

Psychometric characteristics of the caregiver burden inventory in caregivers of adults with heart failure

European Journal of Cardiovascular Nursing
2017, Vol. 16(6) 502–510

© The European Society of Cardiology 2017

Reprints and permissions:

sagepub.co.uk/journalsPermissions.nav

DOI: 10.1177/1474515117693890

journals.sagepub.com/home/cnu



**Andrea Greco¹, Luca Pancani¹, Marta Sala¹, Anna Maria Annoni¹,
Patrizia Steca¹, Marco Paturzo², Fabio D'Agostino²,
Rosaria Alvaro² and Ercole Vellone²**

Abstract

Background: A better understanding of caregiver burden and its determinants is essential to support caregivers. Many instruments have been developed to measure caregiver burden in various illness contexts, but few have been psychometrically tested for caregivers of heart failure patients.

Aims: The aim of this study was to test the validity (factorial and concurrent validity) and reliability (internal consistency) of the caregiver burden inventory (CBI) in a cohort of caregivers of heart failure patients.

Methods: This was a secondary analysis from a cross-sectional study on heart failure patients and their caregivers enrolled from various Italian outpatient centres. The factorial validity of the CBI was tested with confirmatory factor analysis, and concurrent validity was tested correlating CBI scores with the short form-12 health survey scores. The internal consistency reliability was assessed with Cronbach's alpha.

Results: In total, 505 caregivers of heart failure patients (52.2% women, mean age 56.59 ± 14.9 years) were enrolled. Confirmatory factor analyses confirmed the original five-factor model: time-dependence, developmental, physical, social and emotional burden. This model fits the data better than the single-factor model, and the dimensions showed high internal consistency reliability (Cronbach's alpha 0.91 for time-dependence burden, 0.92 for developmental burden, 0.88 for physical burden, 0.89 for social burden and 0.93 for emotional burden; 0.96 for the total score of burden).

Conclusion: The CBI proved to be a good multidimensional instrument for evaluating the burden in caregivers of heart failure patients and can be used in clinical practice and research. This tool can be considered to tailor interventions aimed at improving caregiver outcomes.

Keywords

Caregiver, heart failure, burden, psychometrics

Date received: 23 July 2016; revised: 20 December 2016; accepted: 24 January 2017

Introduction

Caregivers play a key role in the management of all chronic conditions.¹ Several studies have shown that caregiver support improves patients' outcomes in various diseases, from cognitive impairment disorders² to heart failure (HF).³ For this reason, the maintenance of an acceptably healthy condition for the caregivers and the avoidance of their burden, defined as the self-perception of psychological, physical, emotional, social and financial consequences of the direct care of a family member, have been underlined as central issues.⁴ Many studies have highlighted that caregivers' burden negatively impacts their health, the

quality of care given to the care recipients and, consequently, the patients' health.^{3,5}

¹Department of Psychology, University of Milan - Bicocca, Italy

²Department of Biomedicine and Prevention, University of Rome "Tor Vergata", Italy

Corresponding author:

Andrea Greco, Department of Psychology, University of Milan - Bicocca, Piazza dell'Ateneo Nuovo, 1, Milan 20126, Italy.

Email: andrea.greco@unimib.it

The attention to the burden of caregivers in the HF population is due to the high diffusion of this pathology (over 15 million people in Europe) that is expected to increase in the future. Prior to 1990, up to 60% of patients with severe HF died within five years of diagnosis, but now, advances in medicine are decreasing the mortality and hospitalisation and increasing life expectancy.^{6,7} Moreover, as hospitalisations have been reduced and HF has increased, the role of caregivers has become more and more important. HF patients should adhere to strict pharmacological and non-pharmacological treatment; thus, HF management is complex and may often become even more difficult in the presence of cognitive impairment, which is common in HF patients (about 25–80% depending on the characteristics of the disease).⁸

Patient support requires appropriate care,⁹ and typically an unpaid family caregiver provides this assistance to the patient. Caregivers' support of patients could last for a decade or more,¹⁰ and this imposes significant physical and emotional demands, resulting in caregiver burden.⁵ Various studies have shown that caregivers of HF patients experience the same levels of strain as caregivers of patients with other chronic diseases,¹ and that they experience higher levels of psychosocial distress and lower feelings of wellbeing compared to the general population.³ Therefore, a preliminary step in supporting caregivers of HF patients is to develop and/or test valid and reliable measures of caregiver burden to identify those who are at higher risk. Although many instruments have been developed to measure caregiver burden in the context of chronic illnesses,¹¹ little attention has been dedicated to caregiver burden in HF.

Caregiver burden can be measured in terms of objective and/or subjective burden:¹² objective burden reflects the concrete activities and tasks that caregivers perform in the caregiving process (e.g. helping patients in activities of daily living); instead, subjective burden refers to caregivers' evaluation of the caregiving situation and the extent to which they perceive the situation as strenuous.¹² Both aspects are relevant for caregivers, and the same levels of objective burden may result in different levels of subjective burden.¹²

The literature reports several instruments to measure caregiver burden in HF patients. The Dutch objective burden inventory (DOBI)¹³ and the caregiver burden questionnaire for heart failure (CBQ-HF)¹⁴ are two disease-specific instruments to measure caregiver burden in HF. The DOBI measures caregiver burden in terms of personal care and motivational, diet, emotional and practical support given by the caregiver to the patient. It was developed in a cohort of 321 partners of HF patients and showed good factorial and concurrent validity and good internal consistency reliability as well. However, one limitation of the DOBI is that it measures only the objective burden. The CBQ-HF is another disease-specific instrument and measures caregiver burden on physical, psychological/

emotional, social and lifestyle dimensions. However, it measures only subjective burden and was tested only for face and content validity in 18 caregivers, not for reliability. A well-known generic and psychometrically sound instrument to measure caregiver burden is the caregiver burden inventory (CBI).¹⁵ The CBI is a multidimensional scale that was initially developed to evaluate caregiver burden in dementia, but, after its development, it was tested in other caregiver populations as well and showed strong validity and reliability characteristics.^{16,17} The CBI is a multiple-choice 24-item instrument with five dimensions: time-dependent burden, evaluating stress caused by the restriction of caregivers' personal time; developmental burden, referring to the sense of failure regarding personal hopes and expectations; physical burden, referring to physical stress and somatic disorders; social burden, caused by conflicts on the job or with family; and emotional burden, referring to feelings of shame caused by a patient's behaviours. Moreover, the CBI is often used as a total score, suggesting the existence of a unique component of caregiver burden.¹⁸ Although the CBI is not specific for caregivers of HF patients, it has the advantages of measuring objective and subjective burden simultaneously. In addition, the dimensions explored with the CBI have been demonstrated to be important in caregivers of HF patients. For example, Blackburn et al.¹⁹ showed that in caregivers of HF patients, four domains of caregiver burden can be identified: physical burden, including tiredness, health deterioration and a lack of sleep; emotional/psychological burden, including feeling overly depended on, worried and stressed; social burden, including spending less time with family and friends and the decline in the quality of relationships; the impact on caregivers' lifestyles, including a lack of time for themselves, for non-caregiving tasks and changing plans. Moreover, other studies exploring the problems experienced by caregivers of HF patients have emphasised similar domains of caregiver burden in HF, in terms of physical, social and psychological wellbeing.^{20,21} These domains of burden are all explored by the CBI that could complement disease-specific measures of caregiver burden in HF.

Despite its wide use in several caregiver populations, no studies have tested the validity and reliability of the CBI in caregivers of HF patients thus far. Therefore, the aim of this study was to test the validity (factorial and concurrent validity) and the reliability (internal consistency reliability) of the CBI in a large cohort of caregivers of HF patients.

Methods

Study design and procedure

This was a secondary analysis of data from a multi-site, cross-sectional descriptive study of HF self-care behaviours conducted on a large cohort of HF patients and their

principal informal caregivers in Italy. The primary aim and detailed study procedures have previously been published.²² HF patients from ambulatory cardiovascular clinics in 28 Italian provinces were screened and offered enrolment in the study by trained research nurses. A patient was enrolled if she/he met the following criteria: (a) was being seen at the clinic for a routine HF appointment; (b) had a diagnosis of HF confirmed by echocardiograms; (c) had clinical evidence of HF as outlined by the European Society of Cardiology Guidelines;⁶ and (d) was willing and able to provide informed consent. Patients were excluded if they were younger than 18 years of age, had had an acute coronary event within the three months prior to enrolment or had clear evidence of dementia.

A caregiver in this study was defined as an unpaid person (family member or non-family member), designated by an HF patient, who informally provides the most care to the person affected by HF. Caregivers accompanied the patients to the enrolment visit and were asked to participate in the study. All questionnaire data were collected by trained nurses.

The study complied with the Declaration of Helsinki. Ethics committees at each site approved the research protocol, and informed consents were signed both by patients and caregivers before data collection.

Measurements

Caregiver burden. Caregiver burden in terms of time-dependent, developmental, physical, social and emotional burden was evaluated by the CBI.¹⁵ Each item used a 5-point self-report scale, with a score system ranging from 0 (minimum burden) to 4 (maximum burden). All but the physical burden subscale consisted of five items; as suggested by the authors,¹⁵ the physical burden score, based on 4 items, was weighted by a factor of 1.25 to enable comparison with the other subscales. For all the burden subscales, 0 was the minimum score possible, 20 the maximum. A higher score on the CBI means higher burden.

Caregivers' quality of life. The two subscales of the short form-12 health survey (SF-12)²³ were used to assess caregivers' physical component (PC) and mental component (MC) of quality of life (QOL). Higher scores indicate better QOL. The SF-12 has been widely used in caregiving research, demonstrating good validity and reliability in HF populations.

Caregivers' and patients' sociodemographic characteristics. Self-reported sociodemographics (i.e. gender, age, education level, marital status, employment, relationship between the patient and the caregiver, if the caregiver lived with the patient, and hours a day of caregiving) were collected.

Patients' clinical characteristics. Patients' clinical information (New York Heart Association (NYHA) functional class, HF

duration, medications, hospitalisation for HF within the last year and left ventricular ejection fraction) was collected from the patients' medical records by trained nurses during patient visits. Comorbidity was measured using the Charlson comorbidity index,²⁴ in which higher scores indicate more comorbid conditions. We also assessed patients' cognitive functions using the Mini Mental State Examination,²⁵ in which a higher score indicates better cognition and a score of 24 or less indicates cognitive dysfunction.²⁶

Statistical analysis

Data analyses were performed using IBM SPSS Statistics version 22 (IBM, Armonk, NY, USA) and Mplus software version 7 (Muthén and Muthén).²⁷ For baseline characteristics, mean values and standard deviations (SDs) for continuous variables were calculated for patients and their caregivers; for categorical/nominal variables, frequencies and percentages were computed. Skewness and kurtosis of the CBI items were first checked to assess normal distribution, following Bulmer guidelines.²⁸

Factorial validity was assessed with confirmatory factor analysis (CFA). In particular, the first-order penta-factorial model of the CBI and the second-order unique factor of the CBI were tested. To prevent multivariate non-normal distribution, robust maximum likelihood estimation was employed. Hu and Bentler's guidelines²⁹ for various fit indices were used to determine whether the expected model fits the data. The chi-square test statistic was used, but considering its sensitivity to sample size, other fit indices were evaluated: (a) the comparative fit index (CFI ≥ 0.90 indicates a good fit); (b) the root mean square error of approximation (RMSEA ≤ 0.08 indicates an acceptable fit); and (c) the standardised root mean square residual (SRMR ≤ 0.08 indicates an adequate fit). The first-order penta-factorial model of the CBI and the second-order unique factor of caregiver burden were compared by a chi-square difference test using the Satorra–Bentler scaled chi-square test.³⁰

The concurrent validity of the CBI was evaluated by correlating the CBI scores with PC and MC scores of the SF-12 with the Pearson's r correlation coefficient. Following Cohen's guidelines,³¹ we interpreted correlations as measures of the effect size. Correlations were considered weak ($|0.10| < r < |0.29|$), moderate ($|0.30| < r < |0.49|$) or strong ($|0.50| < r < |1|$).

The CBI's internal consistency was tested using Cronbach's alpha coefficients; values below 0.60 were considered unacceptable.³²

Results

Demographics and clinical characteristics

A total of 505 HF patients and their caregivers were enrolled. Slightly more than half of the caregivers and just

Table 1. Characteristics of heart failure caregivers ($n=505$) and patients ($n=505$).

	Mean \pm standard deviation, or n (%)	
	Caregivers	Patients
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)	264 (52.3%)	119 (23.6%)
Married	370 (73.3%)	282 (55.8%)
Currently employed	286 (56.6%)	51 (10.1%)
Relationship with patient		
Spouse	167 (33.1%)	–
Adult child of patient	267 (52.9%)	–
Other family or friend	71 (14.0%)	–
Living with patient	191 (37.8%)	–
Hours of caregiving per day	7.4 \pm 7.2	–
New York Heart Association functional class		
I or II	–	276 (54.7%)
III or IV	–	229 (45.3%)
Ejection fraction	–	44.1 \pm 10.9
Months with heart failure	–	57.8 \pm 47.3
Number of medications	–	4.9 \pm 2.4
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)	–	240 (47.5%)

under half of the patients were women. On average, caregivers were approximately 19 years younger than the patients. Slightly more than half of the caregivers were adult children of the patients, and the majority did not live with the patients. The duration of HF was about five years, and about half of the patients were in the III/IV NYHA class. The co-morbidity level was moderate, and about half of the patients showed cognitive dysfunction. The characteristics of the sample are presented in Table 1.

Descriptive analysis of CBI items

The descriptive analysis of the CBI items is presented in Table 2. The average scores of the responses to the 24 items from all the participants ranged from 0.59 to 2.13 ($SD_{MIN}=1.15$ – $SD_{MAX}=1.38$). Moreover, in line with recommendations by Bulmer,²⁸ the results showed that some items had a non-normal distribution, with skewness and kurtosis higher than ± 1 ($skewness_{MIN}=-0.10$ – $skewness_{MAX}=1.88$; $kurtosis_{MIN}=-0.03$ – $kurtosis_{MAX}=2.27$). To overcome problems of non-normality, the maximum likelihood estimation with robust standard errors method was used in the following CFA models.

Validity of the CBI

The CFA fits statistics of both the penta-factorial ($\chi^2(242)$ 513.29, $P \leq 0.001$; CFI 0.95; RMSEA 0.047; SRMR 0.067) and the second-order unique factor models ($\chi^2(247)$

573.15, $P \leq 0.001$; CFI 0.94; RMSEA 0.051; SRMR 0.075) exhibited a good fit. A chi-square difference test using the Satorra–Bentler scaled chi-square test³⁰ was used to compare the fit of the more restricted model (second-order) with the less restricted model (first-order), which is nested within the former. The test yielded a significant result ($\Delta\chi^2(5)$ 53.75, $P \leq 0.001$), indicating that the first-order factor model fits the data significantly better than the second-order factor model.

Figure 1 reports the standardised factor loadings for the five identified caregiver burden factors. As shown, all items had significant and sizeable loadings on their respective factors, ranging from 0.72 to 0.89, all above the cut-off value of 0.40 for item-factor retention.

Figure 1 reports the correlations among the five factors, which were all significant; the correlations were all strong (ranging from 0.51 to 0.94), apart from the relation between time-dependence burden and emotional burden, which was moderate ($r=0.45$).

Moreover, Figure 1 also reports the mean values and SDs of the caregiver burden dimensions. Since the scores range from 0 to 20, the average scores of the five dimensions were low to medium. The dimension for which caregivers reported the highest levels was time-dependence burden; this was followed by physical, developmental and social burden. The dimension for which caregivers reported the lowest level was emotional burden.

The concurrent validity of the CBI, evaluated correlating the CBI scores with PC and MC scores of the SF-12,

Table 2. Descriptive statistics of the CBI items.

	Mean	Standard deviation	Skewness	Kurtosis
Time-dependence burden				
My care receiver needs my help to perform many daily tasks	2.13	1.30	-0.13	-1.10
My care receiver is dependent on me	2.04	1.35	-0.10	-1.18
I have to watch my care receiver constantly	1.87	1.32	0.11	-1.12
I have to help my care receiver with many basic functions	1.68	1.38	0.24	-1.19
I don't have a minute's break from my caregiving chores	1.35	1.27	0.56	-0.77
Developmental burden				
I feel that I'm missing out on life	0.97	1.27	1.10	-0.03
I wish I could escape from this situation	1.07	1.32	0.95	-0.37
My social life has suffered	1.34	1.27	0.61	-0.71
I feel emotionally drained. due to caring for my care receiver	1.05	1.31	0.97	-0.37
I expected that things would be different at this point in my life	1.18	1.36	0.78	-0.75
Physical burden				
I'm not getting enough sleep	1.23	1.32	0.75	-0.63
My health has suffered	1.15	1.24	0.82	-0.39
Caregiving has made me physically ill	0.99	1.24	1.03	-0.17
I'm physically tired	1.58	1.32	0.33	-1.03
Social burden				
I don't get along with other family members as well as I used to	0.90	1.27	1.27	0.40
My caregiving efforts aren't appreciated by others in my family	1.06	1.33	0.97	-0.34
I've had problems with my marriage	0.88	1.25	1.19	0.12
I don't do as good a job at work as I used to	0.92	1.22	1.12	0.07
I feel resentful of other relatives who could but do not help	0.94	1.25	1.09	-0.06
Emotional burden				
I feel embarrassed by my care receiver's behaviour	0.74	1.21	1.49	0.98
I feel ashamed of my care receiver	0.59	1.15	1.88	2.27
I resent my care receiver	0.67	1.22	1.68	1.48
I feel uncomfortable when I have friends over	0.76	1.22	1.47	0.89
I feel angry about my reactions toward my care receiver	0.99	1.24	1.01	-0.08

CBI: caregiver burden inventory.

showed that all the correlations were significant and negative. As can be seen in Table 3, the lowest correlations, with weak coefficients, were found between time-dependence burden and both PC ($r=0.28$) and MC scores ($r=0.22$); apart from the stronger relations between MC scores and developmental burden ($r=0.52$) and between MC scores and physical burden ($r=0.50$) ($r=0.45$), all the other relations were moderate, with coefficients between -0.41 and -0.48 .

The internal consistency of the five caregiver burden dimensions was excellent: Cronbach's alphas were 0.91, 0.92, 0.88, 0.89 and 0.93 for time-dependence, developmental, physical, social and emotional burden, respectively; moreover, it was 0.96 for the total score of burden.

Discussion

The aim of this study was to test the psychometric characteristics of the CBI in a large cohort of HF patients' caregivers. In fact, assessing the validity and reliability of the CBI in a cohort of HF patients' caregivers is a necessary step to understand whether the CBI could be used to

investigate burden in HF and to assess caregiver strain in clinical practice and research contexts. Moreover, having a shared and common method for scoring caregiver burden may permit a comparison of the findings across different caregiver populations. As in other pathologies,^{16,17,33,34} the CBI proved to be a good tool to identify the caregiver strain dimensions.

Our analysis confirmed the five-factor structure proposed by Novak and Guest,¹⁵ and this result strengthens the factorial stability of the scale across different caregiver populations. Moreover, our findings showed that the first-order penta-factorial model of the CBI fits the data better than the second-order unique factor model; this result confirms the suggestion proposed by Novak and Guest¹⁵ that caregivers with the same total burden scores could have different patterns of burden considering the multidimensional nature of burden. Consequently, a total burden score could give rise to misleading conclusions about caregivers' needs. Instead, the possibility of measuring different dimensions of caregiver burden could allow a fine-grained exploration of this issue in caregivers of HF patients.

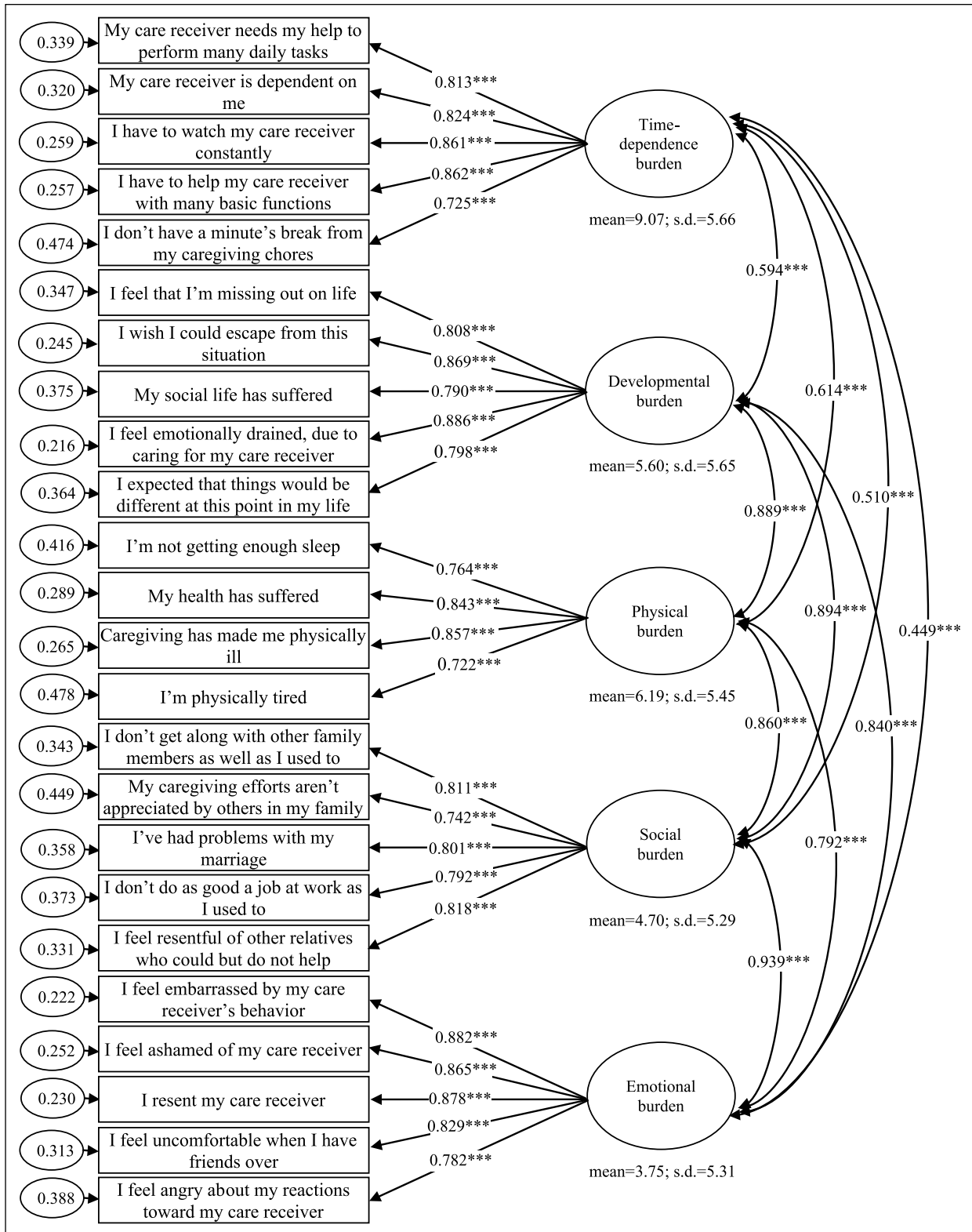


Figure 1. Confirmatory factor analysis for the caregiver burden inventory. *** $P < 0.001$; s.d.: standard deviation.

Concerning the size of the standardised factor loadings of the CFA, all items could be considered good indicators of their respective factors: time-dependence, developmental,

physical, social and emotional burden. Moreover, correlations between the CBI factors and the scales of physical and mental components of the SF-12 used to test concurrent

Table 3. Concurrent validity of the CBI: correlation coefficients between SF-12 dimensions and the CBI factors and CBI total score.

	Time-dependence burden	Developmental burden	Physical burden	Social burden	Emotional burden	CBI – total score
Quality of life – physical component	-0.28***	-0.43***	-0.44***	-0.47***	-0.46***	-0.48***
Quality of life – mental component	-0.22***	-0.52***	-0.50***	-0.41***	-0.41***	-0.48***

*** $P < 0.001$.

SF-12: short form-12 health survey; CBI: caregiver burden inventory.

validity were all highly significant and congruent in their correlations. This finding strengthens the CBI's validity, as previous studies have shown a correlation between burden and QOL in caregivers of HF patients^{5,35} and in other populations.^{36,37} Thus, the empirical evidence supports the usefulness of the CBI for research and clinical purposes because reliability was also adequate.

The CBI explores specific aspects that previous research on caregivers of HF patients suggested as the most important in this pathology.^{13,14,19} First, in line with the study of Luttk et al.,¹³ the CBI, with the time-dependent dimension, measures caregivers' objective burden in terms of problems related to the restriction of caregivers' personal time due to the caregiving process. Moreover, in addition to the importance of objective burden, previous research highlighted the relevance of subjective burden, or caregivers' evaluation of the caregiving situation as strenuous.¹² More specifically, previous studies provided evidence for the role of physical (e.g. physical effort, lack of sleep and health deterioration), psychological/emotional (e.g. feeling mentally drained, guilty and sad), social (e.g. little time with family and friends) and lifestyle (e.g. a lack of time for themselves and changing plans to stay near to the patient) burden on HF caregivers.^{14,19} These domains are measured in the CBI¹⁵ by the physical, emotional, social and developmental burden dimensions, respectively. Thus, in relation to other existing instruments specifically developed for HF patients' caregivers, such as the DOBI¹³ and the CBQ-HF,¹⁴ the CBI¹⁵ may explore both the objective and the subjective as well as other dimensions of caregiver burden in HF that the literature reports as important aspects of this typology of caregivers.^{19–21} Moreover, as the CBI is a globally validated tool for various populations,^{16,17,33,34} it could be easily used to compare caregiver burden across different pathologies. Generic and specific instruments to measure caregiver burden in HF could allow an in-depth and comprehensive assessment of caregivers' experience.

Overall, the findings of the current study suggest the potential applicability of the CBI. The evaluation of caregiver strain is a fundamental aspect of patients' global evaluation. Furthermore, through the evaluation of caregivers' needs, healthcare professionals could more specifically address the help needed and could identify and support caregivers who are more at risk. The administration of the CBI

could provide the opportunity to develop a caregiver burden profile for each respondent. This profile enables each individual burden score to be graphically displayed and compared with different individuals' patterns of burden. Moreover, this multidimensional profile could be helpful in tailoring intervention plans.

Despite its strengths, our study has several limitations. The use of a cross-sectional design limits the results to the CBI's concurrent validity. Although a cross-sectional design can be used to investigate psychometric characteristics of questionnaires, a longitudinal design is recommended to test its predictive validity. Furthermore, comparative studies are needed to evaluate the valence of the CBI with respect to other instruments, such as the DOBI¹³ and the CBQ-HF¹⁴ in caregivers of HF patients. Moreover, future studies could focus on understanding the relationships among caregiver burden and sociodemographic, clinical and psychological characteristics of patients and their caregivers to provide a more in-depth understanding of this important topic that is essential for the development of effective supportive interventions for caregivers of HF patients. In addition, future studies should also consider other mental health factors, such as depression, which is recognised as an increasingly prevalent prognostic factor. Finally, future studies could better deepen the domain of burden separately considering various typologies of caregivers.

Implications for practice

- The evaluation of caregiver strain is a fundamental aspect of patients' global evaluation; through the evaluation of caregivers' needs, healthcare professionals could more specifically address the help needed and could identify and support caregivers who are more at risk.
- The administration of the caregiver burden inventory could provide the opportunity to develop a caregiver burden profile for each respondent. This profile enables each subject's burden scores to be graphically displayed and compared with different individuals' patterns of burden.
- This multidimensional profile could be helpful in tailoring intervention plans.

Conflict of interest

The authors declare that there is no conflict of interest.

Funding

This work was supported by the Center of Excellence for Nursing Scholarship, Rome, Italy.

References

- Garlo K, O'Leary JR, Van Ness PH, et al. Burden in caregivers of older adults with advanced illness. *J Am Geriatr Soc* 2010; 58: 2315–2322. DOI:10.1111/j.1532-5415.2010.03177.x.
- Beinart N, Weinman J, Wade D, et al. Caregiver burden and psychoeducational interventions in Alzheimer's disease: a review. *Dement Geriatr Cogn Dis Extra* 2012; 2: 638–648.
- Dunbar SB, Clark PC, Quinn C, et al. Family influences on heart failure self-care and outcomes. *J Cardiovasc Nurs* 2008; 23: 258–265. <http://doi.org/10.1097/01.JCN.0000305093.20012.b8>.
- Bauer JM and Sousa-Poza A. Impacts of informal caregiving on caregiver employment, health, and family. *J Popul Ageing* 2015; 8: 113–145. DOI: 10.1007/s12062-015-9116-0.
- Ågren S, Evangelista L and Strömberg A. Do partners of patients with chronic heart failure experience caregiver burden? *Eur J Cardiovasc Nurs* 2010; 9: 254–262. DOI: 10.1016/j.ejcnurse.2010.03.001.
- McMurray JJ V, Adamopoulos S, Anker SD, et al. ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012. *Eur J Heart Fail* 2012; 14: 803–869.
- Go AS, Mozaffarian D, Roger VL, et al. Heart disease and stroke statistics – 2014 update. *Circulation* 2014; 129: e28–e292. DOI: 10.1161/01.cir.0000441139.02102.80.
- Leto L and Feola M. Cognitive impairment in heart failure patients. *J Geriatr Cardiol* 2014; 11: 316–328.
- Riegel B and Dickson VV. A situation-specific theory of heart failure self-care. *J Cardiovasc Nurs* 2008; 23: 190–196.
- Saunders M. Factors associated with caregiver burden in heart failure family caregivers. *West J Nurs Res* 2008; 30: 943–959. <http://doi.org/10.1177/0193945908319990>.
- Hébert R, Bravo G and Prévaille M. Reliability, validity and reference values of the zarit burden interview for assessing informal caregivers of community-dwelling older persons with dementia. *Can J Aging/La Revue canadienne du vieillissement* 2000; 19: 494–507. DOI: 10.1017/S0714980800012484.
- Montgomery RJV, Gonyea JG and Hooyman NR. Caregiving and the experience of subjective and objective burden. *Fam Relat* 1985:19–26.
- Luttik ML, Jaarsma T, Tijssen JGP, et al. The objective burden in partners of heart failure patients; development and initial validation of the Dutch Objective Burden Inventory. *Eur J Cardiovasc Nurs* 2008; 7: 3–9.
- Humphrey L, Kulich K, Deschaseaux C, et al. The Caregiver Burden Questionnaire for Heart Failure (CBQ-HF): face and content validity. *Health Qual Life Outcomes* 2013; 11: 84. DOI: 10.1186/1477-7525-11-84.
- Novak M and Guest C. Application of a multidimensional caregiver burden inventory. *Gerontologist* 1989; 29: 798–803.
- Tramonti F, Barsanti I, Bongioanni P, et al. A permanent emergency: a longitudinal study on families coping with amyotrophic lateral sclerosis. *Fam Syst Heal* 2014; 32: 271.
- Zavagli V, Varani S, Samolsky-Dekel AR, et al. Worry as a risk factor for mental and somatic diseases. A research on home-cared cancer patients family caregivers. *G Ital Med Lav Ergon* 2012; 34: 17–22.
- D'Onofrio G, Sancarolo D, Addante F, et al. Caregiver burden characterization in patients with Alzheimer's disease or vascular dementia. *Int J Geriatr Psychiatry* 2015; 30: 891–899. DOI: 10.1002/gps.4232.
- Blackburn S, Humphrey L, Maguire L, et al. PCV90 a novel conceptual model of caregiver burden in chronic heart failure: a qualitative study. *Value Health* 2012; 15: A378.
- Bakas T, Pressler SJ, Johnson E, et al. Family caregiving in heart failure. *Nurs Res* 2006; 55: 180–188.
- Pressler SJ, Gradus-Pizlo I, Chubinski SD, et al. Family caregiver outcomes in heart failure. *Am J Crit Care* 2009; 18: 149–159.
- Cocchieri A, Riegel B, D'Agostino F, et al. Describing self-care in Italian adults with heart failure and identifying determinants of poor self-care. *Eur J Cardiovasc Nurs* 2015; 14: 126–136.
- Ware JE, Jr, Kosinski M and Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care* 1996; 34: 220–233.
- Charlson ME, Pompei P, Ales KL, et al. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis* 1987; 40: 373–383.
- Folstein MF, Folstein SE and McHugh PR. "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975; 12: 189–198.
- Mitchell AJ. A meta-analysis of the accuracy of the mini-mental state examination in the detection of dementia and mild cognitive impairment. *J Psychiatr Res* 2009; 43: 411–431.
- Muthén LK and Muthén BO. *1998–2010 Mplus user's guide*. Los Angeles: Muthén and Muthén, 2010.
- Bulmer MG. *Principles of Statistics*. Dover, NY: Courier Corporation, 2012.
- Hu L and Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Struct Equ Model a Multidiscipl J* 1999; 6: 1–55.
- Satorra A and Bentler PM. A scaled difference chi-square test statistic for moment structure analysis. *Psychometrika* 2001; 66: 507–514.
- Cohen J. *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Lawrence Earlbaum Associates, 1988.
- Nunnally JC and Bernstein IJ. *Teoría psicométrica*. Madrid: McGraw-Hill, 1995.
- Moieni M, Poorpooneh Z and Pahlavanzadeh S. Investigating the effect of family-focused nursing intervention on caregiver burden of the family members of the patients undergoing coronary bypass surgery in Isfahan Shahid Chamran

- Hospital during 2012. *Iran J Nurs Midwifery Res* 2014; 19: 187.
34. Han SH, and Kim B, Lee SA and the Korean QoL in Epilepsy Study Group. Contribution of the family environment to depression in Korean adults with epilepsy. *Seizure* 2015; 25: 26–31.
 35. Luttik ML, Jaarsma T, Veeger N, et al. Caregiver burden in partners of heart failure patients: limited influence of disease severity. *Eur J Heart Fail* 2007; 9: 695–701.
 36. Gauthier A, Vignola A, Calvo A, et al. A longitudinal study on quality of life and depression in ALS patient–caregiver couples. *Neurology* 2007; 68: 923–926.
 37. Marvardi M, Mattioli P, Spazzafumo L, et al.; Study Group on Brain Aging of the Italian Society of Gerontology and Geriatrics. The Caregiver Burden Inventory in evaluating the burden of caregivers of elderly demented patients: results from a multicenter study. *Aging Clin Exp Res* 2005; 17: 46–53.