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Titolo tesi: Caregiver Contributions to Self-Care in Heart Failure: Developing an Instrument and Identifying the Determinants and Impact of Caregiver Contributions on Patients and Caregivers

ABSTRACT

Background. Heart Failure (HF) is a pandemic chronic disease with a prevalence of approximately 1% to 3% in the general population. Self-care is considered a cornerstone of HF treatment because patients who perform self-care have better outcomes; however patients struggle to perform adequate self-care. Caregiver contribution to self-care may be important in helping patients to perform self-care but relatively little is known about this issue. Caregivers are thought to contribute to self-care maintenance (e.g., monitor symptoms and adhere to treatment regimen) and self-care management (e.g., recognize and intervene in HF symptoms). Caregiver contribution to self-care is also influenced by caregiver confidence (e.g., confident to keep patients free of HF symptoms). Although caregiver contributions may be important in HF patient self-care, (1) no instruments are available to measure this contribution; (2) no prior studies have examined caregiver contributions to HF patient self-care and potential determinants of this contribution; and (3) no prior studies have analyzed the manner in which caregiver contribution to patient self-care and patient self-care influence each other's quality of life (QOL).

Objective. The objective of this doctoral program was: (1) to develop a disease-specific instrument to measure caregiver contribution to HF patient self-care (the Caregiver Contribution to Self-Care of Heart Failure Index; CC-SCHFI); (2) to describe caregiver contributions to HF patient self-care and identify the role of caregiver confidence in that contribution; and (3) to explore the manner in which self-care contributes to QOL in patients and caregivers.

Methods. In a cross sectional study, we enrolled a sample of 1.192 HF patients and 515 caregivers (86% spouse and child caregivers, mean age 56.6 years, SD=14.9, 52.4% female) from 28 Italian provinces and then we conducted three separate studies corresponding to each doctoral objective. Caregivers were the main caregivers of HF patients and patients had a confirmed diagnosis of HF without a coronary event in the last 3 months. Caregivers and patients were enrolled during patients' ambulatory visits. Data were analyzed with descriptive statistics and with confirmatory factor analysis (CFA; Study 1), hierarchical regression (Study 2), and Actor-Partner Interdependence Model (APIM; Study 3).

Results. In the first study, CFA showed good fit indices for each CC-SCHFI scale: caregiver contribution to self-care maintenance (comparative fit index = .97); management (comparative fit index = .96); and caregiver confidence in contributing to self-care (comparative fit index = .99). Internal consistency and test-retest reliability were adequate (from .65 to .96). In the second study, caregiver contributions to patient self-care maintenance were low in weight monitoring and physical activity but high in checking ankles, advising on low-salt foods and taking medicines. The caregiver contribution to patient self-care management was low in symptom recognition. Caregiver confidence explained a significant amount of the variance in the caregiver contribution to self-care maintenance ($R^2 = 0.16$) and self-care management ($R^2 = 0.34$). In the third study, both actor and partner effects were found. Higher self-care was related to lower physical QOL in patients and caregivers. Higher self-care maintenance in patients was associated with better mental QOL in caregivers. Higher caregiver confidence in contributing to self-care was associated with improved caregiver mental QOL but worsened physical QOL in patients.

Conclusion. This doctoral program has provided investigators with a new instrument to measure caregiver contribution to patient HF self-care. The instrument has adequate psychometric properties and is ready for use in clinical research.



Using the CC-SCHFI, we have shown that caregivers do not contribute sufficiently to HF self-care, and that caregiver confidence was the most important determinant of a meaningful contribution by caregivers. This evidence is important because caregiver confidence is modifiable and suitable for intervention. We also demonstrated that self-care by patients and caregivers is performed in response to a worsening of the patient's physical QOL. This result emphasizes the importance of educating caregivers and patients on the importance of performing self-care before the illness worsens.

Key words: Caregivers, heart failure, instrument development, self-care, self-efficacy, quality of life.