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**Titolo tesi:** Caregiver contribution to self-care in heart failure: experiences, practices and outcomes

### **ABSTRACT**

**Background.** Heart failure (HF) is a pandemic chronic disease with high prevalence rates; by 2030, more than a quarter of the general population will likely be affected by the disease. Self-care is a cornerstone of HF treatment, because patients who perform self-care have better outcomes (such as fewer hospitalizations and better quality of life), but patients often struggle to perform adequate self-care. Riegel and Dickson (2008) define HF self-care as those activities that patients perform to maintain the physiological stability of the disease (known as self-care maintenance) and to respond to symptoms of HF exacerbation when they occur (known as self-care management). Self-care maintenance and management are both influenced by self-care confidence, which refers to task-specific self-efficacy in the self-care process (Riegel & Dickson, 2008). Caregiver contributions to self-care play an important role in helping patients to perform self-care, but relatively little is known about the issue. Caregivers are thought to contribute to self-care maintenance (i.e., activities caregivers perform to maintain the stability of HF) and self-care management (i.e., activities caregivers perform in cases where HF becomes exacerbated). Although caregiver contributions may be important in HF patient self-care, the literature is still unclear about these contributions. In addition, few studies have rigorously examined (1) caregivers' lived experiences; (2) which practices caregivers perform to contribute to HF patient self-care, specifically self-care maintenance (i.e., symptom monitoring and treatment adherence) and self-care management (i.e., dealing with HF symptoms); and (3) the influence of caregiver contributions on patient clinical outcomes.

**Objective.** The objectives of this doctoral program were (1) to describe the real-live experience of caregivers of HF patients, (2) to describe caregivers' practice in HF self-care maintenance and management, and (3) to quantify the influence of patient and caregiver characteristics on patient clinical-event risk in HF, such as hospitalizations, use of the emergency room, and all-cause mortality.

**Methods.** Three separate studies, corresponding to each doctoral objective, were conducted. Study 1 applied a hermeneutic phenomenological method. Thirty caregivers were enrolled during patients' routine visits to a HF clinic in the Umbria region of Italy; interviews were then conducted at caregivers' homes after making appointments. Study 2 used a qualitative descriptive design. A convenience sample consisting of 40 caregivers from outpatient cardiovascular clinics in three different hospitals located in the south of Italy were enrolled in the study. A semi-structured interview guide was used to elicit in-depth descriptions of how caregivers contributed to HF patients' self-care. In Study 3, a secondary analysis of data from a multi-site observational study of Italian community-dwelling HF patients and their informal caregivers was conducted. Patient-caregiver dyads (n = 183) were enrolled from outpatient cardiovascular clinics across 28 Italian provinces and were followed for 12 months. For all three studies, participants were eligible if (1) the principal informal caregiver of the patient was affected by HF, according to the diagnostic criteria specified by the European Society of Cardiology (Ponikowski et al., 2016); (2) participants were willing and able to provide informed consent; (3) caregivers cared for a patient with a diagnosis of HF for at least three months; and (4) caregivers were at least 18 years old. For Studies 1 and 2, data trustworthiness was ensured following Guba and Lincoln's (1985) criteria. All data was analyzed using descriptive statistics. In Study 1, the data was also analyzed using a phenomenological approach (the Cohen method); Study 2 applied content analysis, and Study 3 used Cox proportional hazards modeling. SPSS (v. 21), Mplus, and Atlas.ti software programs were used for all analyses.

Results. In Study 1, nearly two-thirds of the sample was female, with a mean age of 53 years; most (76%) were married. Six themes emerged from the interviews: (1) fear and worry related to the illness, (2) life changes and limitations, (3) burden due to caregiving, (4) uncertainty about illness management, (5) helping patients to cope with the illness, and (6) love and affection toward the patient. In Study 2, caregivers were 53.6 years old on average (with a range of 38–84) and were mostly female (63.5%). Caregivers contributed to HF patient self-care with behavior-specific (self-care maintenance) and specific-skill (self-care management). Caregiver contributions to self-care maintenance included practices related to monitoring medication adherence, educating patients about HF symptom monitoring, motivating patients to engage in physical activity, and reinforcing dietary restrictions; caregiver contributions to self-care management included practices related to symptom recognition and treatment implementation. Caregivers were able to recognize HF symptoms of exacerbation (such as breathlessness) but were not always fast and confident in treatment implementation, for example in administering an extra diuretic. Study 3 examined 183 caregivers; they were 57.2 years old on average (standard deviation [SD] 14.3) and mostly (67.3%) female. Over the course of the follow-up period, 32.8% of patients died, while 19.7% were hospitalized for HF. Higher caregiver strain, better caregiver mental health status, and greater caregiver contributions to HF self-care maintenance were associated with significantly better event-free survival. In contrast, poorer patient New York Heart Association (NYHA) class and greater caregiver contributions to patient self-care management were associated with significantly worse event-free survival.

Conclusion. This doctoral program has provided investigators with a deeper understanding of HF caregivers and their role in contributing to HF patient care in terms of experiences, practices, and outcomes especially in Italian context. We uncovered new aspects in caregiver lives that had never before been reported in the international literature, such as fear and worry related to the illness. The studies also discovered that caregivers require specific interventions to reinforce correct practices and to discourage incorrect practices related to HF care. We demonstrated that multiple caregiver factors, in particular higher caregiver strain and greater caregiver contributions to day-to-day HF self-care maintenance behaviors, significantly predicted patient event-free survival over a one-year period.

Keywords: Caregivers, heart failure, self-care, phenomenology, hospitalization, mortality