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**The burden of caring: risks and consequences imposed on caregivers of those living and dying with advanced heart failure**

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## **Abstract**

*Purpose of review:* To summarize the latest research on the risks and consequences of the burden that may be imposed on informal carers of persons living and dying with advanced heart failure.

### *Recent findings:*

A systematic search in PubMed over the period 2013-2014 ultimately revealed 24 original articles included in this review. From this research update it can be concluded that the body of knowledge increased with more studies focusing on caregivers of patients with advanced heart failure.

### *Summary:*

Caregivers are important partners in care and that their lives are seriously affected by the condition of advanced heart failure. Studies on the longitudinal effects of the caregiving role on caregiver's quality of life and on caregiver contributions to patient outcomes is still scarce. Focus of current research is moving towards relationship aspects. Dyadic care typologies and the concept of incongruence within dyads in terms of conflicting perspectives on how to manage the heart failure are new and promising concepts presented in studies presented in this review. Heart failure patients and their caregivers still lack sufficient palliative care and communication on prognosis and end-of-life care. More research is needed to determine the optimal time to start palliative interventions to support caregivers of patients with advanced heart failure.

### **Keywords:**

Heart failure, caregiver, palliative care, support

**Introduction:**

Heart failure is one of the most common chronic conditions worldwide. It is more prevalent with increasing age and is one of the leading causes of hospitalization among people over the age of 65 years (1, 2). Patients with advanced heart failure suffer from a number of symptoms that diminish their physical and mental health (3-6). Their long term prognosis is poor, but heart failure treatment has improved and therefore patients live longer and stay more independent caring for themselves at home as long as possible (7). Due to economic and political policy decisions treatment changes and management of deterioration of heart failure is nowadays mostly done in the outpatient setting. As a consequence patients are, with support of their caregivers, supposed to handle self-care to a much higher extent than before (2). Two recent systematic reviews (8, 9) summarize that informal caregivers by providing both emotional and practical support to patients with heart failure, play a major role in increasing their ability to perform self-care (9). Interventions to improve heart failure self-care should therefore include involvement of family caregivers. However, more demands and responsibilities on family caregivers may lead to increased physical and psychosocial distress causing caregiver burden (10, 11). Previous studies have found deteriorating quality of life among partners of patients with heart failure; sometimes their mental health is even lower than the patients (12-14). Twenty to thirty percent of the partners has been found to perceive a moderate caregiver burden and can therefore be at higher risk of poor mental health and decreased perceived control (15, 16).

The purpose of this research update is to assess the latest research on the risks and consequences of this shift in responsibilities in terms of the burden that may be imposed on caregivers of patients living and dying with advanced heart failure.

## **Results**

This paper summarizes findings from original articles and systematic reviews published during 2013 and 2014. PubMed was searched using the terms heart failure and caregiver as well as the keywords careers and family. A total of 111 abstracts were reviewed and 24 articles were included in the update. Inclusion criteria were: systematic reviews or papers reporting on original data and having a clear focus on the life situation of informal carers of persons living and dying with advanced heart failure.

The majority of the most recent studies in the field were conducted in North America, a few from Europe, one from Australia and two studies came from Iran. The cultural imbalance with regard to from which countries that are publishing in the field is noteworthy and impact the generalizability of the findings reported in this review.

### **Caregiving over time**

Until now few studies have evaluated the longitudinal effect of the caregiving role on the caregiver's quality of life and feelings of burden and on caregiver contributions to patient outcomes (9). Kitko et al. (17) conducted serial interviews over a period of 12 to 14 months with 20 partners caring for their loved ones with heart failure. This study conceptualized that caregiving was a constant work. Caregiving took place also during periods of clinical stability and varied throughout the course of the illness. Pressler et al. (18) evaluated changes in caregiver burden and the influence of HF symptom severity over a period of 8 months in 63 HF patients and their caregivers. In this study perceptions of the caregiver experience improved over time, however caregivers of patients with high symptoms seemed to be of risk for a poorer physical health related quality of life and anxiety (18). Caregiver burden should be acknowledged and addressed by health care providers

throughout the heart failure illness trajectory (17), especially in caregivers of patients with a high symptom level (18). Jones et al. (19) identified a series of four different transitions described by patients with HF and their caregivers. The first was the process of handling the shock of being diagnosed with HF, the second learning to adapt to living with a chronic illness such as HF, the third resuming command and control of one's life; and finally accepting that death is inevitable. Concerns about the future were related to the most recent transition. Advanced care for patients with HF and their caregivers should include education and support in relation to transitions and transition-specific concerns.

Buck and co-workers recently presented typologies of patient and caregiver dyadic interdependence in heart failure care. The typologies describe dyads that manage their situation (dealing with heart failure demands) in different ways; either individually in which the patient or the caregiver can take the lead, or jointly in which dyads can work together collaboratively or complementarily (15). Based on these typologies, a new instrument to assess the dyadic care type in patients with heart failure and their caregiving partners was developed (20). The typologies change over the illness trajectories with more often being patient oriented in mild to moderate heart failure and caregiver oriented in more advanced heart failure (21). Future research will focus on the understanding of the relationship between dyadic care types and self-care outcomes in patients with heart failure.

### **Caregiver experiences; measurement and influencing factors**

A recent narrative review including 16 studies explored factors influencing caregiver burden and quality of life in caregivers of patients with heart failure with focus on both negative and positive aspects. The following themes were identified: Perceived carer control; Mental and emotional well-being; Types and impact of caregiving tasks; Impact of patients' physical

condition; Impact of demographic factors and Positive aspects of caregiving. There are individual factors that make caregivers more vulnerable, namely, female gender, younger age, low social support and poorer physical and emotional health. Additionally, there are patient-related factors increasing the risk of caregiver burden including poorer functional status, instability, frequent hospitalizations and higher symptom burden (22).

Family caregivers, especially partners, are affected by both the mental and physical health of the patient. Caregivers to heart failure patients with symptoms of depression had significantly higher levels of caregiving burden and lower levels of quality of life (23). Also the Iranian study of Bahrami and colleagues (24) indicated clear caregiver burden in terms of a lack of care-related knowledge, physical exhaustion, psychosocial exhaustion, and lack of support. The same research group did a small RCT study showing positive effects in terms of reducing caregiver burden by educational support to caregivers (25). Another pilot study evaluating the effects of a coaching home management program for HF caregivers found that caregiver burden, preparedness and confidence to care improved (26).

A study by Kitko et al (27) underlined the need for dyadic communication and support since they found that almost 50% of the 100 dyads being studied had contradicting opinions in relation to illness management, health care issues, and end-of-life decisions. Dyads being incongruent reported higher levels of psychosocial distress both within the dyad as individually (28). Another smaller study had similar results; perspectives of dyad members about the future of HF, perceived care needs and end of life issues were found to be congruent at times and incongruent at other times and incongruence was associated with conflicts and distress within dyads (26). Future research is needed to explore the relationship between e.g. relationship quality and congruence within the dyad. Relationship

quality between the partners and patients with heart failure has been found to be positively associated with caregiver benefit and was negatively associated with caregiver burden (29). A new instrument named “Caregiver burden questionnaire for heart failure (CBQ-HF)” has been developed to assess caregiver burden in relation to heart failure. The content is derived from qualitative interviews with caregivers and heart failure clinicians and face and content validity has been established. Cultural appropriateness and psychometric validation is ongoing to further explore the reliability, and validity in a larger sample of caregivers (30). Another new instrument is the Caregiver Contribution to Self-care of Heart Failure Index (CC-SCHFI), an instrument derived from the Self-care of Heart Failure Index version 6.2. It assesses the contribution of caregivers to the self-care maintenance and self-care management of patients with heart failure and was found to have satisfactory psychometric properties (31).

### **Provision of palliative care**

Patients with advanced heart failure have an uncertain disease trajectory and this places a significant burden on heart failure caregivers. Furthermore, patients with advanced heart failure and their caregivers seldom receive sufficient palliative care services in comparison to for example patients with advanced cancer and their families (32).

Browne et al. (33) conducted focus group interviews with focus on the experiences of patients suffering from advanced heart failure and their caregivers. They described uncertainty related to the understanding of the heart failure diagnosis and prognosis, its complex treatment and side-effects from medications as well as when and how to seek medical care. Patients and their caregivers were heavily burdened by fragmented health care services lacking both coordination and communication (33). Few patients and



caregivers had had conversation with health care professionals about prognosis and preferences for end-of-life care for care despite that they desired these conversations (34). Caregivers to patients with heart failure receiving hospice care recommended providing palliative caregiving interventions earlier in the disease trajectory, rather than at the end (35). However, the optimal timing or if there is a risk to deliver an intervention too early was not revealed. This warrants additional research to determine the ideal time to provide caregiving interventions (36). Another qualitative analysis revealed that caregivers perceived themselves as coaches, managers, advocates and experts in the lived experience of heart failure at home with the mission to improve patients' sense of security, self-care and quality of life. However, these roles could lead to strain (expectations exceeding the ability to perform role) and conflicts (incompatible roles) in interactions with a rigid health care system and health care providers ignoring their importance or putting too much responsibility on their shoulders (37). New models integrating home-based palliative care and standard heart failure care have shown to be effective in improving patient outcomes, reducing costs of care and increasing the likelihood of dying at home. However, the impact on caregiver burden for families in these models have not yet been assessed (38).

**Conclusion:**

From this research update it can be concluded that in the past years research focusing on caregivers of patients with advanced heart failure has expanded. It is now fully acknowledged that caregivers are important partners in care and that their lives are seriously affected by the condition of advanced heart failure. However, still not much is known on the longitudinal effects of the caregiving role on caregiver's quality of life and on caregiver contributions to patient outcomes. Focus of current research is moving towards

relationship aspects. Dyadic care typologies and the concept of incongruence within dyads in terms of conflicting perspectives on how to manage the heart failure are new and promising concepts presented in current studies. Heart failure patients and their caregivers still lack sufficient palliative care and communication on their prognosis and end-of-life care. More research is needed to determine the optimal time to start palliative interventions to support caregivers of patients with advanced heart failure.

**Key points:**

- The concept of dyadic heart failure care typologies describing different ways of dyads managing their situation; either individually or jointly, may be helpful in finding ways to support dyads in managing heart failure
- Contradicting opinions within dyads (incongruence) in relation to illness management, health care issues, and end-of-life decisions is associated with conflicts and higher levels of psychosocial distress within these dyads
- Patients with advanced heart failure and their caregivers still seldom receive sufficient palliative care services and suffer from fragmented health care services and a lack of communication regarding prognosis and end-of-life care

- Palliative care interventions seem to be provided too late in the disease trajectory, however, the optimal timing for delivering these interventions is still to be determined.

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