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UNIVERSITÀ DEGLI STUDI DI ROMA

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

XXXI CICLO - Anno Accademico 2017/2018

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Titolo tesi: Mutuality in heart failure patient and caregiver dyads: its role on self-care, anxiety and depression

ABSTRACT

Background. Heart failure (HF) is a widespread, growing public health problem and major cause of morbidity and mortality, affecting at least 26 million people worldwide. Although significant improvements in treatment have been made, HF outcomes remain poor with patients experiencing several physical and psychological symptoms. Consequently, HF has a large impact on quality of life of patients and their caregivers. In this scenario, some recent studies showed that the relationship between HF patients and their informal caregivers (e.g., a spouse or an adult child) is important for HF outcomes. An aspect of this relationship is mutuality, which was defined as the positive quality of the relationship between a caregiver and a care-receiver. One of the most used scale to measure mutuality is the Mutuality Scale (MS), a 15-item instrument developed by Archbold et al. in 1990 in the USA. The MS measures mutuality from caregiver and patient perspective and includes four dimensions: "love and affection", "shared pleasurable activities", "shared values", and "reciprocity". So far, no study has tested the psychometric characteristics of the MS in HF patient and caregiver dyads. In addition, higher patient-caregiver mutuality has been found to be associated with improved patient and caregiver outcomes, such as self-care and psychological problems (i.e., anxiety and depression). However, the literature that has explored the association between mutuality and self-care and anxiety and depression in HF patient and caregiver dyads is scarce.

Objective. The objective of this doctoral program was (a) to test the psychometric properties (validity and reliability) of the mutuality scale (MS) in both patients affected by HF and their caregivers; (b) to evaluate the influence of the whole mutuality and mutuality dimensions on HF patient and caregiver dyad self-care (maintenance, management and confidence); and (c) to evaluate the influence of mutuality and its four dimensions on anxiety and depression in HF patient and caregiver dyads.

Methods. A cross-sectional design was used in this dissertation program, using the baseline data of the MOTIVATE-HF study (Vellone et al., 2017), a three-arm multicentre randomised controlled study aimed at identifying whether motivational interviewing improves self-care in HF patients and caregivers. We enrolled a sample of 366 patient–caregiver dyads among different Italian hospitals and outpatient settings, and then, we conducted three separate studies to correspond with each doctoral objective. Patient and caregiver mutuality was measured using the Mutuality Scale, Patient self-care and caregiver self-care were measured using the Self-Care of Heart Failure Index and the Caregiver Contribution to Self-Care of Heart Failure Index, respectively. Both patient and caregiver anxiety and depression were assessed using the Hospital Anxiety and Depression Scale. In the first study, Confirmatory Factor Analysis was used to analyze the factorial validity of MS; Cronbach's alpha and model-based internal consistency index were used to determine the internal consistency of MS. The intraclass correlation coefficient was used to determine test-retest reliability. The statistical analyses used in second and third studies was a multilevel modelling dyadic analysis, the Actor–Partner Interdependence Model, with distinguishable dyads to examine how an individual's mutuality influenced his/her own self-care (the actor effect) and the partner's self-care (the partner effect).

Results. In the first study, Confirmatory Factor Analysis supported the factorial validity of the MS in its patient (CFI=0.94; RMSEA=0.061) and caregiver (CFI=0.92; RMSEA=0.073) version. Cronbach's alphas and model-based

internal consistency index were > 0.94. Test-retest reliability resulted with an intraclass correlation coefficient ranging between 0.55 to 0.79. Results of the second study shoed that total mutuality score had an actor effect on patient self-care maintenance (i.e. behaviours aimed at maintaining HF stability) and on patient and caregiver self-care confidence. Total score of patient mutuality also had a partner effect on caregiver self-care management (i.e. responses to symptoms of HF exacerbation). Specific mutuality dimensions had different actor and partner effects on patient and caregiver self-care. In addition, the APIM of the third study showed that higher patient mutuality was associated with decreased patient anxiety and depression (actor effect), but it was not the same for caregivers, rather, higher patient mutuality was associated with higher caregiver depression (partner effect).

Conclusion. Our analysis showed that the MS has good factorial validity and internal consistency and test-retest reliability in HF patient and caregiver dyads. The instrument can be used in clinical practice and research to measure mutuality in this population. In fact, as showed chapters three and four, the assessment of mutuality in HF patient and caregiver dyads is important to drive interventions aimed at improving patient and caregiver self-care and anxiety and depression. Health care systems are being challenged by costs associated with the care of people with chronic conditions. Patient and caregiver dyads are also being challenged by chronic conditions that require them to manage multiple diseases. For health care providers and scientists, identifying predictors of self- care and strategies to improve self-care are the best ways to help people be autonomous and responsible for their health conditions and to empower their resources.