

Determinants of caregiver burden in heart failure: does caregiver contribution to heart failure patient self-care increase caregiver burden?

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Abstract

Background: The burden is high in caregivers of heart failure patients, but the literature on patient and caregiver predictors of caregiver burden is inconsistent. Also, it is unknown if caregiver contribution to heart failure self-care maintenance (i.e. helping patients to maintain heart failure stable) and self-care management (i.e. helping patients to act in case of heart failure worsening) increases caregiver burden.

Aims: To identify caregiver and patient predictors of caregiver burden in heart failure; and to evaluate if caregiver contribution to heart failure self-care maintenance and management increases caregiver burden.

Methods: A cross-sectional study with the enrolment of 505 caregivers of heart failure patients. We used the caregiver burden inventory and the caregiver contribution to self-care of heart failure index. We analysed the data using hierarchical regression.

Results: Heart failure caregivers, mostly women (52.5%), with a mean age 56.5 (± 14.9) years, cared for heart failure patients, mostly men (55.2%), with a mean age of 75.9 (± 10.4) years. Caregiver predictors of higher caregiver burden were older age, female gender, fewer caregiving hours and poor social support. Patient predictors of higher caregiver burden were older age, better education, taking fewer medications and higher quality of life. Caregiver contribution to self-care maintenance and management were not significant predictors of caregiver burden.

Conclusions: Our results could help providers to identify heart failure caregivers who are more exposed to burden. As caregiver contribution to heart failure self-care improves patient outcomes and seems not burdensome for caregivers, providers may consider educating caregivers about self-care as a viable option for improving patient outcomes without increasing caregiver burden.

Keywords

Caregivers, burden, self-care, heart failure

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Introduction

Heart failure is a chronic condition that affect more than 26 million people worldwide^{1,2} and has a great impact on patients' quality of life (QOL), even greater than other chronic diseases.³ The burden of symptoms (e.g. fatigue) and the recurrent hospitalisations that are common in heart failure are similar to cancer,⁴ but if heart failure patients are engaged in self-care behaviours by adhering to a strict pharmacological and non-pharmacological (e.g. exercising) regimen, they can improve their QOL.⁵

Although self-care in heart failure is important in improving patients' outcomes, self-care is insufficient in heart failure

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patients,⁶⁻⁸ consequently informal caregivers can be valid contributors to heart failure care by motivating and supervising patient self-care. It was reported that heart failure caregivers improve patient outcomes, such as QOL, rehospitalisation and mortality.⁹⁻¹¹ However, caregiver contribution to patient self-care may require caregivers to make a great sacrifice that, in the long run, can increase their burden.

One-third of heart failure caregivers are affected by burden.¹² This burden is associated with several issues both in caregivers and patients. In heart failure caregivers, higher caregiver burden is associated with higher psychosocial distress, lower wellbeing,¹³ poorer functional status and health¹⁴ and lower perceived control.¹⁵ In heart failure patients, higher caregiver burden is associated with reduced quality of delivered care and, consequently, reduced patients' health.¹⁶

In consideration of the worse caregiver and patient outcomes associated with heart failure caregiver burden, several studies have investigated caregiver and patient predictors of this burden.¹⁷⁻¹⁹ However, the results of these studies are inconsistent. Also, most of the previous studies conducted on heart failure caregiver burden tended to consider caregiver burden as a unidimensional construct, despite theoretical and research literature being more prone to identify several dimensions within the construct of burden.^{20,21} In fact, Novak and Guest,²² the developers of the caregiver burden inventory (CBI) described caregiver burden as composed of five dimensions: (a) time-dependent burden, meaning the stress caused by caregiver personal time limitations due to caregiving; (b) developmental burden, which refers to the sense of missing personal goals and expectations; (c) physical burden, as related to physical distress and somatisation disorders; (d) social burden, which refers to the relations with others, family members, job colleagues or friends; and (e) emotional burden, which refers to feelings of shame or anger caused by the patients' behaviours. All the above dimensions of burden are consistent with heart failure caregiver burden as they have been reported in a recent phenomenological study conducted in heart failure caregivers,²³ and have been quantitatively found in testing the CBI in this specific population with supportive fit indices at confirmatory factor analysis.²⁴

Caregiver contributions to heart failure self-care was defined as the process that caregivers use to recommend or substitute heart failure patients in maintaining heart failure stable, in monitoring heart failure signs and symptoms and in responding to heart failure exacerbations.²⁵ As the first psychometrically sound instrument to measure caregiver contribution to heart failure self-care was developed, to our knowledge, in 2013,²⁶ we do not yet have sufficient literature showing if this contribution increases caregiver burden. However, as caregiver burden may influence both heart failure caregiver and patient outcomes, it is important to know if caregiver contribution to heart failure self-care increases caregiver burden.

The aim of this study was twofold: (a) to identify predictors of specific dimensions of caregiver burden (namely, time-dependent, developmental, physical, social and emotional burden) considering caregiver characteristics (i.e. age, gender, employment, education level, living with patient, hours of caregiving per day, social support) and patient characteristics (i.e. age, gender, employment, education level, hospitalisation for heart failure in past year, ejection fraction, New York Heart Association (NYHA) class, months of illness, number of taken medications, comorbidities, cognitive impairment, physical and mental QOL); and (b) to evaluate if caregiver contribution to self-care increases caregiver burden over and above caregiver and patient characteristics.

Methods

This is a secondary analysis from a multisite, cross-sectional descriptive study of heart failure self-care behaviours conducted on a large cohort of heart failure patients and their principal informal caregivers in Italy.^{8,27}

A sample of 1192 heart failure patients was enrolled from ambulatory cardiovascular clinics in 28 different Italian provinces. The inclusion criteria for patients were: (a) being seen at the clinic for a routine heart failure appointment; (b) having a diagnosis of heart failure as specified in the European Society of Cardiology Guidelines;²⁸ and (c) being willing and able to provide the signed informed consent form. We excluded: (a) heart failure patients who were younger than 18 years of age; (b) those who had an acute coronary event within the preceding 3 months from enrolment; and (c) those who had clear evidence of dementia (i.e. not oriented to time, spaces and people). The inclusion criteria for caregivers were being identified as a caregiver by the enrolled patient as the unpaid person, inside or outside the family, who provided him/her most of the informal care (e.g. help in daily activities). The exclusion criteria were not willing to participate in the study.

Caregiver burden

The CBI²² is a valid and reliable 24-item multidimensional scale that evaluates caregiver burden in the dimensions of time-dependent, developmental, physical, social and emotional burden. Each CBI item used a five-point Likert scale for responses, with a score system ranging from 0 (minimum burden) to 4 (maximum burden). With the CBI, it is possible to have a total score, ranging from 0 to 100, or a score for each of the above dimensions, ranging from 0 to 20.²⁴ Higher scale and dimension scores indicate a higher burden. To enable comparison across CBI dimensions, as suggested by the authors (Novak and Guest, 1989),²² the physical burden score, which has four items, is weighted by a factor of 1.25.

Caregiver's contributions to heart failure self-care

Caregivers completed the self-care maintenance and the self-care management scale of the caregiver contribution to self-care of heart failure index (CC-SCHF).²⁶ The self-care maintenance scale, with 10 items, measures the extent to which a caregiver helps the heart failure patient to perform self-care by monitoring his/her conditions (e.g. checking ankle for swelling) and recommending the patient adhere to the treatment plan (e.g. recommending exercise). The self-care management scale, with six items, measures the extent to which a caregiver helps the patient recognise signs and symptoms of heart failure exacerbation (e.g. dyspnoea) and then implement actions to reduce the exacerbation (e.g. calling the provider and asking for advice). Both scales use a four-point Likert format for responses from 1 (never or rarely) to 4 (always or daily). Each scale has a standardised score from 0 to 100 with a higher score meaning better self-care.

Caregiver and patient characteristics

Caregiver and patient sociodemographic characteristics (e.g. gender, age) were collected with a questionnaire developed by the research team. Social support received by the caregiver was measured using the four-item subscale from the carers of older people in Europe (COPE) index,²⁹ an instrument used to rate the quality of social support on a scale from 1 (never) to 4 (always). Higher scores indicated greater perceived social support.

Patient clinical characteristics (e.g. NYHA class, ejection fraction) were extracted from patients' clinical records. Comorbidities were extracted from patients' clinical records using the Charlson comorbidity index (CCI),³⁰ allowing comorbidities to be quantified with a possible score from 0 to 36, with higher scores meaning higher comorbidities.

Patients' cognitive functions were measured using the mini-mental state examination (MMSE),³¹ which has a score range from 0 to 30, with higher scores indicating better cognition. A score of 24 or less is used to indicate cognitive dysfunction.³²

The two subscales of the short form-12 health survey (SF-12)³³ were used to assess patients' physical and mental QOL. Higher scores indicate better QOL.

Ethics committees at each site approved the research protocol and informed consents were signed both by patients and caregivers before data collection.

Analysis

Statistical analyses were conducted in three steps. First, caregiver and patient characteristics as well as the scores obtained with the instruments were described with mean

values and standard deviations (SD) for continuous variables and with frequencies and percentages for categorical and nominal variables.

Second, to evaluate multicollinearity issues among the variables to be entered in the regression models (third step) the variance inflation factor (VIF) and tolerance were used: A VIF greater than 4 and a tolerance less than 0.20 are indicative of multicollinearity.³⁴

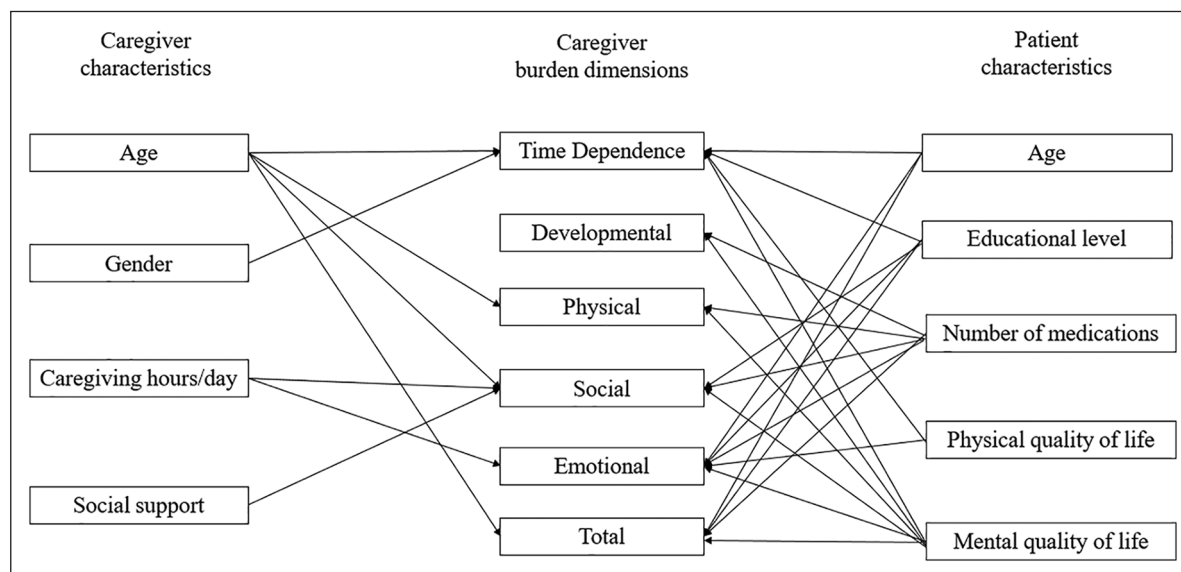
Third, to identify predictors of caregiver burden among caregiver and patient characteristics, and to evaluate if caregiver contribution to self-care maintenance and management increased caregiver burden over and above caregiver burden, five hierarchical regression models for each of the CBI dimensions were implemented. Also, in order to identify predictors of the global burden we performed a hierarchical regression model with the total CBI score. In particular, caregiver characteristics (age, gender, employment, education level, living with patient, hours of caregiving per day, social support) and patient characteristics (age, gender, employment, education level, hospitalisation for heart failure in past year, ejection fraction, NYHA class, months of illness, number of taken medications, comorbidities, cognitive impairment, physical and mental QOL) were entered as independent variables in the first step of each hierarchical regression model. Then, caregiver contribution to heart failure self-care maintenance and management were entered as independent variables in the second step of the hierarchical regressions. To test the hypothesis that caregiver contribution would explain significant variance over and above patient and caregivers' characteristics, we considered change in R^2 and the beta coefficients. Statistical significance was set at $P < 0.05$. Data analyses were performed using IBM SPSS Statistics version 24 (IBM, Armonk, NY, USA).

Results

In the parent study³⁵ we enrolled a sample of 1192 heart failure patients and 505 of them had a caregiver willing to participate in the study. These 505 patient and caregiver dyads were considered in the present study. Slightly more than half of the caregivers and just under half of the patients were women. Slightly more than half of the caregivers were adult children of the patients, and most caregivers did not live with the patients. The mean duration of heart failure was about 5 years, and about half of patients were in the III/IV NYHA class. The comorbidity level was moderate, and about half of the patients showed cognitive dysfunction (Table 1). The scores of CBI dimensions are reported in Figure 1. The dimension for which caregivers reported higher levels was time-dependence burden. The dimension for which caregivers reported lower levels was emotional burden. The mean level of the total burden was 28.30 (SD 22.68). Collinearity analysis showed the VIF for all tested models was 1.8 or less and the tolerance was 0.58 or greater, indicating no collinearity.

Table 1. Heart failure caregiver (n=505) and patient (n=505) characteristics.

| | Caregivers | Mean \pm standard deviation, or n (%) | | |
|--|-----------------|---|-----------------|----------------|
| | | Missing, n (%) | Patients | Missing, n (%) |
| Gender (% female) | 265 (52.5%) | – | 226 (44.8%) | – |
| Age (in years) | 56.5 \pm 14.9 | – | 75.9 \pm 10.4 | – |
| Education (professional/high school/university) | 257 (51.7%) | 8 (1.6%) | 123 (24.2%) | – |
| Marital status | | 16 (3.2%) | | – |
| Married | 366 (72.5%) | | 282 (55.8%) | |
| Single | 66 (13.1%) | | 19 (3.8%) | |
| Divorced | 38 (7.5%) | | 25 (5.0%) | |
| Widowed | 19 (3.8%) | | 179 (35.4%) | |
| Currently employed | 279 (56%) | 7 (1.4%) | 51 (10.1%) | – |
| Relationship with patient | | 23 (4.6%) | | – |
| Spouse | 167 (33.1%) | | – | |
| Adult child of patient | 249 (49.3%) | | – | |
| Other family or friend | 66 (13.7%) | | – | |
| Living with patient | 189 (37.4%) | – | – | – |
| Hours of caregiving per day | 7.5 \pm 7.1 | – | – | – |
| New York Heart Association functional class | | | | |
| I or II | – | – | 275 (54.5%) | – |
| III or IV | – | – | 230 (45.5%) | – |
| Ejection fraction | – | – | 44.5 \pm 11.2 | 6 (1.2%) |
| Months with heart failure | – | – | 58.1 \pm 47.5 | – |
| Number of medications | – | – | 4.9 \pm 2.4 | 39 (7.7%) |
| Hospitalised for heart failure in last year | – | – | 290 (57.4%) | – |
| Charlson comorbidity index | – | – | 3.1 \pm 2.2 | – |
| Cognitive impairment (mini mental state examination \leq 24) | – | – | 241 (47.7%) | – |

**Figure 1.** Caregiver and patient characteristics predicting caregiver burden dimensions.

Note: All arrows mean significant relationships.

The results of the first two hierarchical regression analyses (Table 2, Figure 1) revealed that predictors of higher time-dependence burden among caregiver characteristics

were caregivers' older age and female gender; predictors of higher time-dependence burden among patient characteristics were patients' older age, higher education level,

Table 2. Multivariate linear regression models predicting the dimensions of burden and the total burden in caregivers.

| | Time-dependence | | Developmental | | Physical | | Social | | Emotional | | Total | |
|--|-----------------|-----------|---------------|----------|----------|----------|----------|----------|-----------|----------|-----------|-----------|
| | Model 1 | Model 2 | Model 1 | Model 2 | Model 1 | Model 2 | Model 1 | Model 2 | Model 1 | Model 2 | Model 1 | Model 2 |
| | β | β | β | β | β | β | β | β | β | β | β | β |
| Caregiver characteristics | | | | | | | | | | | | |
| Age | 0.167* | 0.167* | 0.101 | 0.109 | 0.202* | 0.192* | 0.166* | 0.153* | 0.083 | 0.079 | 0.164* | 0.160* |
| Gender ^a | 0.132* | 0.128* | 0.040 | 0.038 | 0.081 | 0.083 | 0.104 | 0.101 | 0.043 | 0.043 | 0.092 | 0.090 |
| Currently employed ^a | -0.012 | -0.008 | 0.134 | 0.135 | 0.059 | 0.057 | 0.054 | 0.058 | 0.114 | 0.114 | 0.082 | 0.084 |
| Education level | 0.031 | 0.035 | 0.082 | 0.088 | 0.063 | 0.055 | 0.051 | 0.048 | 0.086 | 0.084 | 0.073 | 0.072 |
| Living with Patient ^a | -0.002 | -0.002 | -0.022 | -0.020 | 0.014 | 0.012 | -0.012 | -0.015 | -0.013 | -0.014 | -0.009 | -0.010 |
| Hours of caregiving per day | 0.123 | 0.129 | -0.072 | -0.062 | 0.032 | 0.019 | -0.153* | -0.160* | -0.153* | -0.157* | -0.054 | -0.056 |
| Social support | -0.023 | -0.034 | -0.115 | -0.136 | -0.124 | -0.096 | -0.160* | -0.144* | -0.069 | -0.061 | -0.113 | -0.108 |
| CC to self-care maintenance | | 0.036 | | 0.004 | -0.014 | -0.014 | 0.053 | | | 0.005 | | 0.023 |
| CC to self-care management | | 0.022 | | 0.060 | -0.076 | -0.076 | -0.061 | | | -0.027 | | -0.019 |
| Patient characteristics | | | | | | | | | | | | |
| Age | 0.224** | 0.228** | 0.130 | 0.131 | 0.062 | 0.060 | 0.111 | 0.117 | 0.152* | 0.153* | 0.163* | 0.165* |
| Gender ^a | -0.065 | -0.063 | 0.026 | 0.030 | -0.003 | -0.008 | -0.032 | -0.035 | -0.022 | -0.023 | -0.023 | -0.023 |
| Currently employed ^a | 0.095 | 0.098 | 0.070 | 0.072 | 0.105 | 0.102 | 0.104 | 0.106 | 0.089 | 0.088 | 0.120 | 0.121 |
| Education level | 0.148* | 0.151* | 0.105 | 0.106 | 0.083 | 0.081 | 0.181** | 0.185** | 0.195** | 0.195** | 0.154* | 0.156* |
| Hospitalised for heart failure in last year ^a | -0.023 | -0.023 | 0.067 | 0.072 | 0.089 | 0.083 | 0.084 | 0.077 | 0.056 | 0.054 | 0.061 | 0.058 |
| Ejection fraction | -0.105 | -0.109 | -0.067 | -0.069 | -0.063 | -0.059 | -0.047 | -0.049 | -0.058 | -0.057 | -0.079 | -0.081 |
| NYHA class | 0.072 | 0.070 | -0.035 | -0.040 | -0.007 | 0.000 | -0.068 | -0.063 | -0.049 | -0.046 | -0.019 | -0.017 |
| Months of illness | -0.013 | -0.016 | 0.010 | 0.009 | 0.039 | 0.041 | 0.007 | 0.003 | -0.032 | -0.032 | 0.001 | -0.001 |
| Number of medications | -0.096 | -0.092 | -0.228** | -0.214** | -0.158* | -0.175* | -0.220** | -0.237** | -0.194** | -0.201** | -0.209** | -0.214** |
| Comorbidities | 0.016 | 0.010 | -0.020 | -0.025 | -0.030 | -0.022 | -0.055 | -0.056 | -0.053 | -0.051 | -0.032 | -0.033 |
| Cognitive impairment ^a | -0.043 | -0.045 | 0.057 | 0.060 | 0.039 | 0.036 | 0.081 | 0.073 | 0.118 | 0.116 | 0.057 | 0.054 |
| PCS | -0.182* | -0.176* | 0.062 | 0.063 | 0.063 | 0.060 | 0.056 | 0.064 | 0.148* | 0.149* | 0.030 | 0.033 |
| MCS | -0.236*** | -0.233*** | -0.197** | -0.197** | -0.221** | -0.222** | -0.171** | -0.166** | -0.168** | -0.168** | -0.231*** | -0.228*** |
| R² | 0.286 | 0.288 | 0.221 | 0.224 | 0.194 | 0.199 | 0.307 | 0.310 | 0.326 | 0.327 | 0.254 | 0.254 |
| Adjusted R² | 0.219 | 0.214 | 0.147 | 0.142 | 0.117 | 0.115 | 0.242 | 0.237 | 0.262 | 0.256 | 0.183 | 0.176 |

β are standardised.

^aDummy coded: gender: 0=male, 1=female; currently employed: 0=unemployed, 1=employed; living with patient: 0=no, 1=yes; hospitalised for heart failure in past year: 0=no, 1=yes; cognitive impairment: 0=no, 1=yes.

CC: caregiver contribution; NYHA: New York Heart Association; PCS: physical component summary of the SF-12; MCS: mental component summary of the SF-12.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

and lower physical and mental QOL. These predictors explained the 28.6% of the variance of caregiver time-dependence burden variance (model 1 $F=4.321$, $P<0.001$). Caregiver contribution to self-care maintenance and self-care management, added in the second step of the model (model 2), were not significant predictors of this domain. The explained variance increased to 28.8% ($F=3.851$, $P<0.001$) with a non-significant R^2 change (0.02%).

The only two predictors of higher developmental burden were patients taking fewer medications, and lower patient mental QOL (Table 2, Figure 1). Model 1 explained 22.1% ($F=2.994$, $P<0.001$) of the total variance in this dimension and adding caregiver contribution to self-care maintenance and self-care management, which were not significant predictors, model 2 explained 22.4% of the developmental burden variance ($F=2.742$, $P<0.001$) with a non-significant R^2 change (0.03%).

Higher levels of physical burden were significantly associated with caregiver older age, fewer medications taken by the patient and lower patient mental QOL (Table 2). The first model (model 1) explained 19.4% of the total variance in this domain ($F=2.534$, $P<0.001$), while model 2, when caregiver contribution to self-care maintenance and self-care management were added, explained 19.9% of the physical burden variance ($F=2.363$, $P<0.001$). Also, in this case, caregiver contribution to self-care maintenance and self-care management were not significant predictors in the model (R^2 change 0.03%).

Higher levels of social burden were significantly associated with caregivers' older age, fewer hours of caregiving per day, lower levels of caregiver social support, lower caregiver physical and mental QOL, higher patient education, fewer medications taken by the patient and lower patient mental QOL (Table 2). The first model (model 1) explained 30.7% of the total variance in this dimension ($F=4.678$, $P<0.001$), while model 2, when caregiver contribution to self-care maintenance and self-care management were added, explained 31% of the social burden variance ($F=4.268$, $P<0.001$) without a significant R^2 change (0.05%).

Higher levels of emotional burden were significantly associated with fewer hours of caregiving per day, older patient age, higher patient education, fewer medications taken by the patient, higher level of patient physical QOL and lower patient mental QOL (Table 2, Figure 1). The first model (model 1) explained 32.6% of the total variance in this dimension ($F=5.108$, $P<0.001$), while model 2, when caregiver contribution to self-care maintenance and self-care management were added, explained 32.7% of the emotional burden variance ($F=4.609$, $P<0.001$). However, caregiver contribution to self-care maintenance and management were not significant predictors and R^2 change (0.01) was not significant.

Finally, higher levels of total burden were significantly associated with caregivers' older age, patient older age,

higher patient education and lower patient mental QOL (Table 2, Figure 1). The first model (model 1) explained 25.4% of the total variance of the total burden ($F=3.590$, $P<0.001$); also model 2, when caregiver contribution to self-care maintenance and self-care management were added, explained 25.4% of the emotional burden variance ($F=3.240$, $P<0.001$). In addition, in this analysis, caregiver contribution to self-care maintenance and management were not significant predictors of the total burden as well as for the R^2 change.

Discussion

To our knowledge, this is the first study referring to caregivers in heart failure, that has identified predictors of specific burden dimensions (e.g. time-dependence burden), and the first study that looked at the role of caregiver contribution to self-care maintenance and management as potentially caregiver burden predictors. Interestingly, our analyses have shown that caregiver burden predictors change across the caregiver burden dimensions and that caregiver contribution to self-care maintenance and management does not increase either caregiver burden dimension or the total score of caregiver burden. These results improve our understanding of heart failure caregiving.

In our study, we saw caregiver characteristics predicting a higher total score of caregiver burden, and the specific caregiver burden dimensions were a caregivers' older age and female gender, hours of caregiving provided per day and social support. These predictors behaved differently across the five burden dimensions. Older caregivers' age was associated with higher time-dependence, physical, social and the total burden; female caregiver gender was associated with only higher time-dependence burden; more time spent in caregiving was associated with lower social and emotional burden; and finally, higher social support was associated with lower social burden. These different relationships between caregiver characteristics and caregiver burden dimensions are interesting because they make clear that different caregiver characteristics influence different caregiver burden dimensions. For example, female caregiver gender was associated only with higher time-dependence burden and not with other burden dimensions or the total burden. Some of the above findings had already been reported in the literature. For example, we already knew that burden was higher in female³⁶ and older caregivers.^{12,37-40} However, considering the results of our study, it seems that only the burden due to personal time limitations (time-dependence burden) represents a problem in female caregivers because female gender predicted only time-dependence burden. Instead, older caregivers seem to have wider problems associated with the burden because caregivers' older age predicted four out of the six tested

models. Different from other studies in which more hours devoted to caregiving predicted a higher burden,^{38,41} in our study we saw the contrary in relation to social and emotional burden – that is – higher social and emotional burden was predicted by fewer hours of caregiving per week. Actually, the social burden measured by the CBI considers the relations with other family members, job colleagues and friends, which could be affected by caregiving. A caregiver who devotes more time to caregiving also generates an appreciation from other family members, job colleagues and friends, which in turn could reduce the burden. In the same way, the relationship between caregiving hours and emotional burden could be interpreted as follows: the emotional burden reflects feelings of shame and anger that are attenuated by giving more care to the patients. Another reason supporting our interpretation was that a more positive quality of the relationship between heart failure patients and caregivers reduces burden,⁴² thus better relationships between patients and caregivers could lessen the burden. Another interpretation could also be that as social and emotional burden in the CBI includes feelings such as resentment, discomfort, anger and shame, these factors may prevent caregivers from devoting more time to caregiving. However, further studies are needed to understand better the above relations.

Patient characteristics that predicted higher total and specific dimension scores of caregiver burden were older age, higher educational level, fewer medications taken, lower physical and mental QOL, even though higher caregiver emotional QOL was predicted by higher patient physical QOL. As for caregivers, patient predictors behaved differently across the five burden dimensions. Patient older age and higher education were predictors of higher time-dependence, emotional and total burden. Patients with older age may have more health problems than younger patients because of their comorbidities or more dependence in activities of daily living. These aspects can reduce caregiver time for caregivers to live their personal lives and they also could be emotionally burdensome. This finding seems new in the literature since there are no prior studies that have found this relationship. Regarding the association between higher patient education and higher burden, this is also a new finding. Patients with higher education could be more critical regarding the provider prescriptions, and this critical attitude could increase caregiver burden.

More medications taken by the patients predicted better physical, social, emotional and total caregiver burden. This finding is also new in the literature. In a prior study, it was shown that more medications taken by the patients predicted better self-care,⁸ so it could be that patients taking more medications and performing better self-care gave fewer duties and worries to their caregivers that resulted in lower burden.

In general, better patient physical and mental QOL was associated with lower burden; however, while patient mental QOL predicted all caregiver dimensions and the total burden, patient physical QOL predicted only time-dependence burden and emotional burden. The relationship between caregiver physical QOL and emotional burden was unexpected as better patient physical QOL was associated with higher emotional burden. This finding is new in the literature, yet it could be explained that with some heart failure patients, when they have a better physical QOL and do not have symptoms, are less adherent to medical and nursing recommendations even if they have an important disease such as heart failure. Therefore, these ‘low adherent’ behaviours can generate emotional burden in caregivers.

An interesting result of this study was that caregiver contribution to self-care maintenance and management did not increase caregiver burden. To our knowledge, no other studies in the literature have reported this finding. The reason for this finding could be that giving care to a person in need could be highly rewarding for a caregiver, as many studies have shown,^{43,44} and this can compensate the burden due to caregiving. Also, the relationship between the patient and the caregiver could attenuate caregiver burden. In fact, a recent study⁴² showed that higher mutuality (that is the positive quality of the relationship between the patient and the caregiver) not only predicted better self-care in heart failure patients and their caregivers but also decreased caregiver burden.

Further research is needed to understand better heart failure caregiver burden. This research should understand better the relationship between the amount of time given to caregiving and burden. We have seen that caregiver burden is influenced by different patient and caregiver characteristics, but there are many other characteristics that are worth investigating to understand caregiver burden better. For example, we still do not know if caregiver burden changes over time or if it is influenced by others’ family member support; therefore, future longitudinal studies are needed as well as studies with interventions to improve caregiver burden.

This study has several limitations. First, it used a convenience sample from a cross-sectional study. We tried to balance this limitation conducting a multicentre study across several Italian regions. Second, its generalisability to other countries should be done with caution as it was conducted in only one European country.

In conclusion, in this study, we saw that different caregiver and patient characteristics influence different dimensions of caregiver burden, and that caregiver contribution to self-care seems not to increase caregiver burden. Considering that higher scores in caregiver contribution to self-care maintenance were shown to reduce clinical events (mortality, hospitalisations and access to emergency department) in heart failure patients,^{5,45} if our results are

also confirmed by other studies this means that healthcare providers can rely on caregivers and patients' families without increasing their level of burden.

Implications for practice

- Healthcare providers should give special attention to heart failure caregivers who are older, female, and receive low social support because they are more exposed to burden.
- Healthcare providers should give special attention to caregivers who care for heart failure patients who are older, better educated, because they are more exposed to burden.
- Interventions to reduce heart failure caregiver burden should consider which dimension of burden is affected in caregivers.
- Healthcare providers might rely on caregivers in heart failure care because caregiver contribution to heart failure self-care seems not to increase caregiver burden.

Declaration of conflicting interest

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