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Titolo tesi: The experience of caregivers of heart failure patients and the role of preparedness in anxiety, depression, and quality of life

ABSTRACT

Background. Heart failure (HF) is one of the most prevalent chronic conditions, affecting approximately 5.7 million Americans and 15 million Europeans. Patients must be vigilant about signs and symptoms, take prescribed medications, and respond to symptoms when they occur in order to keep the disease stable and to prevent exacerbations. For HF patients, well-prepared caregivers have been identified as an important resource. They help patients to perform many self-care activities and provide emotional support during the disease's progression. However, HF caregivers may feel unprepared and may experience high anxiety and depression and low quality of life (QOL). The Caregiving Preparedness Scale (CPS) has been widely tested and used in the literature but has not been tested among HF caregivers. In chronic conditions, caregiver preparedness has been shown to improve caregiver anxiety, depression, and QOL, but to date, no study has investigated the role of preparedness in HF caregivers.

Objective. The objectives of this doctoral program were as follows: 1) to describe the lived experiences of HF caregivers; 2) to test the psychometric characteristics of the CPS in a population of HF caregivers; and 3) to evaluate the influence of HF caregiver preparedness on caregivers' anxiety, depression, and QOL.

Methods. In the first study, 30 caregivers were enrolled in an HF clinic in central Italy. Interviews were analyzed using a phenomenological approach. In the second study, we tested the CPS factorial structure in a sample of 317 HF caregivers with confirmatory factor analysis and its concurrent validity with the Caregiver Contribution to Self-Care of HF Index (CC-SCHF) and the Hospital Anxiety and Depression Scale (HADS). We also tested CPS reliability with different estimates. In the third study, we enrolled 366 HF caregivers to evaluate the following relationships via path analysis: a) the influence of preparedness on anxiety and depression and b) the influence of anxiety and depression on QOL. We used the HADS and the Short-Form 12 (SF12) to evaluate the physical and mental components of QOL. We also considered the socio-demographic characteristics of caregivers and patients and the patients' clinical data.

Results. In the first study, six themes emerged: 1) fear and worry related to the illness, 2) life changes and restrictions, 3) burden due to caregiving, 4) uncertainty about illness management, 5) helping patients cope with the illness, and 6) love and affection towards the patient. In the second study, the confirmatory factor analysis for a one-factor model resulted in supportive fit indices (e.g., comparative fit index 0.97). Significant correlations ($p < 0.05$) of the CPS with both the CC-SCHF and the HADS supported concurrent validity. Reliability was supported as well (Cronbach's alpha 0.91). In the third study, the tested model showed an excellent fit to the data (e.g., comparative fit index 0.98). The CPS scores predicted the HADS depression scores but not the HADS anxiety scores. The HADS anxiety scores predicted the SF12 mental component of QOL scores but not the physical QOL scores. Finally, the HADS depression scores predicted both the physical and the mental QOL scores.

Conclusion. This doctoral program found a lack in preparedness in HF caregivers and provides investigators with a valid and reliable instrument that shows adequate psychometric properties in a sample of HF caregivers. Finally, we found that caregiver preparedness has important influences on depression and that anxiety and depression have important influences on QOL. These results emphasize the importance of evaluating and considering HF caregiver preparedness to improve caregiver outcomes.



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Key words: caregivers, preparedness, heart failure, validity, reliability, lived experiences, phenomenology, anxiety, depression, quality of life