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CAREGIVER CONTRIBUTION, BURDEN, AND SOCIAL SUPPORT AS FACTORS ASSOCIATED WITH SELF-CARE AMONG PATIENTS WITH HEART FAILURE

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Abstract
Heart failure demands ongoing self-care, and often includes the help of family members who participate in daily management of the condition. A secondary analytical cross-sectional design was employed to explore factors associated with self-care among heart failure patients as related to their caregivers. The study included 270 patient–caregiver dyads. Overall patient self-care was assessed with respect to caregiver contributions to self-care maintenance and management, caregiver confidence, caregiver burden, perception of social support, role adoption, daily care giving time, and selected demographic factors. Participant characteristics and study measures were summarized using descriptive statistics. Bivariate relationships were determined using Spearman rank order correlation and multiple linear regression was used to determine factors independently associated with overall patient self-care. The mean self-care score was 85.10 ± 17.99. There was a positive relationship between caregiver contribution to management of self-care and caregiver confidence with patient self-care; and a significant negative relationship with longer caregiving time. Caregiver contribution to self-care maintenance, self-care management and caregiver confidence predicted self-care scores independently in adjusted model. The longer the time spent by caregivers in a day and the older the patient age, the lower was self-care. This model accounted for 48.6% of variance in self-care. After adjustment, there were no independent associations between caregiver burden, perceived social support, role adoption and caregiver age. These results may suggest that caregiver contribution is a significant correlate of heart failure self-care and that a dyadic approach to chronic disease management is important.

Keywords: Heart failure; Self-care; Family caregivers; Caregiver contribution; Dyadic care

Introduction

Heart failure (HF) is a chronic and progressive cardiovascular condition with need for ongoing involvement in complex self-care (SC) behaviours like adherence to prescribed medications, monitoring symptoms, managing diet, maintaining physical activity and promptly seeking care in response to increased signs and symptoms. Effective self-care is central to maintaining clinical stability and reducing avoidable deterioration, yet many patients experience difficulty performing these activities consistently because of symptom burden, multimorbidity, functional limitations, cognitive demands, and continuing nature of disease management. In the contemporary models of heart failure self-care the importance of self-management is not only associated with HF-related factors, but also with personal and environmental factors that may affect an individual's capacity to carry out proper self-care behaviours (Riegel et al., 2022).

In this setting, family carers are often integral to care of people with heart failure. Caregiver involvement could involve helping to monitor symptoms, helping with the use of medications, encouraging dietary and lifestyle recommendations, making healthcare appointments, and helping with decisions around health changes. The idea of caregiver contribution to self-care thus goes beyond a general sense of assistance and involves the caregiver's active involvement in behaviours that facilitate the process of self-care maintenance, monitoring and management (Harkness et al., 2016). As a result, family care has been seen as an essential part of heart failure care, especially when patients are unable to manage the needs of complex long-term care themselves (Kitko et al., 2020).

However, the effectiveness of the caregiver involvement can vary widely depending on the patient/caregiver relationship and its quality. Mutuality, shared understanding and reciprocity in the dyad can affect patient and carer working together in daily disease management and can impact on patient participation in self-care activities (Hooker et al., 2018). However, there is evidence showing that increasing the role of the caregiver in multiple aspects of HFC self-care can have a meaningful impact on patient management but the extent and consistency of this impact varies by population and caregiving context (Buck et al., 2024).

Social support represents another important interpersonal resource in chronic illness management. Family members and other social networks can provide emotional support, practical help and reassurance which can increase patients' confidence in their efforts to manage their heart failure and stick to the recommended behaviours. There is evidence that greater perceived social support is linked to increased confidence in self-care among people with heart failure (Fivecoat et al., 2018), suggesting the potential importance of supportive social contexts in maintaining disease-management behaviours. Likewise, caregiver factors and context have been found to affect the extent to which caregivers engage in HF self-care, indicating that it is important to consider caregiver contribution along with other social and relational factors (Wilson et al., 2022).

However, caring can be physically, emotionally and socially demanding. Having a long-term responsibility for managing the patient's symptom and everyday activities can lead to caregiver burden, which may impact the care that the patient receives and the well-being of the caregiver. A systematic review revealed that being a caregiver in the context of heart failure leads to several adverse outcomes, both at the caregiver level and at the patient level, and that burden should always be taken into account when assessing caregiver processes (Suksatan et al., 2022). On a larger scale, the well-being of caregivers has been shown to be associated with patient outcomes in heart failure, highlighting the interdependence of health in patient–caregiver dyads (Bidwell et al., 2017).

A recent study also indicates that caregiver involvement can be more than just direct self-care actions; it can be a factor in other patient outcomes. As to longitudinal outcomes, results have suggested that caregiver involvement in self-care could affect the patient's quality of life because of such involvement's relationship with self-care processes, thus reinforcing the clinical and social importance of exploring caregiver involvement in heart failure management (Caggianelli et al., 2024). Although these relationships are increasingly recognized, the contribution, burden, social support, role adoption, and caregiving intensity of caregivers are usually analyzed separately. Taking these factors into consideration together might offer a broader view of caregivers' conditions that relate to patient self-care.

Accordingly, the objectives are:

1. To describe self-care among patients with heart failure and selected caregiver-related characteristics.
2. To examine the relationships between caregiver contribution, caregiver burden, social support, caregiver role adoption, caregiving intensity, and patient self-care.
3. To identify caregiver-related factors independently associated with self-care among patients with heart failure.

2. Methodology

2.1 Study Design and Data Source

The secondary analytical study design was cross-sectional to analyze the factors associated with self-care among heart failure patients from caregiver perspective. Data were collected from publicly available data set that included paired heart failure (HF) and family caregiver (FC) data. The information collected encompassed sociodemographic data, patient self-care, caregiver's participation in patient's self-care, caregiver burden, perceived social support, caregiver role adoption, and characteristics of the caregiving relationships (Arias-Rojas, 2026).

2.2 Study Population

270 patient–caregiver dyads were included in study. The analysis took into account patient characteristics such as age, sex, and actions taken to self-care. Caregiver characteristics comprised age, gender, hours spent per day, caregiver involvement in patient self-care, caregiver burden, perceived social support and caregiver role adoption. One family caregiver was identified for each patient and patient self-care was studied in relation to family caregiver-related characteristics.

2.3 Study Variables and Measures

The main outcome was overall patient self-care (measured by composite self-care score). Caregiver contribution to patient self-care was explored in three aspects: contribution to self-care (SC) maintenance, contribution to SC management, and caregiver confidence in contributing to SC. Other explanatory factors included caregiver burden, perceived social support, adoption of the caregiving role and amount of time spent per day providing care. Demographic co-variates included in the multivariable analysis were patient age and caregiver age. The continuous measures were kept as numbers.

2.4 Data Preparation

The data were inspected for completeness, duplicate data, coding consistency and implausible ranges of values prior to statistical analysis. Wherever possible, composite scores were checked on the relevant item-level variables. The data for continuous variables remained in its original numerical form and the distribution of overall self-care score was examined to determine the appropriate statistical procedures.

2.5 Statistical Analysis

For the major self-care and caregiver-related measures, median and interquartile range (IQR) were reported in addition to mean and SD for continuous variables. Categorical data were shown in terms of frequencies and percentages.

The distribution for the overall patient self-care score was positively skewed so bivariate associations were examined using Spearman rank-order correlation coefficients (ρ). Correlations were conducted between overall patient self-care and caregiver contribution to SC maintenance, caregiver contribution to SC management, caregiver confidence in contributing to SC, caregiver burden, perceived social support, caregiver role adoption, daily time spent on caregiving, patient age, and caregiver age.

A multiple linear regression analysis was then carried out to find factors that were independently associated with overall patients' self-care. In overall, patient SC was designated as the dependent variable. The explanatory variables were simultaneously used: caregiver contribution to self-care maintenance, caregiver contribution to self-care management, caregiver confidence in contributing to self-care, caregiver burden, perceived social support, caregiver role adoption, daily care-giving time, patient age, and caregiver age.

Unstandardized coefficients (B), standardized coefficients (β), HC3 heteroskedasticity-robust standard errors, 95% confidence intervals (CI) and p values were reported for the regression findings. The performance of models was evaluated by R^2 and adjusted R^2 and the multicollinearity was measured by variance inflation factors. Statistic analyses were 2-sided and p values < 0.05 were regarded as statistically significant.

3. Results

3.1 Participant Characteristics

270 patient-caregiver dyads participated in this study. Patients' average age was 61.09 ± 15.54 years old with a range of 27-89 years old. On the other hand, the average age for the caregivers was 44.65 ± 13.09 years old, with range of 18-70 years old. For the patients, the majority were male (n=150; 55.6%), with females making up the remainder (n=120; 44.4%). There was a greater number of female (n=201; 74.4%) than male caregivers (n=69; 25.6%). The mean daily caregiving time was 13.84 ± 5.55 hours, with an observed range of 3–23 hours. Participant and caregiving characteristics are given in Table 1.

Table 1. Sociodemographic and Caregiving Attributes of Patients and Family Caregivers

Attribute	n (%) or Mean ± SD	Range
Patients		
Age, years	61.09 ± 15.54	27–89
Male	150 (55.6)	—
Female	120 (44.4)	—
Family caregivers		
Age, years	44.65 ± 13.09	18–70
Male	69 (25.6)	—
Female	201 (74.4)	—
Daily caregiving time, hours	13.84 ± 5.55	3–23

3.2 Patient Self-Care and Caregiver-Related Measures

Mean overall patient SC score was 85.10 ± 17.99, with a median of 81.00 (IQR: 76.00–87.00) and an observed range of 47–174. The distribution of overall self-care scores was positively skewed, with most observations concentrated within the lower-to-middle portion of the observed range and relatively few substantially higher values, as illustrated in Figure 1.

Mean score for caregiver contribution to SC maintenance was 19.94 ± 4.25, while caregiver contribution to self-care management averaged 10.14 ± 2.71. The mean caregiver confidence in contributing to SC was 12.23 ± 2.76. Caregiver burden had a mean score of 80.75 ± 10.05, whereas mean perceived social support and caregiver role-adoption scores were 74.91 ± 6.22 and 48.33 ± 5.60, respectively. Table 2 give descriptive statistics for the principal study measures.

Table 2. Descriptive Statistics of Patient Self-Care and Caregiver-Related Measures

Measure	Mean ± SD	Median (IQR)	Range
Overall patient self-care	85.10 ± 17.99	81.00 (76.00–87.00)	47–174
Caregiver contribution to self-care (SC) maintenance	19.94 ± 4.25	19.00 (17.00–21.00)	12–36
Caregiver contribution to self-care (SC) management	10.14 ± 2.71	10.00 (8.00–12.00)	4–19
Caregiver confidence in contributing to self-care (SC)	12.23 ± 2.76	12.00 (10.00–14.00)	7–22
Caregiver burden	80.75 ± 10.05	83.00 (78.00–87.00)	30–97
Perceived social support	74.91 ± 6.22	75.00 (71.25–79.00)	47–91
Caregiver role adoption	48.33 ± 5.60	48.00 (44.00–52.00)	36–65
Daily caregiving time, hours	13.84 ± 5.55	13.00 (9.00–18.00)	3–23

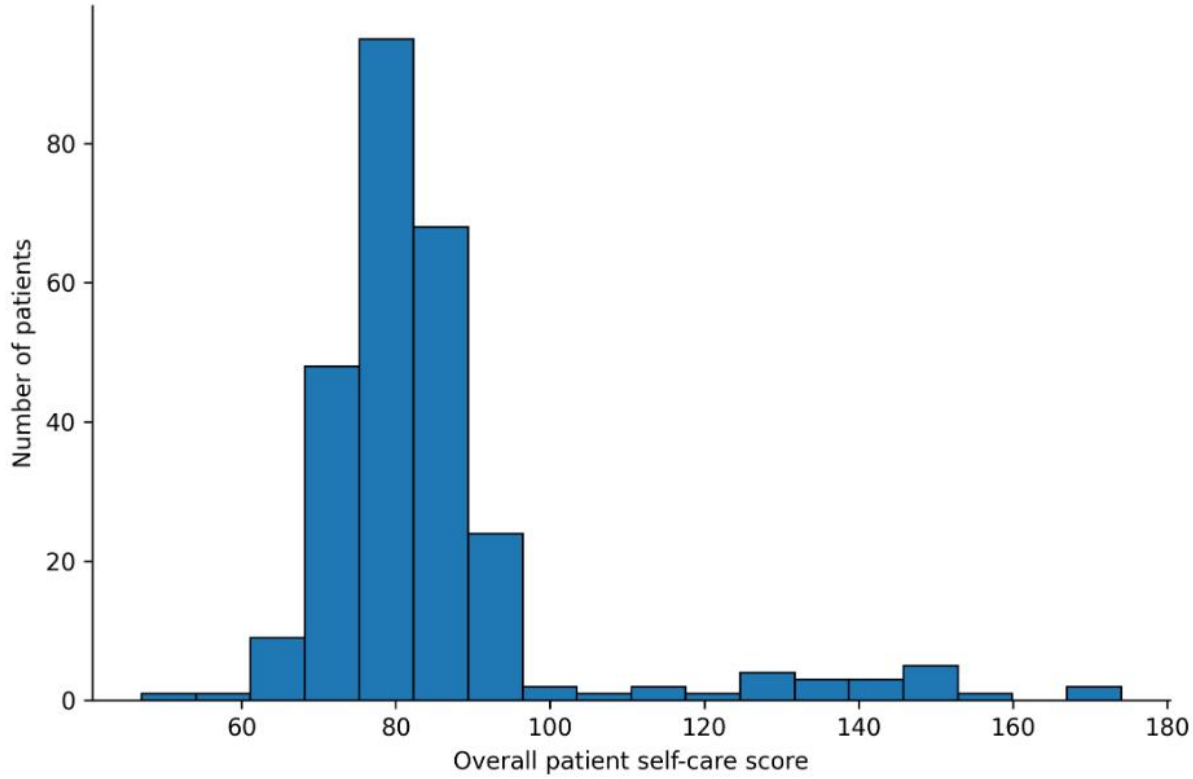


Figure 1. Distribution of Overall Patient Self-Care Scores

3.3 Bivariate Associations with Patient Self-Care

Spearman rank-order correlation analysis demonstrated significant positive associations between overall patient self-care and caregiver contribution to SC management ($\rho = 0.180$, $p = 0.003$) and caregiver confidence in contributing to SC ($\rho = 0.205$, $p < 0.001$). In contrast, caregiver contribution to SC maintenance was not significantly associated with overall patient SC at bivariate level ($\rho = 0.058$, $p = 0.346$).

Daily caregiving time was significantly and inversely associated with patient SC ($\rho = -0.193$, $p = 0.001$). Caregiver burden showed weak inverse correlation and was not statistically significant ($\rho = -0.095$, $p = 0.121$). Perceived social support and caregiver role adoption were not significantly associated with overall self-care. Similarly, neither patient age nor caregiver age demonstrated a statistically significant bivariate association. The correlation coefficients are presented in Table 3.

Table 3. Correlations Between Caregiver-Related Factors and Overall Patient Self-Care

Factor	Spearman's ρ	*p* value
Caregiver contribution to SC maintenance	0.058	0.346
Caregiver contribution to SC management	0.180	0.003
Caregiver confidence in contributing to SC	0.205	<0.001
Caregiver burden	−0.095	0.121
Perceived social support	0.019	0.758
Caregiver role adoption	0.010	0.866
Daily caregiving time	−0.193	0.001

Patient age	−0.109	0.075
Caregiver age	−0.060	0.330

Figure 2 illustrates the weak positive association between caregiver confidence in contributing to self-care and overall patient self-care.

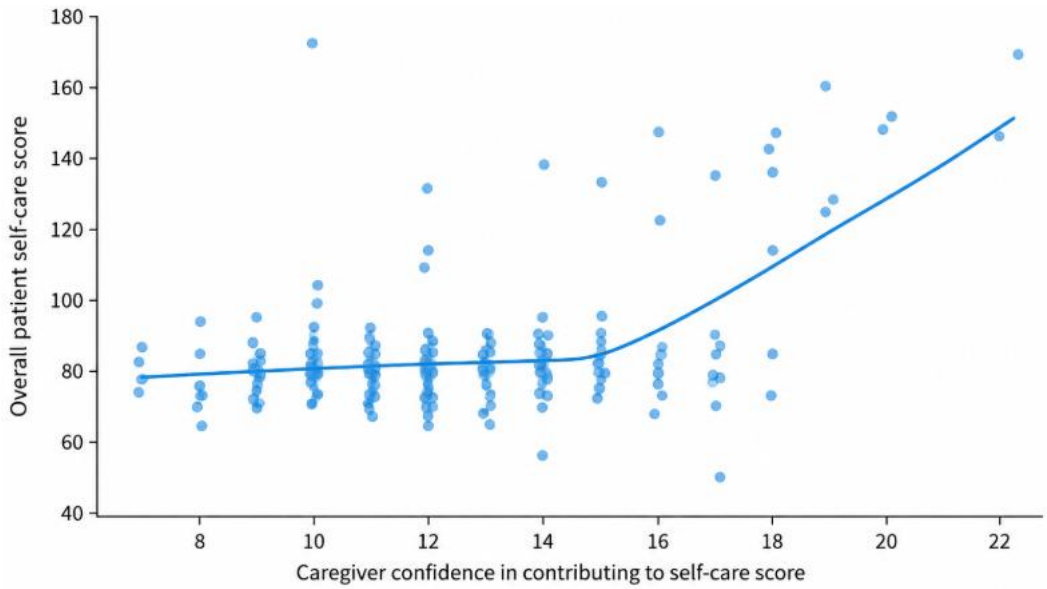


Figure 2. Relationship Between Caregiver Confidence in Contributing to Self-Care and Overall Patient Self-Care

3.4 Multivariable Factors Associated with Patient Self-Care

The multivariable linear regression model was statistically significant and accounted for 48.6% of variance in overall patient self-care (R^2 = 0.486; adjusted R^2 = 0.468; overall $p < 0.001$). No evidence of problematic multicollinearity was observed, with variance inflation factors ranging from 1.03 to 1.37.

After simultaneous adjustment for caregiver burden, perceived social support, caregiver role adoption, daily caregiving time, patient age, and caregiver age, all three caregiver contribution measures were independently and positively associated with patient self-care. Caregiver contribution to self-care maintenance demonstrated the largest standardized association (B = 1.325, β = 0.313, 95% CI: 0.712–1.939, $p < 0.001$). Caregiver confidence in contributing to self-care was also positively associated with patient self-care (B = 1.475, β = 0.226, 95% CI: 0.643–2.307, $p = 0.001$), as was caregiver contribution to self-care management (B = 1.256, β = 0.189, 95% CI: 0.641–1.870, $p < 0.001$).

Daily caregiving time showed an independent inverse association with patient self-care (B = −0.542, β = −0.167, 95% CI: −0.865 to −0.220, $p = 0.001$). Patient age was similarly associated with lower self-care scores (B = −0.165, β = −0.142, 95% CI: −0.295 to −0.035, $p = 0.013$).

Caregiver burden showed a negative adjusted association but did not reach statistical significance (B = −0.226, β = −0.127, $p = 0.120$). Perceived social support (B = 0.161, β = 0.056, $p = 0.301$), caregiver role adoption (B = −0.180, β = −0.056, $p = 0.295$), and caregiver age (B = 0.064, β = 0.046, $p = 0.395$) were also not independently associated with overall patient self-care. The complete multivariable estimates are reported in Table 4.

Table 4. Multiple Linear Regression Analysis of Factors Associated With Overall Patient Self-Care

Predictor	B	Robust SE	Standardized β	95% CI for B	*p* value
Caregiver contribution to self-care maintenance	1.325	0.313	0.313	0.712 to 1.939	<0.001
Caregiver contribution to self-care management	1.256	0.314	0.189	0.641 to 1.870	<0.001
Caregiver confidence in contributing to self-care	1.475	0.424	0.226	0.643 to 2.307	0.001
Caregiver burden	−0.226	0.146	−0.127	−0.512 to 0.059	0.120

Perceived social support	0.161	0.156	0.056	−0.144 to 0.466	0.301
Caregiver role adoption	−0.180	0.171	−0.056	−0.515 to 0.156	0.295
Daily caregiving time	−0.542	0.165	−0.167	−0.865 to −0.220	0.001
Patient age	−0.165	0.066	−0.142	−0.295 to −0.035	0.013
Caregiver age	0.064	0.075	0.046	−0.083 to 0.210	0.395

Model $R^2 = 0.486$; adjusted $R^2 = 0.468$; $p < 0.001$. B, unstandardized coefficient; β, standardized coefficient.

The standardized regression coefficients and corresponding 95% confidence intervals are illustrated in Figure 3. Caregiver contribution to self-care maintenance showed strongest positive adjusted association with patient self-care, followed by caregiver confidence and contribution to self-care management, whereas daily caregiving time and patient age showed significant inverse associations.

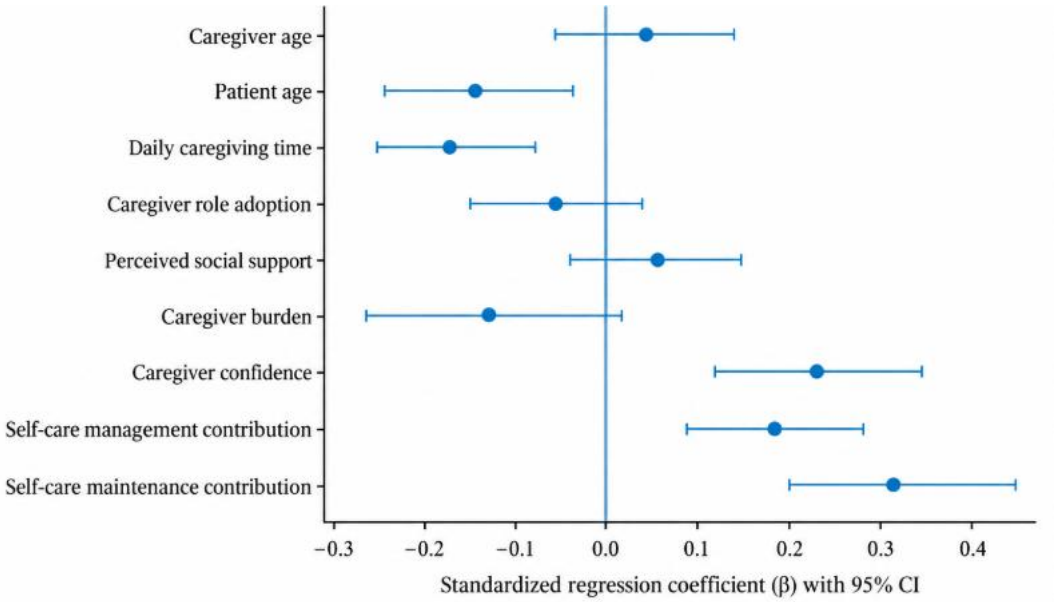


Figure 3. Standardized Regression Coefficients for Factors Associated with Patient Self-Care

4. Discussion

Results showed that self-care (SC) was significantly correlated with patients' caregiver involvement but the extent of these relationships varied by domain of caregiver involvement. We found each of these three factors, caregiver contribution to SC maintenance, caregiver contribution to SC management, and caregiver confidence in contributing to SC, was independently associated with higher overall patient SC in the adjusted model. Longer duration of daily care and older age of the patients, however, were independently related to lower SC scores. After adjustment, there was no longer a statistically significant association with caregiver burden, perceived social support, caregiver role adoption, and caregiver age. Finally, these findings corroborate the idea that the support offered in the patient–caregiver dyad influences heart failure SC, in addition to patient level factors.

The standardized correlation of caregiver contribution to SC maintenance was the highest correlate with overall SC. The finding indicates that hands-on experience with standard disease-management practices may be crucial in maintaining self-care activities. This can include strengthening treatment plans, reminding patients about adhering to medications and diet, assisting with monitoring symptoms and educating patients about self-management routines in daily life. The same holds true for family caregivers and their involvement in self-care behaviours among patients with heart failure, as meaningful evidence has demonstrated that family caregivers play a role in the practice of self-care behaviours and that the level of involvement depends on patient and caregiver characteristics (Alharrasi et al., 2025). Thus, the current results further support the need to see caregivers as a part of chronic disease management and not as an outside entity that provides support.

There was also a positive correlation between caregiver contribution to SC management and caregiver confidence with SC management of the patient. Importantly, both variables showed strong bivariate

relationships and contribution to SC maintenance was significant when accounting for the larger array of caregiver and demographic factors. This pattern indicates that there are certain variables in the dyad that may influence each other and that certain variables may be better understood when considered in conjunction with others. Dyadic approach highlights the interdependency between patient and caregiver behaviours, and the ability of one member to impact on health related behaviours of the other (Uchmanowicz et al., 2022). The current multivariate results support this view and emphasize the importance of considering the contribution of caregivers as a multi-dimensional phenomenon and not as one single global measure.

The bivariate and adjusted analyses showed that the daily time spent on care was negatively related to patient self-care. This relationship should be interpreted cautiously. More time spent in caregiving is not necessarily a bad thing as it might also be an indicator of increased patient dependency, increased symptom burden, increased complexity of care requirements, or decreased capacity for independent patient self-management. Patients who need a lot of help may show less self-care, simply because more of the tasks of disease management have been delegated to the caregiver. Meanwhile, ongoing caregiving needs can lead to fatigue, competing demands and limited caregivers' ability to deliver consistent care. Previous studies have reported significant physical, emotional, and practical strain on family caregivers of individuals with HF and that the caregiving burden is closely related to the burden intensity and complexity of family caregivers (Lahoz et al., 2021). The inverse relationship presented here may thus be due to the severity of the care needs and not directly to the negative impact of hours spent caring.

Likewise, overall self-care was found to be lower with each additional year of age. Self-management in older people with heart failure can sometimes be difficult because of the presence of other illnesses, functional limitations, cognition problems, impaired mobility, polypharmacy and dependency on family members. These factors can interfere with medication management, symptom recognition, dietary adherence, physical activity, and timely responses to worsening clinical status. Similarly, studies on self-care of older people with HF have highlighted the impact of age-related physical, psychological, cognitive and social issues on the older adults' capability to enact the recommended self-care behaviours (Attaallah et al., 2016). Based on these current results, it may therefore be assumed that patients of older age groups may benefit specifically from structured involvement of caregivers and individual self-care support.

There was a negative association between caregiver burden and patient SC, but not statistically significant after multivariable adjustment. Perceived social support and adoption of caregiver role were also not independently related to self-care. The results suggest that practical caregiver involvement is closer to patient self-management than are more general attitudes about support or the sense of being a caregiver. Social support can be reassuring, companionate and emotional, but not always directly related to concrete aspects of disease management. Similarly, self-identification with or acceptance of the caregiver role does not necessarily indicate the quality, the amount or effectiveness of help provided. So, these non-significant findings should not be interpreted as evidence that burden, social support, or role adoption are unimportant; their effects may be indirect, mediated through caregiver contribution, relationship quality, patient dependency, or other contextual pathways.

The results further support the clinical relevance of viewing heart failure management as a shared process. Dyadic studies have indicated that both patient and provider attributes can have individual and partner effects on self-care, highlighting that optimal disease management might rely on the patient–provider relationship more than on the patient alone (Kim et al., 2024). This means that in practice, evaluation of self-care may not only refer to the patient but also to the level of involvement of the caregiver, the tasks for which the caretaker is supporting the patient and the level of confidence that the caregiver has in supporting the patient with heart failure. Patient/carers receiving significant assistance on a daily basis and older patients may benefit from combined educational interventions.

Results have implications for caregiver support. While more caregiver contribution was correlated with better patient self-care, the negative correlation with caregiving time indicates that more may be too much, unless differences in caregiving time are taken into account. There is a need, therefore, for support strategies that will not only enhance the effective caregiver contribution, but that will also limit the intensity of excessive caregiving and avoid unnecessary stress. The quality and sustainability of the involvement of caregivers is important as it may be more clinically meaningful than the time spent with the caregiver.

There are a number of limitations that should be taken into account. A cross-sectional design does not allow the temporal sequence or cause-and-effect to be determined. More caregiver involvement can be helpful to the patient's self-care, while some patients may have specific self-care abilities that can affect the amount and kind of caregiver involvement. Furthermore, composite measures do not necessarily reflect the intricacies of interpersonal relationships, shifts in care needs, or how caring relationships occur. However, the dyadic nature and simultaneous examination of multiple caregiver-related factors make it helpful to examine relationship of caregiving characteristics and patient SC.

The results indicate need for caregiver involvement in heart failure self-management, and suggest that caregiving intensity and patient age may be indicators of vulnerability. Future longitudinal and intervention studies could help resolve this uncertainty and establish if increasing the levels of specific caregiver contributions are likely to enhance patient self-care without putting additional burden on caregivers.

5. Conclusion

Caregiver contribution became a significant correlate of self-care (SC) among the patients with heart failure which highlighted importance of patient–caregiver dyad in chronic disease management. More caregiver involvement in SC maintenance and SC management and more task-specific and active involvement in self-care were each independently associated with better patient self-care, and more caregiver confidence in SC maintenance was also independently associated with better patient SC, suggesting that active and task-specific caregiver involvement may support effective disease-management behaviours. In contrast, longer duration of care per day was associated with lower self-care, and this might be due to higher level of patient dependency, more complex care needs, or decreased ability to take care of oneself. Increasing patient age was also independently associated with poorer self-care, highlighting the additional challenges faced by older adults with heart failure.

After adjustment, caregiver burden, perceived social support, caregiver role adoption and caregiver age were not independently associated. These results indicate that practical factors of caregivers might be more directly linked to patient self-care than psychosocial or role factors. Clinical practice should therefore include, from a patient perspective, an assessment for patient-focused education, as well as an assessment of the caregiver's participation, confidence, and caregiving demands. Dyadic interventions that enhance effective caregiver support and reduce excessive caregiving burden may prove to be especially useful with older patients or those who need significant caregiver support. Due to the cross-sectional design, causality cannot be determined. Future longitudinal and intervention studies are necessary to better understand the directionality of these relationships and whether or not caregiver-based interventions could result in long-term improvements in self-care and other heart failure outcomes.

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