

CAREGIVERS' CONTRIBUTION TO THE CARE OF PATIENTS WITH HEART FAILURE: A REVIEW

Wkład opiekunów nieformalnych w opiece nad pacjentem z niewydolnością serca – przegląd literatury

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SUMMARY

Background. Heart failure (HF) is a chronic syndrome affecting more than 64 million people worldwide. Effective HF management depends on consistent self-care, which is increasingly performed with the support of informal caregivers.

Objectives. To review current evidence on caregivers' contribution (CC) to HF management, including its theoretical foundations, determinants, impact on patient and caregiver outcomes, and implications for clinical nursing practice.

Material and methods. A narrative review of peer-reviewed literature published between January 2014 and October 2025 was performed using PubMed, Scopus, and CINAHL. Search terms combined «heart failure», «caregiver», «caregiver contribution», «self-care», and «caregiver burden». Original studies, systematic reviews, theoretical articles, and current European Society of Cardiology guidelines were included.

Results. Caregivers contribute to two complementary processes: self-care maintenance and self-care management. Higher CC is associated with better patient self-care, fewer hospitalisations, and improved quality of life. Caregiver confidence is the strongest determinant of CC. Caregiving is, however, frequently linked to elevated burden, anxiety, depression, sleep disturbance, and reduced quality of life. Multicomponent interventions, including psychoeducation, motivational interviewing, and dyadic approaches, can improve outcomes for both members of the dyad.

Conclusions. Caregivers are an indispensable extension of the formal HF care team. Nurses should systematically assess caregivers' skills, confidence, and burden, and integrate them as partners in care planning.

Key words: heart failure; caregivers; self-care; quality of life; nursing care.

STRESZCZENIE

Wstęp. Niewydolność serca (NS) jest przewlekłym zespołem chorobowym, który dotyka ponad 64 milionów osób na świecie. Skuteczne leczenie NS zależy od konsekwentnej samoopieki, coraz częściej realizowanej przy wsparciu opiekunów nieformalnych.

Cel pracy. Przegląd aktualnych dowodów dotyczących wkładu opiekunów (*caregiver contribution*, CC) w opiekę nad chorym z NS, w tym podstaw teoretycznych, determinant, wpływu na wyniki kliniczne pacjenta i opiekuna oraz implikacji dla praktyki pielęgniarstwa.

Materiał i metody. Przeprowadzono przegląd narracyjny piśmiennictwa opublikowanego w latach styczeń 2014 – październik 2025 z wykorzystaniem baz PubMed, Scopus i CINAHL. Zastosowano kombinacje słów: „heart failure”, „caregiver”, „caregiver contribution”, „self-care”, „caregiver burden”. Włączono prace oryginalne, przeglądy systematyczne, artykuły teoretyczne oraz aktualne wytyczne Europejskiego Towarzystwa Kardiologicznego.

Wyniki. Opiekunowie uczestniczą w dwóch procesach: utrzymaniu samoopieki i zarządzaniu samoopieką. Większy CC wiąże się z lepszą samoopieką pacjenta, mniejszą liczbą hospitalizacji i lepszą jakością życia. Najsilniejszą determinantą CC jest pewność siebie opiekuna. Sprawowanie opieki wiąże się jednak ze zwiększonym obciążeniem, lękiem, depresją, zaburzeniami snu i obniżeniem jakości życia. Wieloskładnikowe interwencje (psychoedukacja, wywiad motywujący, podejście diadyczne) mogą poprawić wyniki obu członków diady.

Wnioski. Opiekunowie nieformalni stanowią nieodzowne uzupełnienie formalnego zespołu opieki kardiologicznej. Pielęgniarki powinny systematycznie oceniać umiejętności, pewność siebie i obciążenie opiekunów oraz włączać ich jako partnerów w proces planowania opieki.

Słowa kluczowe: niewydolność serca; opiekunowie; samoopieka; jakość życia; opieka pielęgniarstwa.

BACKGROUND

Heart failure (HF) is a complex clinical syndrome in which structural or functional cardiac abnormalities lead to reduced cardiac output and/or elevated intracardiac pressures. According to the most recent global epidemiological estimates, HF affects more than 64 million individuals worldwide, and its prevalence continues to rise as a result of population ageing, improved post-myocardial infarction survival, and the growing burden of cardiometabolic comorbidities [1, 2]. Despite considerable advances in pharmacological and device-based therapy, HF remains associated with high mortality, frequent hospitalisations, poor functional capacity, and impaired quality of life [3].

Modern HF care extends beyond the cardiology clinic. The 2021 European Society of Cardiology (ESC) Guidelines for the

diagnosis and treatment of acute and chronic HF, together with the 2023 focused update, emphasise that long-term outcomes critically depend on adherence to self-care behaviours, including medication intake, daily weight monitoring, fluid and salt restriction, regular physical activity, and prompt recognition of decompensation symptoms [3, 4]. Many patients, however, are unable to perform such tasks alone because of advanced age, cognitive decline, frailty, depression, or knowledge deficits [5, 6].

In this context, informal caregivers – most often spouses, adult children, or other close relatives – play a fundamental role. Over the past decade, the construct of caregiver contribution (CC) to HF self-care, formalised by Vellone and colleagues, has become a central concept in cardiovascular nursing science [7, 8]. It captures the extent to which caregivers actively support patients in

performing self-care maintenance and self-care management, as well as their confidence in doing so.

OBJECTIVES

The aim of this review is to synthesise current evidence on caregivers' contribution to HF management, with a particular focus on (i) the theoretical foundations of the construct, (ii) the determinants of CC, (iii) the impact of CC on patient and caregiver outcomes, (iv) the available evidence on supportive interventions, and (v) the implications for clinical nursing practice.

MATERIAL AND METHODS

This is a narrative review based on peer-reviewed literature retrieved from PubMed, Scopus, and CINAHL databases for the period January 2014 to October 2025. Search terms combined controlled vocabulary and free-text words including "heart failure", "caregiver", "informal caregiver", "family caregiver", "caregiver contribution", "self-care", "dyadic", "caregiver burden", and "quality of life". Reference lists of key articles and the most recent ESC HF guidelines were screened to identify additional relevant publications.

Original studies, systematic reviews, theoretical papers, and clinical guidelines published in English were considered. The review focused on adult patients with chronic HF and their adult informal caregivers. As this is a narrative review of published data, ethics committee approval was not required.

RESULTS

Conceptual framework of caregiver contribution to HF self-care

Self-care has been conceptualised by Riegel and colleagues as a naturalistic decision-making process composed of self-care maintenance, self-care monitoring, and self-care management [9]. In HF, these processes translate into adherence to treatment, recognition of bodily changes (e.g., weight gain, dyspnoea, oedema), and adequate response to symptom worsening.

Building on this framework, Vellone, Riegel and Alvaro proposed a situation-specific theory of caregiver contributions to HF self-care [7]. According to this theory, caregivers contribute through behaviours that mirror those of patients (CC to self-care maintenance and CC to self-care management) and through their confidence (caregiver confidence). The theory describes how patient, caregiver, and dyadic factors influence CC, which in turn affects patient outcomes such as quality of life, hospitalisation, and mortality. To operationalise this construct, the Caregiver Contribution to Self-Care of Heart Failure Index (CC-SCHF) was developed and validated in multiple languages, including a Polish adaptation of related self-care measures [10, 11].

Caregivers' roles in heart failure management

Empirical work has consistently shown that informal caregivers undertake a wide spectrum of activities. A qualitative study by Durante et al. found that caregivers actively participate in self-care maintenance by reminding patients to take medications, preparing low-sodium meals, encouraging fluid restriction, helping with weight monitoring, and supporting physical activity [12]. At the level of self-care management, caregivers monitor for signs of deterioration, interpret symptoms, decide whether to seek medical advice, and accompany patients to appointments [12].

A systematic review by Buck et al. identified five overarching domains of contribution: facilitating treatment adherence, symptom recognition, emotional and psychological support, navigating the healthcare system, and maintaining the home environment [13]. Caregivers' tasks typically expand as the disease progresses, especially in advanced HF and at the end of life [14]. Caregivers also act as a key communication bridge between patient and healthcare team, often detecting early signs of cognitive decline, frailty, or depression that may otherwise be missed in the clinic [5].

Impact of caregiver contribution on patient outcomes

A growing body of evidence demonstrates that CC to HF self-care is associated with clinically meaningful improvements in patient outcomes. In a multicentre observational study, Bidwell et al. showed that caregivers' characteristics – including their contribution to self-care and their confidence – independently predicted patients' clinical event risk over a one-year follow-up [15].

More recently, a longitudinal mediation analysis based on the MOTIVATE-HF randomised controlled trial demonstrated that CC exerts a significant indirect effect on patient quality of life through the mediation of patient self-care behaviours [16]. In 510 patient-caregiver dyads, CC had a direct effect on patient self-care, and patient self-care in turn improved health-related quality of life. Dyadic studies analysed using the Actor-Partner Interdependence Model (APIM) have further confirmed that patient and caregiver characteristics are mutually interdependent and jointly shape self-care, symptom perception, and emotional outcomes [17].

Caregiver burden, mental health, and well-being

Although CC improves patient outcomes, providing care for an HF patient is itself a demanding task. A systematic review by Suksatan et al., synthesising thirty studies from ten countries, concluded that HF caregivers experience significant physical, psychological, social, and lifestyle burden, with high rates of depressive symptoms, anxiety, sleep disturbance, and reduced quality of life [18].

Durante et al. examined determinants of caregiver burden and reported that higher CC to self-care management – but not maintenance – was associated with increased perceived burden [19]. Other consistent predictors of higher burden include longer hours of caregiving, female sex of the caregiver, depressive symptoms, and patient functional impairment [18, 19]. Recent work has also addressed mental health and cognitive aspects of HF dyads. Jędrzejczyk et al. reported significant changes in mental health, cognitive function, and self-care behaviours in patients with HF over time, and showed that affective symptoms, cognitive function, and self-care differ across HF phenotypes (HFrEF, HFmrEF, HFpEF), with implications for the type and intensity of caregiver support required [20, 21].

Determinants and predictors of caregiver contribution

Identifying the determinants of CC is essential to design effective interventions. Vellone et al. were among the first to demonstrate, in a multivariate analysis, that caregiver confidence is the strongest predictor of CC to both self-care maintenance and management [22]. Other relevant determinants include: caregiver education, employment status, the quality of the patient-caregiver relationship, the duration of caregiving, social support, and patient clinical severity [8, 22].

Patient-level factors also matter. Patients with greater cognitive impairment, frailty, or more advanced NYHA class typically require more caregiver involvement [5, 6]. Cultural and contextual factors should not be overlooked: studies from Italy, Poland, the United States, China, and other settings show that family structures, gender roles, and the organisation of formal long-term care services influence both who acts as a caregiver and how the caregiving role is enacted [11, 17, 18].

Interventions to support caregivers

Several intervention strategies have been tested to enhance CC and reduce caregiver burden. A systematic review and meta-analysis of randomised controlled trials targeting caregivers of patients with heart disease found that most studies focused on improving quality of life and reducing burden, depression, and anxiety, with psychoeducation being the most common component [23].

The MOTIVATE-HF trial evaluated motivational interviewing (MI) delivered to patients alone, to patient-caregiver dyads, or compared with usual care [24]. MI delivered to dyads improved

patient self-care behaviours and quality of life. Subsequent secondary analyses by Locatelli et al. have shown that interventions improving CC do not necessarily increase caregiver anxiety, depression, or sleep problems, and may improve caregiver outcomes when appropriately designed [25]. For patients with frailty – a frequent and prognostically important comorbidity in HF – multiprofessional interventions integrating exercise, nutrition, cognitive support, and caregiver education have been recommended in a recent comprehensive review by Uchmanowicz, Jędrzejczyk and colleagues [26].

DISCUSSION

The literature reviewed converges on the conclusion that informal caregivers are central, and not auxiliary, actors in the management of chronic HF. The situation-specific theory of CC provides a coherent framework that links patient and caregiver characteristics to dyadic processes and clinical outcomes [7]. Empirical studies, including dyadic and longitudinal designs, support the predicted pathways: CC influences patient self-care, which in turn shapes hospitalisation risk and quality of life [15, 16].

From a clinical-nursing perspective, several practical implications emerge. First, caregivers should be systematically identified and engaged from the time of HF diagnosis. Second, clinicians – and especially HF nurses – should routinely assess not only patients' self-care but also caregivers' contribution, confidence, and burden, ideally using validated instruments such as the CC-SCHFI and the Zarit Burden Interview [10, 18]. Third, education provided in clinics, hospitals, and community settings should be tailored to the dyad rather than to the patient alone, with clear, written, and culturally adapted materials [11, 24].

Fourth, caregivers showing signs of clinically significant burden, depression, or anxiety should be referred for additional support, including psychological services and social-care resources [18, 25]. Fifth, in advanced HF, palliative care teams

should integrate family caregivers as central partners in goals-of-care discussions and end-of-life planning [14]. Healthcare systems and policy makers should recognise informal caregiving as a critical, often invisible component of chronic HF management.

This review has limitations. As a narrative review, it does not provide a quantitative synthesis of the included studies and is potentially subject to selection bias. However, it integrates the most influential and recent evidence in the field, including key randomised controlled trials, systematic reviews, and theoretical contributions, and offers a clinically oriented synthesis useful for nursing practice.

CONCLUSIONS

Informal caregivers are an indispensable extension of the formal HF care team. Their contribution to patient self-care has measurable effects on adherence, clinical events, hospitalisations, and quality of life. At the same time, caregiving is associated with substantial burden and adverse psychological consequences, particularly when caregivers feel under-prepared or unsupported.

The situation-specific theory of caregiver contributions to HF self-care provides a robust framework supported by an expanding empirical literature, including longitudinal and dyadic studies. Future research should focus on rigorously designed dyadic interventions, on digital health tools (telemonitoring, mobile applications, virtual nursing visits) that are acceptable to older caregivers, and on the implementation of caregiver-targeted strategies into routine HF clinics. International collaboration between research groups from Italy, Poland, and other countries will be essential to develop evidence-based, culturally sensitive models of dyadic HF care.

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