

# **Longitudinal effects of self-care (and baseline quality of life) on caregiver burden and quality-of-life outcomes in patients with heart failure and their family caregivers**

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## **ABSTRACT**

**Background:** Heart Failure (HF) is a complex, progressive syndrome which is recognised as being disabling and deadly; and it impacts on the patient's ability to self-care. Caregivers are pivotal in supporting patients' self-care, but often their own health is affected. The burden associated with caregiving is often influenced by certain patient and caregiver sociodemographic and personal characteristics, as well as the patient's engagement and the caregiver's contribution to self-care. With the interdependence of the patient–caregiver relationship, it is therefore essential to examine self-care, quality of life and caregiver burden. To date there is limited empirical evidence that examines specifically the nature in which HF patients and their caregivers influence each other. Previous studies have been cross-sectional and have either compared health outcomes for patients as a group or caregivers as a group. No known studies in Scotland have looked at the association between self-care and quality-of-life outcomes in HF patients and caregivers over time.

**Aims:** To explore longitudinally: 1) the effects of patients' and caregivers' baseline characteristics and self-care on caregiver burden at 6 months' follow-up (TP2); and 2) the effects of self-care on quality-of-life outcomes in patients with HF and their family caregivers (dyads) at 6 months' follow-up (TP2).

**Design and methods:** A multifactorial, exploratory longitudinal study was carried out. A survey approach was used to collect data from patient and family caregiver dyads at two time-points: following hospital discharge (TP1) and again at six months (TP2). Patients completed the SF-12 version 2 Health Survey, the Minnesota Living with Heart Failure Questionnaire, and the Self-Care of Heart Failure Index. Caregivers completed the same questionnaires, as well as the Zarit Caregiver Burden Interview Questionnaire. Dyadic data were analysed using the Actor-Partner-Interdependence Model.

**Results:** There were statistically significant differences between patients' and caregivers' physical and emotional quality of life (SF-12 PCS, MLwHFQ total score, MLwHFQ PCS and ECS) at time-point one and time-point two. These differences were accounted for by the patients' poorer physical and emotional health at both TP1 and TP2. However, the patients' and caregivers' mental health (SF-12 MCS) was similarly affected and the results for both were below that of the general population. There were statistically significant differences between patients' and caregivers' self-care maintenance at TP1, but not at TP2. These differences were accounted for by the patients contributing more to self-care maintenance than their caregivers were assisting them with at TP1 (research question one).

Caregiver burden scores did not change significantly from time-point one to time-point two. Patients' lower physical activity levels, caregivers' emotional health and caregiver burden at TP1 significantly predicted caregiver burden at TP2 (research question two).

Quality of life was associated with patients' self-care and caregivers' contribution to self-care (*actor effects*). Patients' baseline self-care confidence significantly predicted their own mental (SF-12 MCS) at TP2. Patients' baseline self-care maintenance and self-care confidence significantly predicted their quality of life (MLwHFQ total score) at TP2. Patients' baseline self-care confidence significantly predicted their physical quality of life (MLwHFQ PCS). Patients baseline self-care management, maintenance and confidence significantly predicted their emotional health (MLwHFQ ECS) at TP2. The caregivers' baseline contribution to self-care maintenance and self-care confidence significantly predicted their physical (SF-12 PCS) and mental (SF-12 MCS) health at TP2. Caregivers' baseline contribution to self-care maintenance and self-care confidence significantly predicted their quality of life (MLwHFQ total score) and their emotional health (MLwHFQ ECS) at TP2 (research question 3).

Patient's baseline self-care significantly predicted the caregiver's quality of life at TP2 and vice-versa (*partner effects*). Patient's baseline self-care management significantly predicted the caregiver's physical health (SF-12 PCS) at TP2. Patient's baseline self-care maintenance significantly predicted the caregiver's emotional health (MLwHFQ ECS) at TP2. The caregiver's baseline self-care management significantly predicted the patient's physical health (SF-12 PCS) at TP2. Caregiver's baseline self-care

management and self-care maintenance significantly predicted the patient's mental health (SF-12 MCS) at TP2. Caregiver's baseline self-care maintenance significantly predicted the patient's overall quality of life (MLwHFQ total score), physical health (MLwHFQ PCS) and emotional health (MLwHFQ ECS) at TP2 (research question 3).

**Conclusion:** Patients physical and emotional health was poorer than their caregivers at both TP1 and TP2. The perceived mental health of both patients and caregivers were similar at both TP1 and TP2. Statistically significant differences were found for self-care maintenance at TP1, but not at TP2, which is accounted for by the patients contributing more to self-care maintenance than their caregivers were assisting them with. Confidence was gained, in that, clinicians can rely on family caregivers to support patients in their self-care, without increasing the level of caregiver burden. Early assessment of emotional health in the patient is needed to prevent a deterioration later in the clinical trajectory.

This longitudinal study has found that self-care maintenance, management and confidence influence quality of life outcomes in both members of the dyad. Indeed, the mutual dyadic effect of self-care maintenance on the emotional quality of life of the dyad supports the need for early assessment of emotional health and consideration of an early clinical psychology referral.