

Heart Failure Caregiver Burden and Outcomes: A Systematic Review

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Abstract

Introduction/Objective: This review aimed to summarize articles describing caregiver burden and the relationship between health outcomes as well as describing interventions focusing on this population. **Methods:** The review used the PRISMA statement and Whitemore and Knafl guidelines. The search engines Scopus, PubMed, Ovid (PsycINFO), and CINAHL were searched for articles published in English. **Results:** This review included 30 studies that met the criteria. Physical, psychological, and social factors were associated with HF caregiver burden. HF caregiver interventions included health education, post-discharge home visits, phone calls, counseling, and support groups that demonstrated some potential to reduce the caregivers' burden. **Discussion:** Healthcare provider team should screen for caregiver burden and promote healthy behaviors, and strategies to improve quality of life. Further studies should include caregivers as care team members and embed social networking in the interventions for reducing HF caregiver burden. The caregivers' burden could influence the poor outcomes of care, including physical, psychological, societal, and functional dimensions. Future interventions should develop to alleviate HF caregiver burden.

Keywords

heart failure, caregivers, caregiver burden, chronic illness, systematic review

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Introduction

Heart failure (HF) is a condition in which the heart cannot supply enough blood to meet the metabolic demands of vital organs.^{1,2} In the United States, roughly 5.7 million people live with HF and 870 000 new cases are diagnosed annually.^{3,4} Patients with HF mostly suffer the burden of symptom exacerbation (eg, dyspnea, fatigue, weakness, depression, edema, and fluid overload), which often results in poor health outcomes including decreased quality of life (QOL), increased rehospitalization, and mortality.^{5,6} The limitations due to HF cause people to be more dependent on others and maintaining cardiac function can be helped with medication management, symptom recognition, and adhering to diet and exercise regimens from others.⁷

Caregivers play a significant role in patients with HF as they support symptom management, self-care, and decision-making, particularly in regard to the transition from the hospital to home.⁸ A lack of caregiver's support has been associated with increased rehospitalizations and mortality.⁹ While caregiver support has been shown to improve a patient's health, assuming the role of a

surrogate and advocate for patients with HF may cause a burden on the caregiver. Caregiver burden is defined as "The extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning."¹⁰ The outcome of caregiver burden is the multidimensional impact of caregiver burden caused by an imbalance between caregivers' demand and their ability to cope with demands, which is similar across caregivers of chronic conditions such as dementia, cancer, diabetes.^{11–14} For instance, caregivers' reported burdens have consisted of physical,

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psychological, and lifestyle issues such as insomnia and fatigue,¹⁵ depressive symptoms and anxiety,⁹ limited social life, and changed roles.¹⁵

Several literature reviews have examined caregiver burden in patients with HF; however, previous studies focused on caregivers' individual perceptions of physical and psychological burden.^{16,17} However, there was limited knowledge of caregivers' burden in social dimensions such as social interaction.¹⁸ There is a need to improve the understanding of the relationship between caregiver burden and HF caregiver outcomes because the effects of caregiving on the patient and caregiver can have extensive impacts on both individuals' physical, psychological, and financial factors.¹⁸ This review will determine what factors of HF caregiver's burden are associated with HF caregiver outcomes and which interventions are the most effective at improving the well-being of HF caregivers to help guide the development of a novel intervention to influence the design of a future clinical study. Therefore, the aims of the current review were to summarize articles describing caregiver burden and the association between health outcomes as well as describing interventions focusing on this population.

Methods

Study Design

This review was conducted using PRISMA guidelines¹⁹ and followed the Whitemore and Knafel²⁰ methods for a systematic review. The review consisted of 5 steps: (1) problem identification; (2) literature searching; (3) data review and evaluation; (4) data synthesis and analysis; and (5) data presentation.

Search Methods

The current review performed a search for relevant articles in 4 electronic databases: Scopus, PubMed, Ovid (PsycINFO), and CINAHL. The article search used the Medical Subject Headings (MeSH) to create the search keywords: (1) "caregiver*" OR "caregiving" OR "family caregiver*"; (2) "burden"; and (3) "heart failure" OR "HF" OR "HF Patients." Criteria for articles to be included in the review were: (1) the subjects were caregivers or family caregivers of patients with HF; (2) published in peer-reviewed journals in English; (3) original research articles; and (4) studies published between 2011 and 2020. Our search excluded: (1) focus on only patients with HF (not caregivers); (2) focus outside of HF; (3) outcomes not related to family caregivers or HF caregivers (eg, questionnaire development); (4) non-research articles (eg, review articles, editorials, letter to editor papers); (5) articles with non-empirical data; and (6) unpublished

masters and doctoral dissertations that did not go through the peer-review process.

Search Outcome

The search resulted in 1398 articles that were published between 2011 and 2020, which were identified in the initial databases (Figure 1). After duplicates were removed, 778 articles remained. Of these, 499 were excluded based on irrelevant studies; 249 full articles were excluded for other reasons, such as abstract screening, wrong outcomes, review articles, or master's theses and doctoral dissertations without publication and peer-review. Finally, 30 publications met the criteria and were included in this review.

Quality Appraisal

Two researchers (W.S. and T.T.) were independently screened and identified primary studies based on the inclusion criteria. Any disagreements between the appraisals were discussed and resolved among the authors (W.S., T.T., and P.D.). Then 30 studies were evaluated using the Mixed Methods Appraisal Tool (MMAT).²¹ The MMAT is beneficial to use as a quality appraisal for quantitative, qualitative, and mixed-method studies. No studies were excluded based on the quality appraisal using the MMAT.

Results

Study Characteristics

The review (Table 1) included 20 cross-sectional studies,^{4,15,22-39} 5 randomized controlled trials,⁴⁰⁻⁴⁴ 2 qualitative studies,^{5,45} 1 quasi-experimental study,⁴⁶ 1 mixed-methods study,⁴⁷ and 1 multicenter case-control study.⁴⁸ This systematic review included studies conducted in the USA (n=11), China (n=7), Italy (n=3), Turkey (n=2), Iran (n=2), Spain (n=1), Sweden (n=1), Australia (n=1), United Kingdom (n=1), and Taiwan (n=1). The number of participants ranged from 18 to 530.

Sample Characteristics of Caregivers

Over 60% of caregivers were older than 50 years (65.52%) and the majority of the participants were female and married. Most of the studies reported that caregivers had a primary school education or higher (82.35%). The majority of the participants had a monthly income between 237 and 3330 US dollars; 53.33% of the studies indicated that the HF caregivers were unemployed. Most of the studies reported that 52.25% received care from spousal caregivers; the majority of caregivers provided care for more than 1 year (77.78%). Most caregivers (91.67%) spent more than 4 h per day taking care of HF patients.

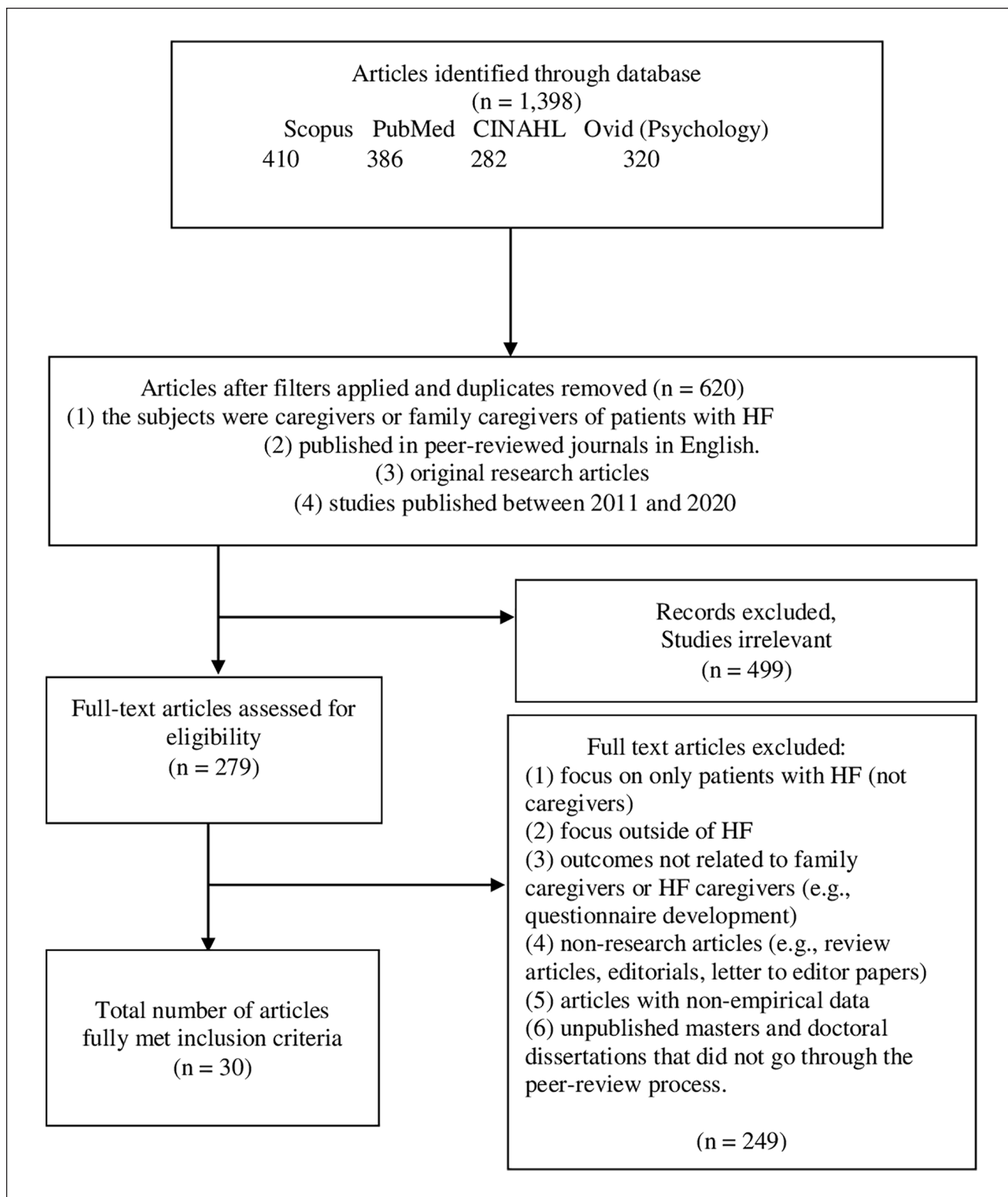


Figure 1. PRISMA flow chart for literature selection adopted from PRISMA Guidelines.¹⁹

Table 1. Characteristics of the Included Studies.

Author Country	Purpose	Study design	Sample	Demographics data (mean ± SD) (%)	Instruments	Findings
Al-Rawashdeh et al ¹² USA	To determine whether sleep disturbances of patients and their spousal caregivers predicted their own and their partners' QOL	CS	78	<ul style="list-style-type: none"> Age 59.53 ± 12.3 years Female (74.4) High school (50) Chronic disease (81.9) 	<ul style="list-style-type: none"> Beck depression inventory II (BDI-II) Minnesota living with heart failure PHQ-9 Restfulness of sleep QOL 	<ul style="list-style-type: none"> Patients' mental well-being was sensitive to their spouses' sleep disturbance. Patients' sleep disturbance was significantly correlated with spousal caregivers' mental well-being ($P < .01$). Sleep disturbance scores were negatively correlated with age in spouses ($r = -.220$, $P = .05$)
Bahrami et al ¹⁵ Iran	To explore the Iranian family caregivers' burden of caregiving for patients with HF	QS	18	<ul style="list-style-type: none"> Age 31-50 years (77.78) Female (77.8) Married (66.67) Patient's daughter (38.89) Primary school (50) Homemaker (61.11) Monthly family income <US\$200 (61.11) Providing care >6h/day (77.78) Age 65.9 ± 13.5 years 	<ul style="list-style-type: none"> In-depth understanding of the experiences of caregiving for HF patient and challenges in the caregiving situation 	<ul style="list-style-type: none"> Four major themes emerged from the analysis of the transcripts: Lack of care-related knowledge, physical exhaustion, psychosocial exhaustion, and lack of support. Family caregivers believed that they have little knowledge about the patients' disease, drugs, and how to perform caregiving roles. CGs experienced negative physical and psychosocial consequences of full-time and highly extended caregiving roles, such as musculoskeletal disorder, fatigue, and sleep disturbance, and a high level of anxiety, stress, and social isolation CGs believed that they receive little familial and organizational support on the emotional and financial dimensions of caregiving.
Bangertter et al ¹⁷ USA	To examine the predictors of self-gain and gain a holistic, in-depth understanding of the challenging and positive aspects of caring for a person with HF.	MS	108 (CS) 16 (QS)	<ul style="list-style-type: none"> Female (83.8) Some college (37) Married (63.9) Retired (48.8) Providing care <1 year (40.6) Spousal caregiver (32.5) 	<ul style="list-style-type: none"> Caregiver self-gain Caregiver mastery scale Caregiver preparedness scale Zarit Burden inventory (ZBI) Health literacy marital satisfaction Qualitative data: <ul style="list-style-type: none"> In-depth understanding of the challenging and positive aspects of caring for a person with HF 	<p>Quantitative results:</p> <ul style="list-style-type: none"> Spouse caregivers had 3.3 times higher odds of high self-gain compared with non-spouse caregivers (95% CI 1.15-9.48, $P = .023$). Caregivers with higher preparedness had 1.12 times greater odds of high self-gain (95% CI 1.03-1.21, $P = .003$). Caregivers with higher mastery had 1.16 times greater odds of high self-gain for caregiver age and sex (95% CI 1.00-1.35, $p = 0.045$). <p>Qualitative data: authors revealed three themes of self-gain including: (1) caregiving as a means to enhancing relationships, (2) success in negotiating care and healthy behaviors with patients with HF, (3) caregiving as a means of preparing caregivers for the future.</p>

(continued)

Table 1. (continued)

Author Country	Purpose	Study design	Sample	Demographics data (mean ± SD) (%)	Instruments	Findings
Bidwell et al ²³ USA	To quantify the influence of patient and caregiver characteristics on patient clinical event risk rehospitalization or death) in HF	CS	183	<ul style="list-style-type: none"> Age 57.2 ± 14.3 years Female (67.3) High school (51.2) Spousal caregiver (32.5) 	<ul style="list-style-type: none"> Caregiver burden inventory (CBI) Caregiver mental health status Caregiver contributions (CC-SCHF) 	<ul style="list-style-type: none"> Higher caregiver strain had a 0.94 times lower risk of clinical event (95% CI 0.91-0.97, $P < .001$). Higher mental health status of caregiver had 0.41 times lower risk of clinical event (95% CI 0.20-0.84, $P = .01$). Greater caregiver contributions to HF self-care maintenance had 0.99 times lower risk of clinical event (95% CI 0.97-0.99, $P = .04$). Greater caregiver contributions to patient self-care management had 1.01 times higher risk of clinical event (95% CI 1.00-1.03, $P = .04$). Family CGs in both groups had significantly lower burden, higher stress mastery, and better family function at 1-month follow-up compared to before discharge The total score of CG burden, stress mastery, and family function were significantly more improved for the family CGs in the experimental group than the comparison group at post-test.
Chiang et al ⁴⁶ Taiwan	To evaluate the effectiveness of nursing-led transitional care combining discharge plans and telehealth care on family CG burden, stress mastery and family function in family CGs of HF patients compared to those receiving traditional discharge planning only.	QE	30	<ul style="list-style-type: none"> Age >60 years (50) Female (76.7) Bachelor's degree (53.4) Married (86.7) Total household income ≤US\$1670-6250 (45) Spousal caregiver (50) Employed (60) 	<ul style="list-style-type: none"> The Chinese version of the caregiver burden inventory (CBI) The mastery of stress scale The Chinese version of the Feetham family functioning survey 	<ul style="list-style-type: none"> The reduction in caregiver-patient mutuality over the 12 months of the study amplified the association between patient functioning (ie, dyspnea, symptom burden, and disability) and caregiver burden. Caregiver burden at wave 1 correlated with patient disability at wave 2 $P < .05$
Cooney et al ²⁴ USA	To test the moderating role of changes in caregivers' social support and patient-caregiver relationship mutuality in the association between HF patient functioning and caregiver burden	CS	100	<ul style="list-style-type: none"> Age 57.22 ± 15.66 years Female (81) Married (60) Relationship with the patient: child (26) Age 31-50 years (77.78) Female (77.8) Married (66.67) Patient's daughter (38.89) Primary school (50) Homemaker (61.11) Monthly family income <US\$200 (61.11) Providing care >6h/day (77.78) 	<ul style="list-style-type: none"> ZBI The ENRICH social support scale Family caregiving inventory Index of socioeconomic disadvantage (SEIFA) index 	<ul style="list-style-type: none"> Two factors were significant predictors of unmet needs at the time of death which related to caregiver burden compared between caregivers for people with HF and caregivers for people with other diagnoses. First, the increase a year of age (OR 1.02; 95% CI 1.01-1.04; $P = .005$) and not having access to palliative care services (OR 0.39; 95% CI 0.24-0.64; $P = .000$).
Davidson et al ²⁵ Australia	To describe the profile of those providing care in the community and their needs.	CS	373	<ul style="list-style-type: none"> Relationship with the patient: child (26) Age 31-50 years (77.78) Female (77.8) Married (66.67) Patient's daughter (38.89) Primary school (50) Homemaker (61.11) Monthly family income <US\$200 (61.11) Providing care >6h/day (77.78) 	<ul style="list-style-type: none"> The ENRICH social support scale Family caregiving inventory Index of socioeconomic disadvantage (SEIFA) index 	<ul style="list-style-type: none"> Two factors were significant predictors of unmet needs at the time of death which related to caregiver burden compared between caregivers for people with HF and caregivers for people with other diagnoses. First, the increase a year of age (OR 1.02; 95% CI 1.01-1.04; $P = .005$) and not having access to palliative care services (OR 0.39; 95% CI 0.24-0.64; $P = .000$).

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Table 1. (continued)

Author Country	Purpose	Study design	Sample	Demographics data (mean \pm SD) (%)	Instruments	Findings
Dirikkan et al ⁵ Turkey	To evaluate the relationship between the caregiver burden and the psychosocial adjustment of caregivers to cardiac failure patients	CS	200	Completed primary school (37.5) Retired (24.0) Spousal caregiver (43)	ZBI The psychosocial adjustment to illness scale (PAIS-SR)	<ul style="list-style-type: none"> 94% of the caregivers remarked that after the diagnosis they experienced physical, psychological, social, occupational, or economic changes. 71.5% of caregivers faced difficulties with care provision, and 84% experienced the anxiety. Caregiver burden were statistically significant relationships with psychosocial adjustment to illness subscale including vocational environment ($r = .484$); domestic environment ($r = .416$); sexual relationship ($r = .182$); social environment relationships ($r = .182$); social environment ($r = .365$); psychological distress ($r = .493$). The only two predictors of higher developmental burden were patients taking fewer medications, and lower patient mental QOL ($F = 2.994, P < .001$). Higher levels of physical burden were significantly associated with caregiver older age, fewer medications taken by the patient and lower patient mental QOL ($F = 2.534, P < .001$). 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, and fewer medications taken by the patient and lower patient mental QOL ($F = 4.678, P < .001$). 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 ($F = 5.108, P < .001$). Higher levels of total burden were significantly associated with caregivers' older age, patient older age, higher patient education, and lower patient mental QOL ($F = 3.590, P < .001$). Caregiver contributions to self-care maintenance included practices related to: (1) monitoring medication adherence, (2) educating patients about HF symptom monitoring, (3) motivating patients to perform physical activity, (4) reinforcing dietary restrictions
Durante et al ⁴ Italy	To identify predictors of caregiver burden in heart failure; and to evaluate if caregiver contribution to heart failure self-care maintenance and management increases caregiver burden.	CS	505	Age 56.5 \pm 14.9 years High school (51.7) Married (72.5) Currently employed (56)	CBI CC-SCHF) Social support received by the caregiver	
Durante et al ⁵ Italy	To describe CG contributions to HF self-care maintenance (ie, treatment adherence and symptom monitoring) and management (ie, managing HF symptoms when they occur).	QE	40	Hours of caregiving per day (7.5 \pm 7.1) Relationship with the patient; child (49.3) Age 53.6 \pm 15.66 years	Elicit in-depth descriptions of how caregivers contributed to the self-care of the patients	

(continued)

Table 1. (continued)

Author Country	Purpose	Study design	Sample	Demographics data (mean \pm SD) (%)	Instruments	Findings
Ghasemi et al ²⁶ Iran	To investigate the relationship between caregivers burden and family functioning in family caregivers of older adults with HF	CS	140	<ul style="list-style-type: none"> Female (82.5) High school (52) Married (80) Employed (52.5) Age 38.74 \pm 12.77 years Female (61.9) 	<ul style="list-style-type: none"> ZBI Family assessment device 	<ul style="list-style-type: none"> Caregiver contributions to self-care management included practices related to: (1) symptom recognition, (2) treatment implementation Caregivers were able to recognize symptoms of HF exacerbation (eg. breathlessness) but lacked confidence regarding treatment implementation (eg. administering an extra diuretic) A direct correlation between mean score of care burden and total score of family functioning ($r = .345, P = .047$). A direct relationship between the score of burden of care and the dimensions of problem solving ($r = .206, P = .032$) and affective responsiveness ($r = .115, P = .045$). Caregivers of HF patients with chronic disease had higher burden scores than caregivers of HF without chronic disease ($t = 2.76, P = .007$) and older age ($r = .257, P = .007$).
Grant et al ²⁷ USA	To examine predictors that influence depressive symptoms in informal caregivers of IHF.	CS	530	<ul style="list-style-type: none"> Married (79) Bachelor's or higher degree (37.7) Employed (50) Monthly income US\$237.5 (44.2) Average care rate 5-8h/day (31.4) Affected by a chronic disease themselves (48) Relationship with the patient; child (49.29) No chronic disease (65) Age 41.39 \pm 10.38 years Married (92.3) Spousal caregiver (44.9) 	<ul style="list-style-type: none"> Social support Social problem-solving Family functioning CBI Depressive symptoms 	<ul style="list-style-type: none"> 57.7% of caregivers were experiencing depressive symptoms Caregivers who provided care for 3-4 years had 2.9 times higher odds of depression than caregivers who have provided care for 6 months to 1 year (95% CI = 1.02-8.60, $P < .05$). Rural caregivers had 2 times higher odds of depression than caregivers in urban areas (95% CI = 1.03-3.88, $P < .05$). Odds of depression decreased 1.28 times with each 1 unit increased in social support (95% CI = 1.21-1.37, $P < 0.05$). Odds of depression decreased 1.20 times with each 1 unit increased in social problem-solving (95% CI = 1.07-1.36, $P < .05$).

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Table 1. (continued)

Author Country	Purpose	Study design	Sample	Demographics data (mean ± SD) (%)	Instruments	Findings
Graven et al ²⁸ USA	To examine whether social support and problem-solving mediate relationships among caregiver demands and burden, self-care, and life changes in HF caregivers.	CS	530	<ul style="list-style-type: none"> Age 41.39 ± 10.38 years Female (49.1) Married (92.5) Bachelor's degree (54.9) Spousal caregiver (44.9) Length of time providing care: 1-2 years (40.9) Age 57.4 ± 15.8 years Female (80.8) High school (36) Retired (32) Married (82) Total household income ≤US\$40,000 (45) Spousal caregiver (60) Providing care > 8h/day (58) Age 41.9 ± 13.8 years Female (57.6) Married (75.8) Junior high school or above (71.2) Monthly family income <US\$500 (82.8) Spent >4 h/day providing care for the patients (84.1) Cared for the patients > 1 year (47.8) 	<ul style="list-style-type: none"> Dutch objective burden inventory Interpersonal support evaluation Social problem-solving inventory The center for epidemiological studies-depression scale Denyes self-care practice Bakas caregiving outcomes scale ZBI Mutuality scale of FCI Caregiver contributions self-care of heart failure index (CC-SCHF) Social support rating scale General self-efficacy scale 	<ul style="list-style-type: none"> Social support may be a relevant mediator of the relationship between caregiver burden and depression (indirect effect = 0.25), with increases in social support associated with decreased depression. Increased caregiver burden is associated with worse caregiver self-care, more depression, and negative perceptions of life changes due to caregiving. Clinicians should assess caregivers' available support and make appropriate referrals to community services and resources. Patients and caregiver's mutuality increased the confidence in-patient self-care ($P < .05$). Regression models indicated that caregivers with greater mutuality reported less perceived burden ($P < .01$). Perceived caregiver burden was also significantly and negatively associated with caregiver confidence in patient self-care ($b = -.76$, $SE = 0.25$, $\beta = -.29$, $P = .003$) The mean ZBI score was 37.1 (SD = 12.3) 86.7% of caregivers perceived a high level of burden. The caregiver burden was inversely associated with social support ($r = -.527$, $P < .01$) and self-efficacy ($r = -.509$, $P < .01$). The payment type for treatment ($b = -.431$, $P < .01$), monthly family income ($b = -.133$, $P < .01$), relationship to the patient ($b = .404$, $P < .01$), self-efficacy ($b = -.314$, $P < .01$), and social support ($b = -.137$, $P < .01$) were significantly related to the caregiver burden.
Hooker et al ²⁹ USA	To examines the associations among mutuality, patient self-care confidence and maintenance, caregiver confidence in and maintenance of patient care, and caregiver perceived burden.	CS	99			
Hu et al ³⁰ China	To investigate the status of caregiver burden and identified the factors related to caregiver burden among family caregivers of patients with HF	CS	226			

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Table 1. (continued)

Author Country	Purpose	Study design	Sample	Demographics data (mean ± SD) (%)	Instruments	Findings
Hu et al ⁴⁰ China	To examine the effects of the multidisciplinary supportive program on caregiver burden, QOL, and depression.	RCT	118	<ul style="list-style-type: none"> <40 years (58.5) Female (57.6) 	<ul style="list-style-type: none"> ZBI HRQOL SF-36 	<ul style="list-style-type: none"> Intervention consisted of: (1) health education; (2) peer support group; and (3) regular follow-up and consultations There were significant improvements in caregiver burden ($F=65.345, P<.001$), mental component of QOL ($F=22.482, P<.001$), and depression ($81.589, P<.001$) after post-test and 3 months after post-test in the experimental group. The physical component of QOL did not improve after the intervention. There was no significant improvement in caregivers' physical health at either 3 or 6 month following discharge.
Hu et al ³¹ China	To investigate the QOL and to identify the factors (characteristics of patients and caregivers, caregiver burden, self-efficacy, and social support) related to QOL among family caregivers of patients with HF	CS	251	<ul style="list-style-type: none"> Married (83.1). Senior high school (32.3) Employed (75.4) Monthly family income <US\$500 (82.2). Taken care of the patients for > 1 year (54.2) Spent >4 h/day on caregiving (84.7) <50 years (78.1) Female (58.2) Married (76.1) Junior high school education or higher (71.7) Monthly family income <US\$500 (82.9) Unemployed while taking care of patients (52.6) Spent >4 h/day providing care (75.3) Cared for the patients > 1 year (47.8%) 	<ul style="list-style-type: none"> Center for epidemiologic studies depression scale (CES-D) Social Support Rating Scale (SSRS) ZBI General self-efficacy scale (GSE) HRQOL SF-36. 	<ul style="list-style-type: none"> The median scores of physical and mental QOL were 70 and 60, respectively. NYHA classification ($b = -.675, P < .01$), caregiving h per day ($b = -1.929, P < .01$), number of readmissions ($b = -.344, P < .01$), caregiver burden ($b = -.013, P < .05$), social support ($b = -.039, P < .05$), and self-efficacy ($b = .217, P < .05$) were associated with PCS. NYHA classification ($b = -.700, P < .01$), caregiving hours per day ($b = -1.608, P < .01$), number of readmissions ($b = -.362, P < .01$), caregiver burden ($b = -.015, P < .05$), and social support ($b = .039, P < .05$) were significantly associated with MCS.

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Table 1. (continued)

Author Country	Purpose	Study design	Sample	Demographics data (mean \pm SD) (%)	Instruments	Findings
Hu et al ³² China	To investigate the status of depressive symptoms and to identify the factors that are associated with depressive symptoms in family care-givers of patients with HF	CS	134	<ul style="list-style-type: none"> Age 41.4 \pm 13.6 years Female (58.2) Married (83.6) Equivalent to junior high school or below (58.2) Monthly family income <US\$500 (82.8) Spousal caregivers accounted for 29.1% of the sample Unemployed (61.9) Spent >4h./day caregiving (84.3) Provided care to the patient > 1 year (53) 	<ul style="list-style-type: none"> ZBI Caregivers' Depressive symptoms (the CES-D scale) Coping ability (the 20-item SCSQ) 	<ul style="list-style-type: none"> 31% of the caregivers experienced depressive symptoms. The type of payment for treatment ($b = -.312$, $P < .01$), readmissions within the last 3 months ($b = .397$, $P < .01$), duration of caregiving ($b = -.213$, $P < .05$), caregiver burden ($b = .299$, $P < .05$), active coping ($b = -.235$, $P < .01$), and negative coping ($b = .245$, $P < .05$) were related to caregivers' depressive symptoms.
Hwang et al ³³ USA	To identify factors associated with the impact of caregiving	CS	76	<ul style="list-style-type: none"> Female (54) High school (33.5) Married (54) Total household income \leqUS\$1670-6250 (45) Spousal caregiver (56) Employed (41) Providing care > 7h/day (64) 	<ul style="list-style-type: none"> Dutch objective burden inventory The medical outcome study social support survey The control attitudes scale-revised The caregiver reaction assessment (CRA) The physical and mental component summary scores of the short form 36 health survey The patient health questionnaire (PHQ-8) 	<ul style="list-style-type: none"> Impact on finances was related to CGs' economic status, perceived control, and social support. Although caregivers' economic status ($\beta = -.43$; $P < .001$) explained a considerable amount of variance in the financial strain (16%), CGs' perceived control ($\beta = -.24$; $P = .01$) and the availability of social support ($\beta = -.26$; $P = .01$) Impact on schedule was associated with patient's NYHA class ($\beta = .27$; $P = .003$), amount of care tasks performed ($\beta = .43$; $P < .001$), CG's perceived social support ($\beta = -.37$; $P < .001$) CG's esteem was associated with CGs perceived social support and the patient's comorbid conditions ($\beta = 1.57$; $P = .01$), nonwhite caregivers felt more positive about their role as a CG than did white CGs ($\beta = .29$; $P = .006$). The more often a patient had visited the emergency department in the preceding 12 months, the less positive CGs felt about their role as a CG ($\beta = -.25$; $P = .02$).

(continued)

Table 1. (continued)

Author Country	Purpose	Study design	Sample	Demographics data (mean ± SD) (%)	Instruments	Findings
Jackson et al ³⁴ China	To describe the burden of caregiving on informal caregivers of patients with chronic HF	CS	458	<ul style="list-style-type: none"> Age 60.1 ± 10.6 years Female (60) Retired or pensioners (74) Full-time employment (16) Commonly spouses (77) or a son/daughter (20). Spent time taking care of the patients 24.5 ± 16.9h/week 	<ul style="list-style-type: none"> Caregiver self-completion (CSC) EuroQol (EQ-5D-3L) HF caregiver questionnaire (HF-CQ) 	<ul style="list-style-type: none"> Time spent and activity: caregivers were most often required to provide support included reminding patients to take their medication (70%), helping patients prepare meals (65%), and providing emotional support and encouragement (59%). Social life and employment: 63% of caregivers reported that caregiving had resulted in changes to some aspects of their lives such as reduction in their social activities (33%), followed by reductions in time for themselves (21%) and time for their other family members (12%). Caregivers' own health: 57% of the caregivers reported that caregiving had negatively affected their health in some way such as stress (23%), anxiety (23%), sleeping problems (14%), migraines/headaches (9%), and depression (7%). QOL: 79%-99% reported that HF had no impact on QOL Economic burden: 22% reported that a change in their job or a reduction in working hours had resulted in a decrease in income. (95% were not receiving financial support from the health care system or social services Depression was not significantly associated with caregiving strain (IRR 1.00, 95% CI 0.81: 1.23, P = .984). CPs who provided greater in-person support h per week had significantly greater MCSII scores (IRR = 1.03, 95% CI 1.01-1.06, P = .008). However, CPs' weekly telephone support hours were not significantly associated with their MCSII scores (IRR = 1.02, 95% CI 0.98-1.06, P = .341). Patient depression had no effect on caregiver burden (IRR = 1.00, P = .843).
Lee et al ³⁵ USA	To examine whether HF patients with depression received assistance from CPs living outside of their homes	CS	372	<ul style="list-style-type: none"> Age 47 ± 13.20 years Female (64.4) Married (69.9) Employed (63.1) At least some college education (73.1) CPs were most commonly the adult child of their support recipient (61.8) 	<ul style="list-style-type: none"> Care partners support Modified caregiver strain index (MCSI) 	<ul style="list-style-type: none"> Depression was not significantly associated with caregiving strain (IRR 1.00, 95% CI 0.81: 1.23, P = .984). CPs who provided greater in-person support h per week had significantly greater MCSII scores (IRR = 1.03, 95% CI 1.01-1.06, P = .008). However, CPs' weekly telephone support hours were not significantly associated with their MCSII scores (IRR = 1.02, 95% CI 0.98-1.06, P = .341). Patient depression had no effect on caregiver burden (IRR = 1.00, P = .843).

(continued)

Table 1. (continued)

Author Country	Purpose	Study design	Sample	Demographics data (mean \pm SD) (%)	Instruments	Findings
Leung et al ³⁶ China	To examine whether support from family and friends would associate with caregiver burden and patient's QOL to different extents, mediated via caregiving self-efficacy in patient-caregiver dyads with patients requiring palliative care using a structural equation modeling approach.	CS	225	<ul style="list-style-type: none"> • Age 57.1 \pm 14.6 years • Females (64.9) • Married (83.1) • Secondary education or above (68.4) • Relationship with the patient (child) 51.6 • Perceived health status 3.28 \pm 0.97 • Had a domestic helper (25.3) • Age 67.1 \pm 12.1 years 	<ul style="list-style-type: none"> • Caregiver burden Chinese version (C-CGI-18) • Chinese version of the multidimensional scale of perceived social support (C-MSPSS) 	<ul style="list-style-type: none"> • The final model provided a satisfactory fit (SRMR = 0.070, R-RMSEA = 0.055 and R-CFI = 0.926) with the data, as good as the hypothesized model did ($P = .326$). • Family support had a significant negative indirect effect on caregiver burden and a significant positive indirect effect on patient's QOL through caregiving self-efficacy, whereas friend support had a significant positive direct effect on caregiver burden but a minimal effect, if any, on a patient's QOL.
Liljeroos et al ⁴¹ Sweden	To describe the 24 month effects from a psycho-educational intervention in relation to caregiver burden and morbidity in partners to HF patients	RCT	155	<ul style="list-style-type: none"> • Females (75) • Retired (68) • Exercised > 3 h/week (50) 	<ul style="list-style-type: none"> • CBI • QOL (SF-36) • Beck depression inventory II (BDI-II) • Control attitude scale (CAS) 	<ul style="list-style-type: none"> • A younger partner, less comorbidity, higher levels of perceived control, better physical health and less symptoms of depression in patients, and better mental health in the partners were factors associated with absence of increased caregiver burden over time. • Intervention: consisted of: face-to-face counseling; educational booklets; and computer programs. • The intervention focused on help partners develop problem-solving skills to be able to recognize and alter factors contributing to emotional and psychological stress. • The mean total caregiver burden in both groups was found to be significantly increased compared to baseline (36 \pm 12 vs 38 \pm 14, $P = .05$). • There were no significant differences between the intervention and control group in any dimension of caregiver burden after 24 months • Higher burden was associated with poorer "quality of patient care" and worse CGs' psychological health ($R^2 = 0.37$, $F = 12.2$, $P = .01$) • Caregiver depression and looking after more breathless patients were associated with fewer positive caring experiences ($R^2 = 0.15$, $F = 4.4$, $P = .04$).
Malik et al ³⁷ UK	To compare experiences of caring for a breathless patient with lung cancer versus those with heart failure and to examine factors associated with CG burden and positive caring experiences	CS	51	<ul style="list-style-type: none"> • Age 65.8 \pm 12.7 years • Female (82) • Married (86.7) • Spousal caregiver (70) • Employed (82) 	<ul style="list-style-type: none"> • The modified Borg breathlessness scale • ZBI • Hospital anxiety and depression scale • Short form-36 (SF-36) 	<ul style="list-style-type: none"> • Higher burden was associated with poorer "quality of patient care" and worse CGs' psychological health ($R^2 = 0.37$, $F = 12.2$, $P = .01$) • Caregiver depression and looking after more breathless patients were associated with fewer positive caring experiences ($R^2 = 0.15$, $F = 4.4$, $P = .04$).

(continued)

Table 1. (continued)

Author Country	Purpose	Study design	Sample	Demographics data (mean ± SD) (%)	Instruments	Findings
Metin and Helvacı ³⁸ Turkey	To examine the correlation between quality of life, depression, anxiety, stress, and spiritual well-being in patients with heart failure and their family caregivers	CS	60	<ul style="list-style-type: none"> Age 52.0 ± 13.5 years Females (25.0) Primary school (80) Married (100.0) Income levels (moderate) (85.0) Employed (81.7) Relationship (Spouse) (53.3) Duration of caregiving ≤5 years (75) Daily caregiving time >8h. (40.0) Age 78.3 ± 16.8 years Females (56.1) 	<ul style="list-style-type: none"> FCI Depression anxiety stress scale (DASS) FACIT-Sp WHOQOL-BREF 	<ul style="list-style-type: none"> QOL was negatively associated with depression ($r = -.808, P < .05$). QOL was positively correlated with spiritual well-being ($r = .548, P < .05$). Depression was negatively associated with spiritual well-being ($r = -.640, P < .05$). QOL was associated with health status and spiritual well-being respectively ($r = .434, r = .575, P < .05$). Depression was negatively correlated with health status and spiritual well-being respectively ($r = -.390, r = -.513, P < .05$).
Ng and Wong ⁴² China	To examine the effect of a home-based palliative heart failure (HPHF) program on QOL, symptoms burden, functional status, patient satisfaction, and caregiver burden among patients with ESHF	RCT	84	<ul style="list-style-type: none"> No schooling (44.2) Retired (97.7) Perceived economic status (just enough) (58.1) Age 61.4 ± 15.7 years Female (85) High school (60) Married (70) Employed (60) 	<ul style="list-style-type: none"> ZBI QOL 	<ul style="list-style-type: none"> The structure of the HPHF program included post discharge home visits and telephone calls. A statistically significant between-group effect was found, with the HPHF group having significantly higher QOL total score than the control group ($P = .016$) and there was significant group × time interaction effect ($P = .032$). QOL: there were significant improvements over time in the physical ($P = .011$), psychological ($P = .04$), and existential ($P = .027$) domains between the intervention and control groups. Caregiver burden: a significant difference was noted between the intervention and control groups at 4 weeks in the aspects of dyspnea ($P = .02$), emotional function ($P = .014$), mastery ($P = .019$), and the total score ($P = .01$). Caregiver burden: there was no between-group effect noted at 12 weeks for any group. At 6 months, compared to standard care, the intervention group had significantly fewer rehospitalizations ($P = .03$), higher caregiver confidence ($P = .003$) and higher social support ($P = .01$) were significantly higher, and lower caregiver depression ($P = .01$) than control. While preparedness on HF home care and caregiver burden were not statistically significant differences.
Piamjariyakul et al ⁴³ USA	To improve family caregiver outcomes	RCT	20	<ul style="list-style-type: none"> Perceived economic status (just enough) (58.1) Age 61.4 ± 15.7 years Female (85) High school (60) Married (70) Employed (60) 	<ul style="list-style-type: none"> Preparedness scale Perceived social support CBI The center for epidemiologic studies depression scale (CES-D) Helpfulness rating 	<ul style="list-style-type: none"> Perceived economic status (just enough) (58.1) Age 61.4 ± 15.7 years Female (85) High school (60) Married (70) Employed (60)

(continued)

Table 1. (continued)

Author Country	Purpose	Study design	Sample	Demographics data (mean ± SD) (%)	Instruments	Findings
Timonet-Andreu et al ⁴⁶ Spain	To analyze the relationship between HF patients' use of hospital services and the HRQOL of their family caregivers.	MCS	530	<ul style="list-style-type: none"> • Age 56.3 ± 14.3 years • Female (77.4) • Primary school (62.6) • Relationship with patient; child (50.9) 	<ul style="list-style-type: none"> • Caregiver Strain Index (CSI) • PHQ-9 • HRQOL 	<ul style="list-style-type: none"> • Patients' use of hospital services was associated with worsened QOL for family caregivers, with an overall OR of 1.48 (95% CI: 1.23-1.79, $P < .001$). • A positive correlation was found between patients' perceptions of their physical health and the perceived mental health of caregivers ($r = .127$, $P = .004$) and between the perceived mental health of both ($r = .291$; $P < .001$). • There is also evidence of actor effects of patient and caregiver mutuality on patient self-care confidence ($B = 4.144$, $P = .039$) and on caregiver self-care confidence ($B = 9.209$, $P < .001$). • The only partner effect that we found was the effect of patient mutuality total score on caregiver contribution to self-care management ($B = 5.756$, $P = .014$). • Total score of patient mutuality also had a partner effect on caregiver self-care management (ie, responses to symptoms of HF exacerbation).
Vellone et al ⁴⁴ Italy	To evaluate the influence of mutuality as a whole and of its dimensions on self-care maintenance, management, and confidence in HF patient caregiver dyads	RCT	366	<ul style="list-style-type: none"> • Age 58.61 ± 15.66 years • Female (73.3) • Married (69.6) • Unemployed or retired (53.44) • High school (37.5) • Relationship with patient; child (43.5) 	<ul style="list-style-type: none"> • Mutuality scale • Caregiver contribution to self-care of heart failure index 	<ul style="list-style-type: none"> • JAREL spiritual well-being scale (SWBS) • Carers' assessments of managing index (CAMI) • Care continuity scale • Caregiver reaction assessment (CRA) • Caregiver's esteem subscale • Lack of family support subscale • Index of ADL
Yeh and Bull ³⁹ USA	To examine the influences of older peoples' activities of daily living dependency, family CGs' spiritual well-being, quality of relationship, family support, coping, and care continuity on the burden of family CGs of hospitalized older people with CHF using the Resiliency Model of Family Stress, Adjustment, and Adaptation.	CS	50	<ul style="list-style-type: none"> • Age 60.33 ± 14.42 years • Female (70) • High school (58) • Monthly income > US\$ 2000 (48) • Married (86.7) • Spousal caregiver (40) • Employed (82) • Length of time in the caregiver role > 1 year (68) • Providing care > 6 months (80) 	<ul style="list-style-type: none"> • JAREL spiritual well-being scale (SWBS) • Carers' assessments of managing index (CAMI) • Care continuity scale • Caregiver reaction assessment (CRA) • Caregiver's esteem subscale • Lack of family support subscale • Index of ADL 	<ul style="list-style-type: none"> • Patients' ADL dependence, spiritual well-being coping, quality of relationships, lack of family support, and care continuity accounted for 66% of the variance in family CG burden.

Abbreviations: CBI, caregiver burden inventory; CG, caregiver; CPs, caregiver partners; CS, cross-sectional study; FACIT-Sp, functional assessment of chronic illness therapy-spiritual well-being scale; FCI, family caregiving inventory; HF, heart failure; HRQOL, health-related quality of life; MCS, multicenter case-control study; MS, mixed-methods study; PHQ-9, the patient health questionnaire 9-it; QE, quasi-experimental study; QOL, quality of life scale; QS, qualitative study; RCT, randomized controlled trial study; WHOQOL-BREF, the world health organization quality of life short form; ZBI, Zarit Burden Inventory.

Caregivers Burden Measurement

The instruments included the direct measurement of caregiver burden and the consequence of caregiver burden measurement. First, caregiver burden was measured by the Zarit Burden Inventory (ZBI) and the Caregiver Burden Inventory (CBI). Second, the consequence of caregiver burden was measured by physical, psychological, and societal health outcomes.

Eleven researcher teams used the ZBI for measuring caregiver strain and stress. The ZBI is a 22-item self-reporting survey consisting of a 5-point Likert-scale, with responses of 0=never, 1=rarely, 2=sometimes, 3=most often, and 4=always. The total scores ranged between 0 and 88, with higher scores representing a higher burden of care. Scores of less than 30 were considered mild, scores that ranged between 30 and 60 represented moderate, and scores higher than 60 represented severe burden of care. In addition, researchers also used the CBI in some studies ($n=7$) to measure the individual's levels of strain of caregiver and caregiver burden. This tool is a 24-question self-report questionnaire with 5-point Likert-scale responses. The total scores ranged from 0 to 100, with responses from 0=minimum burden to 4=maximum burden, a higher scale and dimension scores represented a higher burden of care.

Several researchers (Table 1) indicated that caregiver burden in HF influenced physical, psychological, social and lifestyle outcomes as a consequence of providing care and support. Physical outcome was measured by the Caregiver Strain Index.⁴⁸ Psychological outcomes consisted of depression and psychological health. Depression was measured by the Center for Epidemiological Studies-Depression Scale,^{28,30-32,40} and the Patient Health Questionnaire (PHQ-9).^{22,27,48} Psychological health was evaluated by Caregiver Mental Health Status,²³ Depression Anxiety Stress Scale (DASS),³⁸ and the Psychosocial Adjustment to Illness Scale (PAIS-SR).¹⁵

Societal outcomes were measured by social support.^{5,27,31,36} Functional outcomes were measured by the following factors: (1) self-care,^{5,23,28} (2) QOL: Minnesota Living with Heart Failure questionnaire,²² the Health-Related QOL questionnaire (HRQOL),⁴⁸ (3) self-efficacy,^{30,31} (4) self-gain,⁴⁷ (5) the 36-Item Short Form Survey (SF-36),^{33,37} (6) activities of daily living,³⁹ and (7) clinical events.²³

Caregiver Burden

The majority (86.7%) of caregivers of patients with HF (Table 1) perceived a high level of burden.³⁰ Comorbidity and aging were associated with the severity of caregivers' burden. For instance, caregivers of HF patients with chronic disease had higher burden scores than caregivers of HF without chronic disease ($t=2.76, P=.007$). Age was positively related ($r=.257, P=.007$) with caregiver burden.²⁶ Caregivers' burdens were

significantly related to caregivers' older age, patient's older age, higher patient education, and lower patient mental QOL ($F=3.590, P<.001$).⁴ Moreover, the unmet needs at the time of death, such as physical support and community support, were related to the caregiver burden. For example, patients with HF had 0.39 times lower opportunity to access palliative care compared with patients with other chronic conditions (95% CI 0.24-0.64; $P<.01$).²⁵

Almost all caregivers (94%) remarked that after the HF diagnosis, HF caregivers experienced physical, psychological, social, and economic burden.¹⁵ Physical burden was incurred when providing support for example reminding patients to take their medications (70%), and helping patients prepare meals (65%), etc.³⁴ Higher levels of physical burden were significantly related to caregiver older age, fewer medications taken by the patient, and lower patient mental QOL ($F=2.534, P<.001$).⁵ Psychological burden was identified as one of caregiving's major problematic aspects, more than half (57%) of HF caregivers asserted that caregiving had negatively affected their health due to stress, anxiety, sleeping problems, and depression.³⁴ Moreover, emotional burdens were related to hours of caregiving during the day, patient age, patient education, medications taken, and QOL ($F=5.108, P<.001$).⁵

Social burden also had a large impact on caregivers: most caregivers (63%) noted that caregiving had resulted in changes in some aspects of their lives such as reductions in their social activities, reductions in time for themselves, and reduced time for their other family members.³⁴ Social burdens were significantly related to the caregivers' age, hours of caregiving per day, caregivers' social support, caregivers' QOL, patients' education, medications taken, and patients' mental QOL.⁵ On the other hand, one-fourth of caregivers asserted that economic burden, such as a change in their job or a reduction in working hours had resulted in a reduce in income. Almost all caregivers (95%) were not receiving financial support from the healthcare system or social services.³⁴ Moreover, the following were significantly associated with the caregiver burden: the payment type for treatment ($b=-0.431, P<.01$), monthly family income ($b=-0.133, P<.01$), relationship to the patient ($b=0.404, P<.01$), self-efficacy ($b=-0.314, P<.01$), and social support ($b=-0.137, P<.01$).³⁰

The Relationship Between Caregivers' Burden and Their Health Outcomes

Clinical outcomes (rehospitalization or death), higher caregiver strain had a 0.94 times lower risk of clinical event compared to lower caregiver strain (95% CI 0.91-0.97, $P<.001$).²³ Then, higher mental health status of caregivers had a 0.41 times lower risk of a clinical event compared with lower health status (95% CI 0.20-0.84, $P=.01$). Next, greater caregiver contributions to HF self-care maintenance

had a 0.99 times lower risk of clinical event (95% CI 0.97-0.99, $P=.04$). However, greater caregiver contributions to patient self-care management had 1.01 times higher risk of clinical event (95% CI 1.00-1.03, $P=.04$).²³ As regards societal outcomes, caregiver burden impacted finance. For instance, caregiver economic status was a significant predictor of financial strain, caregivers perceived control and social support.³³

Interventions for Heart Failure Caregivers

Five randomized control trials and 1 quasi-experimental study were identified to reduce caregiver burden. Two experimental studies reported that a brochure for caregivers, education (eg, lectures, skills training), peer support group, regular follow-up and consultations, and computer programs significantly improved caregivers' burden, mental health, and depression in the experimental group.^{40,41} Ng and Wong⁴² found that a home-based palliative HF program (ie, home visits and telephone calls) was statistically significant between groups and at 12 weeks had higher satisfaction ($P=.001$) and lower caregiver burden ($P=.024$) than the control group.

Then, Vellone et al⁴⁴ indicated the effects of patient and caregiver mutuality on patient self-care confidence ($B=4.144$, $P=.039$) and on caregiver self-care confidence ($B=9.209$, $P<.001$) and the effect of patient mutuality total score on caregiver contributions to self-care management ($B=5.756$, $P=.014$). Their study suggests that the intervention could improve mutuality in HF caregivers and may influence patient self-care and caregiver contribution to self-care.⁴⁴ One quasi-experimental design used a telehealth follow-up intervention to implement health education and counseling. The telehealth also indicated that the caregiver burden score was significantly lower in the intervention group than in the control group by the mean score of 23.27 and 32.37, respectively.⁴⁶ However, the telephone was not statistically different at the 6-month follow-up.⁴³ Moreover, there was no significant improvement in caregivers' physical health at either 3 or 6 months following discharge.⁴⁰

Caregiver Perceptions

Two qualitative studies reported that caregiver contributions to self-care maintenance included practices associated with the following: (1) monitoring medication adherence, (2) educating patients about HF symptom monitoring, (3) motivating patients to perform physical activities, and (4) reinforcing dietary restrictions. Researchers also found that caregiver contributions to self-care management included practices associated with (1) symptom recognition and (2) treatment implementation.⁵ In addition, caregivers were able to recognize the symptoms of HF exacerbation (eg, breathlessness)

but lacked confidence regarding the implementation of treatment (eg, administering an extra diuretic). Therefore, caregiving could enhance relationships, lead to success in negotiating care and healthy behaviors with patients with HF, and prepare caregivers for the future.⁴⁷ While one study presented the factors related to caregiver burden including lack of care-related knowledge, physical exhaustion, psychosocial exhaustion, and lack of support.⁴⁵

Discussion

Caregivers benefit patients with HF because they provide care, health support, and improve the patients' QOL.^{24,49} The current review highlights the importance of acting as a caregiver for HF patients that had a strong effect on physical, psychological, and social factors of the caregivers' own lives. This review was concurred with the study of Clements et al⁵⁰ that most caregivers were female and spouses of patients with HF. Several studies found that caregivers experienced physical, psychological, social, occupational, or economic changes due to providing care.^{15,30,48,51} Similarly, 1 study reported that spousal caregiver burden was significantly correlated with relationship dissatisfaction, worse patient depression and decreased patient-perceived social support.⁵²

The findings of several studies showed that HF caregivers spent more than 8 h per day providing care for HF patients.^{31,32} Some studies reported that caregivers spent 5 to 8 h or more each day when taking care of HF patients.^{26,38} Caregivers who cared for patients with HF many hours a day had a higher risk of emotional stress, and some caregivers were not psychologically prepared for the caregiver role. This review found that HF caregivers spent more time providing care, which affected the quality of care and incurred negative caregiver outcomes such as poor psychological well-being, poorer health, burden, and lower QOL.¹⁷

Caregivers of patients with chronic illness shoulder a larger responsibility, and this larger caregiver burden altered their physical, psychological, social, and financial functioning.⁵³ Healthcare providers mostly focus on patients with HF by alleviating HF symptoms and providing a continuing care plan for patients—without assessing the caregivers' burden. The assessment of burden should include both caregiver situation and burden assessment. First, healthcare providers have to collect the information of caregiver situations consisting of needs, strengths, challenges, and resources for the family caregiver.^{54,55} Second, healthcare providers also need to perform a comprehensive assessment of caregivers' burden including physical, psychological, social, and economic burden.⁵⁶

The complexity of HF often overwhelms the caregivers who prioritize the care given to the patients. Patients use of hospital services had 1.48 times higher odds of worsened QOL for family caregivers compared with patients who did

not require hospital services (95% CI: 1.23-1.79, $P < .001$). Then, caregivers' knowledge and experience were the important factors in order to provide effective care because they contributed to caregiver self-gain, which is the strength and confidence to provide care. After that, caregiver contributions to HF self-care maintenance had a 0.99 times lower risk of rehospitalization or death (95% CI 0.97-0.99, $P = .04$). The contributions in self-care of caregivers represented the relationship of caregivers and patients so the engagement between caregivers and patients could prevent clinically adverse events in patients.¹⁶

Several research teams have developed interventions of health education, post-discharge home visits, phone calls, counseling, and support groups to reduce the caregivers' burden.^{40,42} All the interventions were effective in reducing the burden of HF care in caregivers. However, the intervention was effective only for a short period of time. The long-term follow-up found there were no significant differences in caregivers' burden between the intervention and control group at 24 months after intervention. The interventions were not effective in the long-term follow-up because HF is a chronic condition and patients usually suffer from the exacerbation of HF symptoms several times after HF diagnosis—particularly pain, dyspnea, depression, gastrointestinal distress, and fatigue.⁵⁷ The longer caregiving time increased the risk of HF burden in caregivers. Previous interventions tried to solve caregivers' burdens by providing health education, emotional support, and support groups. Another important missing component would be social support in order to promote the support from social service and healthcare systems. Caregiver burden was negatively associated with social support, for example, increasing social support was associated with decreasing depression.^{27,28}

Limitations

The current review had 6 limitations. First, the sample size in each study varied widely, so the findings of comparison between variables might be imprecise. Second, they did not report some variables in the results or did not clearly include details in the table such as outcomes of care, relationships with the patients, lengths of time providing care; it may develop a biased interpretation of the findings which could impact study validity. Third, the instrument of HF caregiver burden in each tool was heterogeneous and based mostly on self-reporting surveys, which are not the most reliable sources of data. Fourth, there was a low diversity of the HF caregiver demographic characteristics, with all of study participants being female, HF caregivers with spouses, and relationships to patients. As such, the results from the studies were not generalizable to males, other relationships to the caregiver, and other status. Fifth, our study did not use

the theory to identify the outcomes. Future research needs to apply the Social Determinant of Health framework with a stronger rationale for the significance of the topic, in particular, it would be stronger if it provided specific information about the domains of caregiver burden and how it is important to understand interpersonal relationships and social interaction components of caregiver burden. Finally, the current review included only English language publications, which might have missed out on pertinent studies performed in other languages and other areas. Future research should be included in all types of studies in other languages; it might change the results that could be improved HF caregivers.

Conclusion

The current findings confirm that HF caregiver burden is significantly related to physical, psychological, and social factors. The current review also confirms that intervention studies can improve mutuality in HF caregivers and influence patient self-care and caregiver contributions to self-care. Despite the early state of the evidence in this field, it seems that effective management of HF caregivers will play a significant role in the future in reducing of caregiver burden for the patients with HF and their caregivers.

Author's Contribution

Two reviewers (W.S., T.T.) screened the titles and abstracts of each article. Disagreements were resolved by discussion with the third reviewer (P.D.). The data were extracted by W.S. and cross-checked by T.T. including the discussion between both authors to reach a consensus where differences arose. The synthesis was carried out by W.S. and reviewed by T.T. All the authors contributed to the interpretation of the final findings and approved the final version of the article.

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