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**DOTTORATO DI RICERCA
IN SCIENZE INFERMIERISTICHE E SANITA' PUBBLICA**

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Titolo tesi: Needs and Burden in caregivers of patients with heart failure

ABSTRACT

Background. Heart failure (HF) is a chronic clinical syndrome resulting from an abnormality of cardiac structure and/or function. HF is not only an urgent health concern in Europe, but also a pandemic health problem worldwide. HF affecting at least 26 million people worldwide and it is increasing in prevalence (1–2% of the population and rising to ≥ 10% among persons aged 70 years or older); these due to the aging of the population and improvements in the treatment of myocardial infarction and acute coronary syndrome. Individuals with chronic heart diseases, such as HF, rely on unpaid care from their families and friends. The roles of such informal caregivers or unpaid carers can range from helping with daily activities to more complex medical care (e.g., drug administration). The help provided by caregivers is fundamental for preserving their patients' good health status and undertaking better self-care. When a caregiver is no longer able to perform one's role effectively, the literature suggests an increased hospitalisation rate of persons with HF, it negatively influences the already high costs related to HF, as well as the quality of life of patients and caregivers. Nevertheless, the impact of HF on carers remains a relatively under-investigated area, and international comparisons are lacking regarding burden predictors and unmet needs.

Objective. The objectives of this doctoral program were as follows. Fist to describe caregiver contributions (CCs) to HF self-care maintenance (i.e., treatment adherence and symptom monitoring) and management (i.e., managing HF symptoms when they occur). Second, to identify caregiver and patient predictors of caregiver burden in HF cases, as well as evaluate if CCs to HF self-care maintenance and management increase caregiver burden. Third, to identify clusters of HF informal caregivers in two Mediterranean countries and associate them with their sociodemographic characteristics.

Methods. In the first study, 40 HF caregivers were enrolled from three outpatient clinics in Italy for a qualitative descriptive study. Data were collected with a semi structured interview and analysed using content analysis. In the second study a secondary analysis of cross-sectional study with the enrolment of 505 caregivers of HF patients was performed. Caregiver Burden Inventory and the Caregiver Contribution to Self-Care of HF Index were used for performing hierarchical regression. For the third study, 41 informal caregivers of HF patients among Spain and Italy were enrolled for a semi structured interview. Data were used for an exploratory analysis of the themes followed by lexicometric and cluster analyses.

Results. From the first study, six area of contribution by caregivers emerged. Caregiver contributions to self-care maintenance included practices related to (1) monitoring medication adherence, (2) educating patients about HF symptom monitoring, (3) motivating patients to perform physical activity, and (4) reinforcing dietary restrictions. However, some of these practices were incorrect (e.g., weighing the patient only once a week). Caregiver contributions to self-care management included practices related to (1) symptom recognition and (2) treatment implementation. Caregivers were able to recognize symptoms of HF exacerbation (e.g., breathlessness) but lacked confidence regarding treatment implementation (e.g., administering an extra diuretic). From the second study, burden predictors were identified. Caregiver predictors of higher caregiver burden were older age, female gender, fewer caregiving hours and poor social support. Patient predictors of higher caregiver burden were older age, better education, taking fewer medications and higher quality of life. CC to self-care maintenance and management were not significant predictors of caregiver burden. By the third study, we know that caregivers, regarding the problems experienced, can be divided into three main categories: spouses, adult children, and non-family members; determined by the type of relationships they have with the patients.

Conclusion. This doctoral program showed that the literature we have about the topic is yet insufficient to fill the gap in knowledge about caregivers. The studies conducted underlined that clinicians should routinely assess caregiver HF self-care practices and provide education and reinforcement regarding evidence-based practices. Since CC to HF self-care improves patient outcomes and seems not burdensome for caregivers, providers may consider educating caregivers about self-care as a viable option for improving patient outcomes without increasing caregiver burden. Our results could help health care providers to identify HF caregivers who are more exposed to burden, and which kind of problems can be priory burdensome due to the sociodemographic characteristics of patients and caregivers. Of course, such variables are immutable, but they can be used as a warning signals for nursing sensitive interventions.

Keywords. Caregivers, heart failure, burden, needs, predictors, contribution, clusters.