, physical and social consequences on individuals and their families. Previous studies showed that people with chronic illness experience loss of self, because they are living a limited and uncertain life (Chiaranai, Chularee & Srithongluang, 2018). People with HF have debilitating symptoms associated with psychological stress, which can burden both them and their family caregivers. There is a lack of qualitative research on the caregiving experience at the end of a heart failure patient’s life.

The aims of this study are to explore meanings of being a family caregiver of a relative with advanced HF in their own home, and to gain understanding of how dignity is upheld in family caregiving context.

A phenomenological-hermeneutical method inspired by the Ricoeurian philosophy was used. Ten Portuguese caregivers of relatives with advanced HF participated in two reflective interviews over a 4 month-period. The transcribed material was imported into the QSR NVivo10 software program for management purposes (QSR International, 2012). Participants were between 50 and 85 years old (mean=70 years) and had 6 months to 2 years caregiving experience at time of data collection. Two main themes emerged from the data: (1) Struggle between inner force and sense of duty; (2) Struggle between feelings of burden and security.

This study adds to current theory guiding HF care by giving voice to caregivers, who are instrumental in supporting their relatives in outpatient management of HF. In accompanying the person with HF along their illness trajectory, family caregivers repeatedly confirm their suspicions of a change in health, challenge the change, and try to establish a new normality, until they acknowledge that the end of life is near (Dionne-Odom et al., 2017).

Findings support that family caregivers require participation in planning and execution of their relative’s health care. Nursing practice in home care should guarantee that caregivers are prepared to sustain the management of HF and able to satisfy their own individual needs as they “adjust to becoming caregivers” (Wingham et al., 2015). Understanding the experience of caregivers, their thoughts, feelings and difficulties can lead to the development of coping strategies that alleviate their stress. Towards this purpose, one must recognize the importance of communication about shared illness experience, decision-making on how to react to the illness, and interpersonal relationship abilities in care actions.

Keywords: advanced heart failure; lived experience; informal caregivers
References


