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# Tools to measure quality of life and carer burden in informal carers of heart failure patients: A narrative review

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## Abstract

**Background:** Heart failure is a complex cardiac syndrome prevalent in an older population. Caring for heart failure patients through the disease trajectory presents physical and emotional challenges for informal carers. Carers have to deal with clinically unstable patients, the responsibility of managing and titrating medication according to symptoms and frequent admissions to acute care. These challenges compound the demands on caregivers' physical and psychosocial well-being. Alongside the negative impact of being a carer, positive aspects have also been demonstrated; carers describe feelings of shared responsibility of caring with professional carers and the reward of supporting a loved one, which creates a new role in their relationship.

**Aim:** This review explores the dimensions that impact caregiver burden and quality of life in carers of patients with heart failure and highlights both the negative and positive aspects of being an informal carer for heart failure patients.

**Design:** This review followed the processes recommended for a narrative review. Studies identified were selected systematically following the PRISMA guidelines.

**Data sources:** Searches were conducted using the Medical Subject Headings (MeSH) and keywords of the following search engines: MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, Applied Social Sciences Index and Abstracts (ASSIA), PsycINFO and Cochrane for literature published until January 2012.

**Results:** Quality assessment of the studies was conducted using quality indicators, and the studies included in this review were categorised as fair or good according to the criteria. Of the 1008 studies initially identified, 16 studies met the inclusion criteria. A thematic synthesis was undertaken, and the following themes were identified

- Perceived carer control;
- Mental and emotional well-being;
- Types and impact of caregiving tasks;
- Impact of patients' physical condition;
- Impact of age/gender/demographic factors;
- Positive aspects of caregiving.

**Conclusions:** This review highlights evidence that informal carers supporting patients with heart failure face many challenges impacting their physical and mental well-being. The studies described provide an insight into the individual dimensions that make a carer particularly vulnerable, namely, younger carers, female carers and carers with existing physical and emotional health issues. Additionally, there are external influences that increase risk of burden, including New York Heart Association Score status of the patient, if the patient has had recurrent emergency admissions or has recently been discharged home and the level of social support available to the carer. A further finding from conducting this review is that there are still limited measures of the positive aspects of caregiving.

## Keywords

Heart failure, informal carers, caregivers, carer burden, quality of life, measurement tools

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## Introduction

Heart failure is a complex cardiac syndrome prevalent in an older population. It is commonly associated with chronic co-morbidities, frequent and prolonged hospital admissions and an unpredictable disease trajectory to end of life.<sup>1-3</sup> Heart failure has a poor prognosis, and while survival rates have improved over the last decade, the median survival is still around 3 years from diagnosis.<sup>4</sup> Caring for heart failure patients through the disease trajectory presents physical and emotional challenges for informal carers.<sup>1</sup>

While caregivers of heart failure patients report similar issues to those caring for patients with other chronic conditions, heart failure presents the additional challenge of coping with frequent decompensations alongside the responsibility of dispensing and titrating medication according to symptoms, emergency admissions to acute care and difficulties associated with prognostication. These challenges compound the demands on caregivers' physical and psychosocial well-being.<sup>5</sup>

In several studies, carers have reported that the physical requirements of the role impact their own health, with some carers being described as at the point of physical exhaustion.<sup>6-8</sup> With a high prevalence of heart failure in people aged above 75 years, a consequence is that many of the carers are elderly themselves and therefore have their own health problems.<sup>9</sup> Evidence suggests that carers may neglect their own health-care needs as a result of focusing on meeting the needs of the patient. In a study by Pressler et al.,<sup>8</sup> older carers reported frequently forgetting to take medications leading to poor control of their own conditions.

Unsurprisingly, these physical aspects of caring affect psychosocial well-being. Feelings of responsibility alongside a sense of being out of control can be linked to levels of anxiety and depression.<sup>7,10,11</sup> The sense of helplessness when patients are symptomatic, particularly when they are struggling to breathe, causes great distress.<sup>5,12</sup> Other predictors of carer burden include carer age, carers' existing health problems, lack of respite care and excessive hours of caring.<sup>7</sup> Burdened, depressed caregivers are more likely to develop health problems.<sup>13</sup>

Being a carer can result in reduced social activities or a change in working patterns, which can impact the individual's mental well-being.<sup>9</sup> By having reduced contact with friends, family or work colleagues, the burden of caring can be increased; carers describe feeling isolated and having no one to share their concerns with.<sup>12</sup> Concerns are often expressed about leaving the patient alone to pursue their own social interests.<sup>7,14</sup>

Conversely, positive aspects of being a carer have also been illustrated. In a narrative review conducted by Stolz et al.,<sup>15</sup> carers described feeling encircled by support and having a sense that a network could help them when they needed it. This network could be a family member or health professional and offered great reassurance. Carers also described having a feeling of shared responsibility of

caring when they experienced togetherness in caring. The manner in which health professionals involved in patient care responded when carers asked for help or if, when visiting the patient, they asked how the carer was coping was both viewed as a positive means of making the carer feel a priority. Being seen and being heard allowed carers to feel that their needs were recognised as important, and this was enhanced when health professionals acknowledged the struggles that carers faced.

Harkness and Tranmer<sup>16</sup> conducted a review of instruments to measure the caregiving experience in caregivers of heart failure patients. The review concluded that while measurement of the caregiving experience had been conducted in several studies, there were no instruments that specifically addressed the particular and complex issues of the heart failure carer population. The authors highlighted a need for further research to consider measurement tools that addressed not only the negative aspects of caring in heart failure but also effectively capture the positive aspects of being a carer and give consideration to the particular dimensions that can contribute to the positive experience. This review aims to address some of the limitations highlighted in the Harkness review and provide added value by considering key themes incorporated in tools developed since the Harkness and Tranmer<sup>16</sup> article, which are specifically aimed at informal carers of heart failure patients.

## Aim

This review aimed to explore dimensions that impact caregiver burden and quality of life (QoL) in carers of heart failure patients.

## Methods

This review followed the processes recommended for a narrative review as outlined by Hawker et al.<sup>17</sup> This review aimed to synthesise evidence from research studies and literature reviews undertaken to explore means of measuring QoL and/or carer burden in informal carers of heart failure patients. The development of the narrative review followed the following stages:

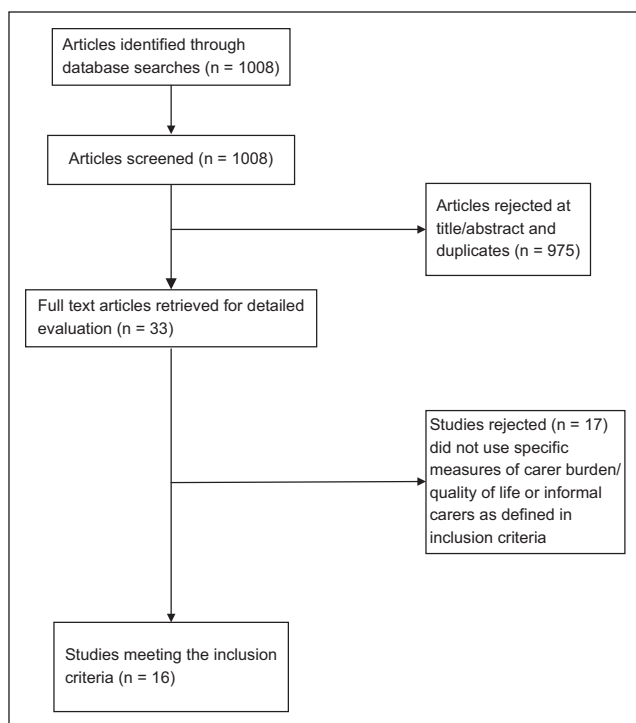
- Defined search strategy;
- Inclusion criteria;
- Critical assessment of relevance;
- Data extraction and critical appraisal;
- Synthesis of data using a descriptive thematic model.

Throughout this review, the following key terms will be defined as follows:

Caregiver burden is described as the physical, emotional and financial challenges of providing care.<sup>18</sup> QoL – burden measures are widely used as a predictor of emotional distress and QoL outcomes in informal carers.<sup>11</sup>

**Table 1.** Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Written in the English language	Written in languages other than English
Articles focusing on informal carers of heart failure patients	Articles focusing on carers of patients with left ventricular assisted devices or pre/post heart transplant due to differing treatment aims, that is, prolong life rather than palliate.
Studies that measure caregiver burden or quality of life	Editorials, commentaries and letters
Empirical studies and literature reviews	Articles focusing on children or young carers
International sources	Articles focusing on paid carers or formal carers
Adult carers (above 18 years)	
Informal/unpaid carers	

**Figure 1.** Flow chart indicating study selection criteria.

Informal caregiver is an unpaid person providing physical, practical and/or emotional care and support to a relative or friend.<sup>19</sup>

## Search strategy

To retrieve a comprehensive list of studies to meet the specified inclusion criteria the Medical Subject Headings (MeSH) were identified for each of the search terms and were as follows:

### Heart failure

Heart failure, myocardial infarction, chronic heart failure, congestive cardiac failure, heart failure righted sided, cardiac failure, heart decompensation, right sided heart failure, left sided heart failure, heart failure congestive.

### Caregiver

Caregiver, care givers, caregivers, caregivers spouse, caregiver family, caregiver, family caregivers, spouse caregivers, care giver, spouse caregiver, caregiver spouse, carer, caregivers, family carers.

### QoL

Quality of life, life qualities, life quality.

Searches of the following databases were conducted using the MeSH headings and keywords:

MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, Applied Social Sciences Index and Abstracts (ASSIA), PsycINFO and Cochrane for literature published until January 2012. The inclusion and exclusion criteria are listed in Table 1.

## Assessment of relevance

Studies identified from the search were selected systematically in the following manner: consideration to the title, abstract and full text. This process is illustrated by the PRISMA flowchart in Figure 1. Studies were included or excluded at each stage of the process, and each study was assessed independently by K.W. and either S.B. or C.G., consensus was reached through discussion in cases where there was disagreement.

## Data extraction, appraisal and synthesis

The initial search of the identified databases using the listed search terms resulted in 1008 studies. A sift of the titles and abstracts resulted in 975 studies being rejected as they did not meet with the specified inclusion criteria. Following extraction of duplicated articles, a total of 33 full-text articles were retrieved and screened for eligibility of which 16 studies met the inclusion criteria (see Table 2). The studies combined a range of research methodologies, and it was therefore fitting to conduct the synthesis utilising a thematic analysis.<sup>17</sup> This approach allowed for systematic data

**Table 2.** Details of studies that met the inclusion criteria.

Author	Aims	Participants/sample	Study setting	Method/intervention	Description of tool used to measure caregiver burden/QoL	Relevant findings
Agren et al. <sup>20</sup>	To describe the levels of carer burden and identify independent predictors of caregiver burden in partners of patients with HF.	135 dyads participated in the study. Both patients and carers completed the questionnaire.	Acute hospital and outpatient HF clinic.	Descriptive correlational cross-sectional study over a 3-year period. A questionnaire packet was sent to the partner and patient who had agreed to participate.	Caregiver burden scale, SF-36, Beck Depression Inventory, Control Attitude Scale, Knowledge Questionnaire (RAND) and Charlson Co-Morbidity Index.	68% of carers reported low levels of carer burden, 30% reported medium and 2% reported high levels of caregiver burden. Medium and high levels were correlated with poor physical condition of the patient alongside poor functioning and mental health of the carer.
Bakas et al. <sup>10</sup>	To examine relationships among age, perceived control over managing heart problems, perceived difficulty with tasks, perceived outcomes and perceived mental and general health among caregivers of persons with HF; describe caregivers perceptions of control over managing heart problems, describe the tasks and outcomes perceived as being difficult and negative by caregivers.	21 family caregivers	Primary care medicine outpatient clinic.	Non-experimental, exploratory, descriptive design. Questionnaire using tools listed.	Control Attitudes Scale, Oberst Caregiving Burden Scale, Bakas Caregiving Outcomes Scale and SF-36.	43% caregivers perceived a lack of control in relation to the patients' HF problems, younger carers perceived tasks to be more difficult and indicated poorer mental health, 47% reported difficulty in managing household tasks, 57% reported that they felt that their emotional well-being had been effected by being a carer.
Chung et al. <sup>21</sup>	To examine the effect of patients and partners depressive symptoms and anxiety on QoL in patient-spouse dyads.	58 dyads participated in the study.	Outpatient HF clinic.	Cross-sectional, descriptive study in which depressive symptoms, QoL and anxiety were assessed concurrently in patients and spouses using tools listed.	Brief symptom Inventory and Minnesota Living with HF questionnaire (modified version for carers).	Dyads showed greater depressive symptoms and anxiety than the mean reported in healthy communities. No significant gender differences in anxiety and depression. Spousal caregivers depression and anxiety correlated with their own QoL but not with their partners'. This had a direct negative impact on the patients' QoL.
Dracup et al. <sup>5</sup>	To describe the emotional well-being of spouses of patients with HF, to identify factors associated with decreased emotional well-being and to compare well-being between spouses with higher and lower levels of perceived control.	69 spouses of patients with HF.	Outpatient HF clinic.	Cross-sectional correlational design using questionnaire incorporating the tools listed.	SF-36, Control Attitudes Scale-Family Version and Caregiver Appraisal Tool	SF-36 scores showed lower levels of QoL and poorer mental health when compared to the general population, higher caregiver burden and lower perceived control led to increased distress. Higher levels of perceived control are linked to significantly higher levels of emotional well-being. Younger spouses were found to be at increased risk of poor emotional well-being.

(continued)

Table 2. (Continued)

Author	Aims	Participants/ sample	Study setting	Method/intervention	Description of tool used to measure caregiver burden/QoL	Relevant findings
Evangelista et al. <sup>22</sup>	To describe and compare the emotional well-being of HF patients and their caregivers, identify gender differences in emotional well-being of patients and caregivers and identify factors associated with emotional well-being of HF patients.	103 dyads participated in the study.	Outpatient HF clinic.	Prospective, comparative design using questionnaires incorporating the SF 12. Convenience sample.	SF-12.	Caregivers had a significantly higher emotional well-being than patients. Authors allude to the higher levels of emotional well-being as a result of the positive association of being a carer and the responsibility that the roles can bring. Relates to the commitment and satisfaction. The relationship between the desire for communication and caregiver burden was examined – 93.8% of caregivers and 88.6% of patients recognised that it was important to talk to each other about the illness, 39.9% of caregivers desired more communication with patients and 37.35% found communication with the patient difficult. The need for more communication with the patients was linked to higher levels of carer burden and emotional stress. NB overall the level of emotional burden reported by caregivers was low - this highlights that caregiving has both positive and negative aspects.
Fried et al. <sup>23</sup>	To examine the adequacy of caregiver-patient communication in serious illness and its relationship to caregiver burden.	193 caregivers and 33 patients participated in the study. COPD and HF patients and caregivers participated in the study. There were 52 caregivers for HF patients.	Participants were recruited from an outpatient clinic. Interviews were conducted at the participants' own home (carers and patients were interviewed separately).	Cross-sectional cohort study. Telephone screening to ascertain number of ADLs patient needed support with. Carer interview using tools listed.	Zarit burden inventory.	23% of carers for HF patients reported needing help with daily tasks; this was higher than other caregivers. Strong association between carer perceived need for social support and higher levels of burden.
Garlo et al. <sup>24</sup>	To examine caregiver burden over time in caregivers of patients with advanced HF.	179 caregivers of patients with COPD, cancer and HF.	Recruited from acute and outpatient settings. Participants interviewed in own homes at 3- and 12-month periods.	Longitudinal cohort study over 12-month period. Interviews using Zarit Burden Inventory.	Zarit Burden Inventory.	Lack of family support for caregivers was associated with patients' NYHA class, relationship with the patient and caregivers perceived control and social support. Many family caregivers reported that caregiving had impacted their health negatively. Findings were comparable to carers of patients with colorectal cancer. The caregiving experience was more positive when social support was readily available. It was seen as vital that carer needs were assessed immediately after patient's discharge from hospital.
Hwang et al. <sup>25</sup>	To identify factors associated with the impact of caregiving.	76 dyads of patients with HF.	Participants recruited from outpatient HF clinics.	Cross-sectional descriptive design using a convenience sample. Participants given opportunity to complete the questionnaire on their own or by interview (in person or over the telephone). If they completed it independently, they were asked to do so by themselves with no discussion with their partner.	Charlson Co-Morbidity Index, Dutch Objective Burden Inventory, Medical Outcomes Study Social Support Survey, Control/Attitudes Scale-revised, Caregiver Reaction Assessment, SF-36 and Patient Health Questionnaire (carer focused).	

(continued)

Table 2. (Continued)

Author	Aims	Participants/sample	Study setting	Method/intervention	Description of tool used to measure caregiver burden/QoL	Relevant findings
Hooley et al. <sup>26</sup>	To describe levels of caregiver burden and depressive symptoms and correlate this to patients' QoL and depression.	50 patient–carer dyads.	Participants recruited from outpatient HF clinics. Participants complete a self-administered questionnaire. NB patients and carers completed the questionnaire in separate rooms in the clinic.	Self-administered questionnaire using validated tools. Linear correlation to examine the carer burden score with the three other questionnaires scores. NB does not state the time period over which the study was conducted.	Patients – Minnesota Living with HF and Beck Depression Inventory.	Caregiver burden is related to the levels of depression and poor QoL in the patients they are caring for. While carers of HF patients do experience huge burden (ZCB 16) this is lower than carers of patients with cognitive impairment.
Iqbal et al. <sup>27</sup>	To assess factors affecting health-related QoL in HF patients and their carers.	179 patients and 131 carers.	Cardiology wards on discharge (n = 101) or outpatients clinic (n = 78).	Self-administered questionnaires completed at 1 month post-discharge or in the outpatient clinic.	Patients – QoL (EQ-5D), Minnesota Living with HF.	QoL of carers correlated to QoL of the patients. QoL was lower in female carers than male. NYHA class and socio-economic status correlated to lower QoL.
Luttik et al. <sup>28</sup>	To investigate QoL in partners of people with congestive cardiac failure in comparison to individuals living with a healthy partner.	303 partners of people with congestive cardiac failure.	Recruited from a larger RCT conducted in 17 cardiology centres.	Cross-sectional comparative design. Population was compared to an age- and gender-matched control group selected from the general population. Conducted over a 3-year period.	RAND 36, Cantril's Ladder of Life (measure of global well-being), Dutch Objective Burden Inventory (measure of tasks carer conducts).	Small differences in QoL between carer population and general population, female carers had lower scores than male carers in QoL measures and variations in carer QoL correlated to the severity of the patient's disease.
Makdessi et al. <sup>18</sup>	To examine the effectiveness of a disease-specific tool to measure carer burden.	88 caregivers.	Participants were carers attending an outpatient HF clinic with the patient.	Cross-sectional descriptive design. Self-administered questionnaire. Carers completed questionnaire independently and returned it stamped addressed envelope.	DOB, Caregiver Reaction Assessment and Hospital Anxiety and Depression Scale.	Responses to the DOBI provided new insight into frequency of caregiving tasks. Study recommended further research into the psychometric properties of the tool.
Molloy et al. <sup>11</sup>	The study aimed to examine the effectiveness of the demand–control module to predict caregiver burden and satisfaction.	60 caregiver–patient dyads.	Participants were recruited from an older person's day hospital and outpatient HF clinic.	Cross-sectional design. Caregivers interviewed independently of the patient. Interviews were conducted in the carers own home or by self-reported questionnaire when an interview was not possible.	Care work strain scale and carer satisfaction (subscales of the Impact of Informal Caring Scale). NB scale acknowledges the positive aspects of caring.	Findings showed no supporting evidence for predictions of the demand–control model in predicting caregiver satisfaction. Control was the strongest predictor of caregiver burden.

(continued)

Table 2. (Continued)

Author	Aims	Participants/ sample	Study setting	Method/intervention	Description of tool used to measure caregiver burden/QoL	Relevant findings
Nausser et al. <sup>29</sup>	To evaluate the psychometric properties of the FAMQOL designed to assess the physical, psychological, social and spiritual dimensions of QoL among caregivers of HF patients.	100 HF caregivers.	Inpatient and outpatient cardiology settings.	Cross-sectional study, convenience sample. Carers recruited if they met two or more of the task criteria on the Oberst Caregiving Burden Scale. Questionnaires administered by telephone interview followed by a 2-week test-retest. NB the FAMQOL can also be self-administered.	FAMQOL, plus the following additional measures to evaluate construct and criteria validity. 19-item Medical Outcomes Study Social Support Survey – to measure social support. Patient cognition measured by 8-item Cognitive Status Scale, Oberst Caregiving Burden Scale – subscale used to measure care giving tasks difficulty; 31-item Parents Perception of Uncertainty in Illness Scale for family members; Appraisal of Caregiving Scale, 9-item depression scale of PHQ; Bakas Caregiving Outcomes Scale and SF-36.	Item to total correlations were examined for the individual domains. Findings indicate that the 16 item FAMQOL tool has validity and reliability, 7 experts assessed the tool's content validity, strong evidence of internal consistency reliability and test – retest reliability. Brief and easy tool to administer. Participants were predominantly women.
Pressler et al. <sup>8</sup>	To determine predictors of family caregiving outcomes among caregivers of patients with HF and to identify the tasks reported as most difficult and most negative outcomes.	63 patients and 63 caregivers.	Outpatient HF clinic.	Prospective study, caregivers completed the questionnaire face to face with an interviewer or by telephone, interview conducted at 4 and 8 months were done so by telephone. Convenience sample – names were put forward for caregivers to participate by clinic staff.	Bakas Caregiving Outcomes Scale, SF-12, Charlson Co-Morbidity Index (assesses medical health of the carers), Family Assessment Device (brief version), Control Attitudes Scale, Patient Health Questionnaire, Brief Symptom Inventory (measure of levels of anxiety in carers) and Oberst Caregiving Burden Scale.	Caregivers reported moderately poor physical and emotional health-related QoL, carers reporting depressive symptoms at baseline were more likely to report that their lives had changed for the worse at 4 months. Pre-existing carer medical conditions and perceived difficulty of caregiving tasks were predictors of physical health-related QoL at 4 months; at 4 and 8 months, depressive symptoms were predictors of emotional health related to QoL.
Saunders <sup>7</sup>	A study examining the association of caregiver characteristics and the caregiving environment on caregiver burden.	55 caregivers and 41 patients.	Participants identified and recruited from the caseload of two community-based HF nurses over a period of 4 months.	Cross-sectional, non-experimental design. Caregivers were interviewed face to face at the home of the patients using a structured format.	The CES-D – depression screen for carers; the Caregiver Reaction Assessment was the main tool in study. NYHA classification was used to assess patients' clinical status.	Higher levels of burden in Caucasian caregivers, those caring for other relatives, unemployed caregivers, older carers, higher numbers of carer hours, poor carer health and depression in carers were all associated with higher levels of burden.

QoL: quality of life; HF: heart failure; COPD: chronic obstructive pulmonary disease; NYHA: New York Heart Association; SF-36: Short Form-36; SF-12: Short Form-12; ADL: activities of daily living; DOBI: Dutch Objective Burden Inventory; RCT: randomised control trials; EQ-5D: EuroQoL-5D; FAMQOL: Family Caregiver Quality of Life Scale; PHQ: Primary Health Questionnaire; CES-D: Centre for Epidemiological Studies Short Depression Scale.



extraction and appraisal and considered the following key aspects: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, findings/results, transferability/generalisability, implications and usefulness. As recommended by Hawker et al.,<sup>17</sup> each of these aspects was rated as good, fair, poor or very poor and conclusions drawn as to the rigour of the studies critiqued.

## Results

The 16 studies in this review are predominantly from the United States and Canada (n = 12) with the remaining studies being European (United Kingdom: n = 2, Sweden: n = 1 and Netherlands: n = 1). The majority of the study designs were descriptive correlational and cross-sectional (n = 12); one study used an experimental exploratory design, one study was a cohort study and two studies were comparative prospective designs. All studies were quantitative and used at least one validated tool to measure carer burden and/or QoL.

All studies were conducted with a heart failure population; studies were inclusive of patient–carer dyads and informal carers. Study settings were acute and primary care.

The quality assessment of the studies was conducted using the range of quality indicators identified by Hawker et al.<sup>17</sup> The majority of articles were categorised as fair or good according to the Hawker criteria; none of the studies received a poor quality assessment. Following the quality assessment, a thematic synthesis was undertaken, and the following themes were identified:

- Perceived carer control;
- Mental and emotional well-being;
- Types and impact of caregiving tasks;
- Impact of patients' physical condition;
- Impact of age/gender/demographic factors;
- Positive aspects of caregiving.

### Perceived carer control

Four studies included in this review used the Control Attitude Scale tool to identify dimensions of carer control and explored how this linked to increased levels of burden.<sup>5,10,20,25</sup> The studies illustrated how perceived control was a contributory factor to caregiver burden. Carers who perceived they had less control showed greater anxiety and poorer mental health. Partners perceiving high levels of control demonstrated lower levels of anxiety, depression and hostility to the caring role.<sup>10</sup> A sense of control experienced by the carers in relation to a patient's health had particular importance in determining a carers' emotional well-being.<sup>5</sup> Low levels of control alongside less social support were linked to a negative impact on the carers' physical and emotional health. A further study exploring

control and its effects on carer burden was conducted by Molly et al.;<sup>11</sup> this study implemented a tool commonly used to examine job strain, namely, the Care Work Strain Scale. The study supported the previous studies' findings, with the results indicating that control was the strongest predictor of caregiver burden. Additionally, Molloy et al.<sup>11</sup> used the model to identify associations between demand and satisfaction, but the findings did not achieve statistical significance. Hwang et al.<sup>25</sup> argued that this lack of positivity about the caring role may be associated with the patient population; commonly, heart failure patients have complex co-morbid conditions that decrease the carers' positive feelings about supporting and caring for the patient.

A partner-centred approach using education and support for carers is advocated to assist the carer in feeling prepared and supported for the complex challenges throughout the disease trajectory in order to facilitate a sense of control over the situation.<sup>5,20</sup>

### Mental and emotional well-being

Many of the studies identified the negative effects of being an informal carer on emotional well-being. A wide range of tools were used to measure emotional and mental well-being (Beck Depression Inventory, Short Form (SF)-36, Zarit Burden Inventory, European Quality of Life, Hospital Anxiety and Depression Scale, Cantril's Ladder of Life, Brief Symptom Inventory and The Centre for Epidemiological Studies Short Depression Scale).

Several studies indicated a strong correlation between the physical condition and QoL of patients and levels of depression in the carer population.<sup>20,21,26–28</sup> Carers' depressive symptoms and anxiety negatively impacted the patients' QoL.<sup>21,26</sup> While QoL of carers was commonly reported as being higher than that of the patients' QoL, QoL of carers did correlate with the QoL of patients.<sup>21</sup> In patients reporting lower levels of QoL, carers also had lower QoL.<sup>21,27</sup> Additionally, several studies indicated that QoL was lower in female carers than male carers, and younger carers reported higher levels of depression and anxiety.<sup>5,10,25,27,28</sup>

Levels of depression were influenced by the carers' physical and mental well-being when undertaking the role of carer.<sup>7,8</sup> Caregivers reporting poor physical and emotional well-being at the onset of undertaking the caring role were more likely to demonstrate depressive symptoms and poor QoL over time. Pressler et al.<sup>8</sup> found that caregivers with poor emotional and physical well-being at the beginning of the study showed progressive deterioration at 4 and 8 months. The study by Dracup et al.<sup>5</sup> indicated lower levels of mental health and health perception scores in the SF-36 of carers than the mean scores of the general population.

Conversely, two studies demonstrated the positive effects of being a caregiver on emotional well-being. Caregivers emotional well-being was significantly higher

than that of the patients they were caring for, and the overall emotional burden was reported by caregivers as being low.<sup>22,23</sup> The authors propose that these are significant findings demonstrating the positive aspects of caring. Caregivers may have increased self-esteem by undertaking activities and responsibilities to support the patient, which positively improves their own mental well-being.

## Types and impact of caregiving tasks

The type and frequency of tasks that carers undertake are significant in how they cope with the role and its impact on their physical and mental well-being. Tools that were utilised to measure the tasks and their effects included Bakas Caregiving Outcomes Scale, Zarit Burden Inventory, Dutch Objective Burden Inventory and Oberst Caregiving Burden Scale.

Two studies demonstrated that younger caregivers, for example, aged below 60 years found day-to-day household tasks to be more difficult to manage.<sup>10,25</sup> These tasks included cleaning; managing the finances, bills and forms relating to the patient's illness and transport issues. A greater perceived difficulty with tasks led to increased burden in the carers. A reason as to why younger caregivers found particular difficulty with these tasks was the fact that many were working full- or part-time alongside being a carer for the patient; in the study conducted by Hwang et al.,<sup>25</sup> over half of the caregivers were employed full- or part-time.

Further studies explored how spousal carers and older carers managed tasks associated with a caring role.<sup>8,18</sup> The Makdessi et al.<sup>18</sup> study involved caregivers with a mean age of 63 who were predominantly female spouses; in the Pressler et al.<sup>8</sup> study, caregivers had a mean age of 59 and again were predominantly female spouses. Spouses performed more caregiving tasks than adult child carers, and female caregivers provided more emotional support than male.<sup>18</sup> Particularly challenging tasks for spousal carers included dealing with the behavioural problems of the patients such as moodiness and giving emotional support, managing dietary needs, monitoring signs and symptoms and obtaining health information from health-care providers.<sup>8</sup>

Two studies indicated that younger spouses reported higher levels of carer burden, and younger caregivers perceived tasks more difficult and their mental health to be worse than older caregivers.<sup>5,10</sup> Reasons linked to these higher levels of burden include additional responsibility of continuing to maintain a job, childcare and a household.

An impact of the responsibility of delivering caregiving tasks is reduced opportunity for social activity for carers. This is a change in their life that caregivers perceived to be negative and results in loss of contact with friends and reduced social activities. This negative perception resulted in the caring role being less enjoyable or rewarding.<sup>10</sup> The strongest variable associated with caregiver burden was a need for increased support with daily tasks and social support.<sup>24</sup>

## Impact of patient's physical condition

A range of tools were used to assess the severity of the patient's heart failure, including the New York Heart Association (NYHA) Score, Minnesota Living with Heart Failure Questionnaire (MLHFQ) and the Charlson Co-Morbidity Index. The NYHA is widely recognised as a measure of how the condition impacts the patients' day-to-day life and is categorised as shown in Table 3.

The MLHFQ is a validated tool to assess QoL in heart failure patients and to examine the effects of different interventions. The Charlson Co-Morbidity Index is a tool to classify conditions that can influence patients' mortality and captures those conditions that will impact overall disease severity.

Three studies indicated that a higher degree of caregiver burden was related to worse physical function of the patients.<sup>20,25,26</sup> NYHA score was a significant indicator of risk of caregiver burden; higher NYHA class correlated with lower QoL in carers.<sup>27</sup> Hwang et al.<sup>25</sup> demonstrated that a higher NYHA score is associated with the sense of less support for caregiving, and overall, a higher NYHA score, indicating severe disease, led to greater disruption to the caregivers' lives.

A further study by Hooley et al.<sup>26</sup> showed increased caregiver burden is linked to the advanced disease of patients. Interestingly, the findings of Hooley et al.<sup>26</sup> indicated that patients' poor QoL related to the number of medications that they were prescribed; the authors concluded that medications are likely to be a surrogate for disease burden.

## Impact of age/gender/demographic factors

Two studies indicated that younger spouses report higher levels of carer burden, and younger caregivers perceive their mental health to be worse than older caregivers.<sup>5,10</sup> Dracup et al.<sup>5</sup> propose that older carers may derive more satisfaction in their role as caregivers and describe this as finding a new purpose in life. The findings illustrate the importance of clinicians being alert to the needs of younger spouses who may be at higher risk for impaired emotional well-being.

**Table 3.** NYHA classification.

Class I	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation or dyspnoea.
Class II	Slight limitation of physical activity. Comfortable at rest but ordinary physical activity results in fatigue, palpitation or dyspnoea.
Class III	Marked limitation of physical activity. Comfortable at rest but less than ordinary activity results in fatigue, palpitation or dyspnoea.
Class IV	Unable to carry out any physical activity without discomfort. Symptoms at rest. If any physical activity is undertaken, discomfort is increased.

NYHA: New York Heart Association.

A differing perspective as regards the effect of employment was found by Saunders,<sup>7</sup> in a study of 50 caregivers, carers who were not employed had greater levels of burden. The author concurred, however, that older caregivers were less likely to be employed than younger carers and that caregiver age maybe an additional correlation in this finding.

There is an established link between spousal caregivers' emotional distress and patient's QoL, with poorer QoL leading to increased distress<sup>21</sup> but non-spousal carers were shown to receive less support from family members than those who were the spouse of the patient.<sup>25</sup> Non-spousal carers may also have additional responsibility to other family members; caring for heart failure patients and other relatives has higher levels of perceived burden.<sup>7</sup> However, Saunders<sup>7</sup> also indicated that adult child carers had greater levels of self-esteem than spousal carers. Carer burden is shown to be less in those carers who are sharing the responsibility with another family member.<sup>7</sup>

A tool used to measure economic status of carers and its influences on carer burden and QoL was the Scottish Index of Multiple Deprivation.<sup>27</sup> The study by Iqbal et al.<sup>27</sup> indicated QoL in carers is lower in those with poor socio-economic status.

Two studies showed interesting findings regarding the gender of carers. Luttik et al.<sup>28</sup> found that partner's illness was associated with lower well-being and a negative change in perceived health in women but not in men. The study showed differences in mental health in relation to gender; female participants reported poorer mental health than male. Female carers also reported more difficulty with the tasks required of them as a carer. In contrast, male partners did not appear to suffer the same stress in taking care of women. The authors' propose that this finding cannot be explained by gender differences in the numbers of caregiving tasks performed. Rather, they argue that in the study, male partners performed more personal care tasks for female patients compared to female partners of male patients. They conclude that the gender differences may be associated with role identity; taking care of the family, partner and children is traditionally seen as the domain of the woman, and therefore, the additional stress of being a carer to a patient may have a stronger effect on female carers. Iqbal et al.<sup>27</sup> support the evidence that QoL is lower in female carers and advocate that further research should be undertaken to explore this issue.

### Positive aspects of caregiving

A limited number of tools considered the positive effects of being a carer; these included Caregiving Appraisal Scale and Caregiver Reaction Assessment. These tools aim to capture dimensions such as satisfaction, mastery and ideology associated with being a carer.

For certain carers, the new role and responsibilities are linked to a positive effect on their well-being.<sup>20,22,23,25</sup> Caregivers can feel rewarded by being able to provide care for a family member. Interestingly, Hwang et al.<sup>25</sup> showed that non-Caucasian carers and those carers whose family members had fewer emergency admissions perceived the role as more enjoyable and rewarding. The ethnic influence was also demonstrated by Saunders<sup>7</sup> who found carer burden to be less in non-Caucasian carers. The authors propose that feelings of negatively in relation to admission to emergency care may be as a result of the carers feeling they have failed in their role. The study also re-emphasises the importance of social support with evidence that increased social support both formally and informally from other family members increases the positive attitude to caring.

### Discussion

This review highlights clear evidence that informal carers supporting patients with heart failure face many challenges impacting their physical and mental well-being. The studies described provide an insight into the individual dimensions, which make a carer particularly vulnerable, namely, younger carers, female carers and carers with existing physical and emotional health issues. Additionally, there are external influences that increase risk of burden, including the NYHA status of the patient, if the patient has had recent emergency admissions or has been discharged home, and level of social support available to the carer.

A further finding from conducting this review is that there are still limited measures of the positive aspects of caregiving. The Harkness and Tranmer<sup>16</sup> review called for the development of objective measures of the subjective caregiving experience to understand what factors contribute to a positive experience for carers and the person they are caring for. Two studies in this review recommended that further investigation be conducted into the dimensions of dyads that may positively influence the caregiving experience.<sup>20,21</sup> These studies propose that it is necessary to explore the effect of marital quality on the relationship between emotional distress and QoL and how the marital quality may affect these variables.

Although the evidence was from varied study types, a quality assessment indicated that the studies were of fair to good quality, and therefore, these results can be interpreted with a reasonable degree of confidence.

A recently developed instrument specifically to measure QoL of heart failure family caregivers<sup>29</sup> shows evidence of reliability and validity in capturing the impact of caregiving. The measure is beneficial in that it is designed specifically for the heart failure carer population and captures the multidimensional concepts of physical, psychological, social and spiritual well-being. Additionally, with only 16 items in the scale, the instrument is quick and easy to

administer. However, as with similar tools discussed in this review, the Nauser et al.<sup>29</sup> measure offers limited opportunity to identify the positive aspects of caring effectively.

Reflecting on the key issues raised by the thematic synthesis, it is recommended that carers should be screened in order for vulnerable carers to be proactively identified and timely interventions instigated. The screening can be achieved quantitatively using the Nauser et al.<sup>29</sup> measure. Proactive planning may be addressed by implementation initiatives such as a Carer Support Plan, which aims to give carers, known to Specialist Heart Failure Nurse Services (SHFNS), an opportunity to discuss their wishes, values and preferences with regards to what they would prefer to happen in the event of a crisis/breakdown in care. Further research by this research group will aim to pilot a Carer Support Plan in a community setting.

The Carer Support Plan acknowledges an approach of offering support advocated by Hanson et al.<sup>30</sup> Hanson et al.<sup>30</sup> developed the Carers Outcome Agreement Tool (COAT) to promote a new model of working with carers that focuses on partnerships between carers, practitioners and service providers. The approach requires a shift from the predominant focus being carer burden and stress to consider the positive aspects of caring and quality relationships. COAT views the carer as a co-expert; carers and practitioners work together to agree on goals and outcomes and the support needed to achieve them. An important aspect is to ensure that the support offered is of a good quality as the carers are often concerned about the poor quality of services they have received in the past, which can lead to reluctance in accepting help. It is envisaged that the Carer Support Plan will endeavour to address this by promoting high-quality existing services, including specialist respite care at home or residentially for heart failure patients.

The authors recommend that the appropriateness and effectiveness of this intervention are explored with a further in-depth qualitative investigation of patient-carer dyad dimensions that increases the likelihood of a positive experience of being an informal carer for a patient with heart failure.

## Limitations

Comprehensive electronic search, retrieval, and review strategies were used in the narrative review. However, the authors acknowledge that this review's searches are subject to some limitations. Due to time and resource limitations, English language databases were used and hand-searches of journals were not completed; consequently, some studies may have been missed.

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## Conflict of interest

The authors declare that there is no conflict of interest.

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