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An integrated review of interventions to improve psychological outcomes in caregivers of patients with heart failure

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Purpose of review

This article examines interventions aimed at improving psychological outcomes (e.g., caregiver burden, quality of life, anxiety, depression, perceived control, stress mastery, caregiver confidence and preparedness, and caregiver mastery) in family caregivers of patients with heart failure.

Recent findings

Eight studies meeting the inclusion criteria were included in the review. The most common intervention involved psychoeducation facilitated by a nurse (6/8) and supplemented with a combination of follow-up face-to-face sessions (2/6), home visits (2/6), telephone calls (3/6), and telemonitoring (3/6). Two studies used a support group intervention of four to six sessions. Half of the interventions reported a significant effect on one or more primary outcomes, including caregiver burden ($n=4$), depressive symptoms ($n=1$), stress mastery ($n=1$), caregiver confidence and preparedness ($n=1$), and caregiver mastery ($n=1$).

Summary

Compared with dementia and cancer family caregiving, few interventions have been evaluated in caregivers of patients with heart failure. Of the existing interventions identified in this review, considerable variability was observed in aims, intervention content, delivery methods, duration, intensity, methodological rigor, outcomes, and effects. Given this current state of the science, direct comparison of heart failure caregiver interventions and recommendations for clinical practice are premature. Thus, research priority is strongly warranted for intervention development and testing to enhance heart failure caregiver support and education.

Keywords

caregiver, caregiver burden, heart failure, quality of life

INTRODUCTION

Heart failure is an increasingly prevalent, often progressive condition associated with high morbidity and compromised physical and mental function that necessitates the regular assistance of a family caregiver [1,2]. Unlike trajectories in dementia and cancer, the heart failure disease course is uniquely characterized by periods of stability that is sporadically interspersed with acute exacerbations that are often unanticipated, life threatening, and requires costly hospitalizations [3]. Advanced heart failure is associated with increased anxiety and depression, significant symptom burden, marked physical disability, and diminished quality of life that impair both mental and physical function [4,5]. Consequently, family caregivers are called on to assume a critical role in providing daily support to the patient with heart failure [6–8].

Family caregivers are typically close relatives or friends of the person with heart failure (usually spouses and adult children) and provide assistance with one or more activities of daily living. This assistance can include a range of responsibilities, including care coordination, symptom management, medication administration, assisting with healthcare decision-making, instrumental support

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KEY POINTS

- Family caregivers have a critical role in providing daily support to patients with heart failure.
- Family caregivers are known to experience similar emotional distress as the patients and have also reported substantial caregiver burden and it is therefore vital to provide them with evidence-based support.
- Few interventions have been evaluated in caregivers of patients with heart failure and the existing interventions are heterogeneous in terms of aims, content, delivery methods, duration, intensity, methodological rigor, outcome measures, and effects. The studies, so far, have also been socially and culturally selective. Therefore, strong recommendations for clinical practice cannot be done yet.
- Further research priority is strongly warranted for intervention development and testing to enhance heart failure caregiver support and education.

with activities of daily living, emotional and spiritual support, and home maintenance [9]. Performing these tasks is critical to heart failure patients' quality of life and survival; however, caregivers have been found to often lack necessary resources to meet patients' complex needs [10,11,12,13]. Moreover, they report feeling unprepared for the caregiving role and inadequately supported by the healthcare team [14,15]. Given the substantial time allocated to performing caregiving tasks, caregivers

often have less time for caring for themselves and their relationships [16,17] which can ultimately have a marked impact on their psychosocial and physical health [11,12,13,18,19]. Reduced caregiver health can in turn reduce their ability to be supportive to the patient with heart failure [20].

Therefore, it is vital to support family caregivers with evidence-based, field-tested programs, not only for their own mental and physical well-being, but also because of the critical role they play in delivering daily care to the patient with heart failure. To assess the current state of the science in interventions to support caregivers of patients with heart failure, we conducted an integrative review of the literature to examine randomized controlled trials (RCTs) focusing on improving psychological outcomes (e.g., caregiver burden, quality of life, anxiety, depression, perceived control, stress mastery, caregiver confidence and preparedness, and caregiver mastery) in caregivers of patients with heart failure.

METHODS

Using the methodology and criteria recommended by Ganong [21] (e.g., purpose, inclusion criteria, literature search sampling decisions, systematic analysis, and reporting), we conducted an integrative review of the literature to identify studies of original research focusing on interventions to support family caregivers of patients with heart failure published between January 2005 and September 2015. As depicted in Fig. 1, electronic databases searched

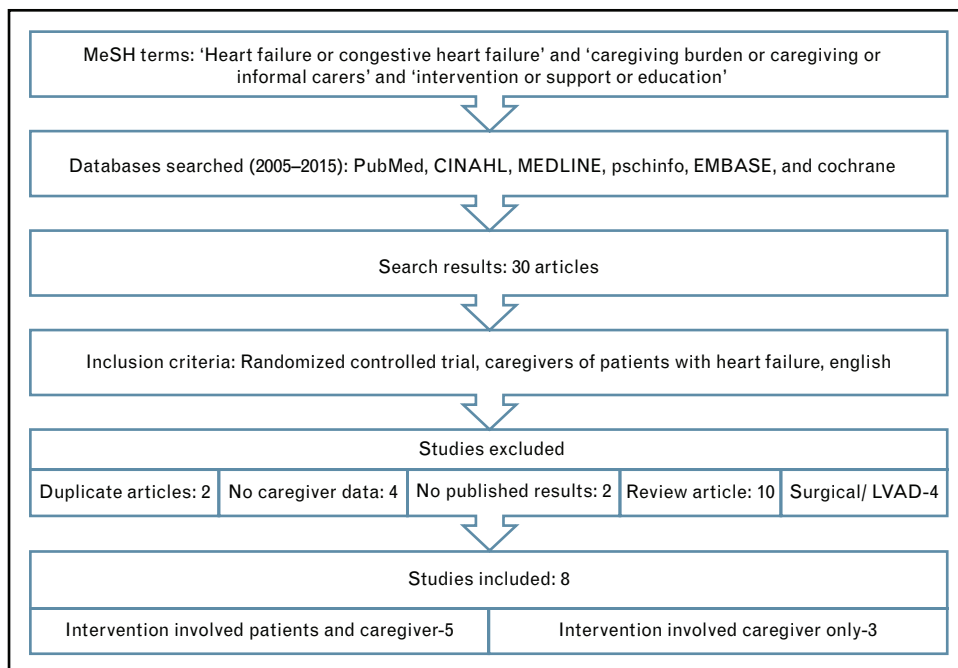


FIGURE 1. Search strategy and eligibility criteria.

Table 1. Caregiver characteristics

Study	Sample size	Age	Sex, (%) male	Education level	Dyadic involvement	Duration of intervention/follow-up
Agren <i>et al.</i> (2012) [22]	155	68.5 ± 11.0	24.5	<High school, 57% High school, 31% College, 12%	Yes	3 months/3 and 12 months*
Chiang <i>et al.</i> (2012) [23]	60	18–39 years, 16.7% 40–59 years, 35.0% ≥60 years, 40.6%	28.3	≤High school, 36.7% College, 53.3% >College, 1.0%	Yes	3 weeks/1 month
Etemadifar <i>et al.</i> (2014) [24*]	50	20–39 years, 48.3% 40–59 years, 50.5% ≥60 years, 2.4%	19.7	Primary, 32.5% Higher, 67.5%	No	4 weeks/1 and 3 months
Löfvenmark <i>et al.</i> (2012) [25]	128	65.0 ± 13.0 >65 years, 56%	23.0	<12 years, 26.0% >12 years, 72.0%	No	6 months/1 year
McMillan <i>et al.</i> (2013) [26]	60	63.3 ± 13.4	30.0	12.9 ± 2.0 years	Yes	5 weeks/5 weeks
Piamjariyakul <i>et al.</i> (2013) [27]	10	62.6 ± 13.7	25.0	≤High school, 8.3% Technical, 58.3% ≥College, 33.3%	No	Not reported/3 months
Piette <i>et al.</i> (2015) [28*]	369	47.1 ± 13.2	34.9	≤High school, 28.1%	Yes	12 months/6 and 12 months
Schwarz <i>et al.</i> (2008) [29]	102	63.5 ± 16.1	Not reported	Not reported		90 days/90 days

Data for long-term (24 months) outcomes were recently published as a follow-up to the original study [30].

included PubMed, CINAHL, MEDLINE, PsycInfo, EMBASE, and Cochrane. Search terms included: ‘heart failure,’ ‘congestive heart failure,’ ‘caregiving burden,’ ‘caregiver,’ ‘informal carers,’ ‘intervention,’ ‘support,’ or ‘education.’ Publications were screened using the following criteria: implementation of a RCT of a nonpharmacological intervention to improve psychological outcomes in caregivers of persons with heart failure; caregivers received an intervention with or without the involvement of the patient with heart failure; written reports in the English language; and measurement of psychological outcomes in caregivers of patients with heart failure. Studies were excluded that focused on evaluation of interventions for caregivers of patients requiring surgical interventions or left ventricular assist devices to manage heart failure. Data extracted from identified studies included study design, sample and setting characteristics, outcomes assessed, and main findings.

RESULTS

Study characteristics

Eight studies met eligibility criteria for this review. Table 1 summarizes these studies’ key

characteristics. Four studies were conducted in the United States, two in Sweden, one in Iran, and one in Taiwan. A total of 934 caregivers were included in the eight studies. Sample sizes ranged from 10 to 369 caregivers, with an average of 117 ± 110 caregivers. Caregivers’ mean ages were 61.7 ± 13.4 years, and were mostly women (73.5%). Educational level was reported in seven studies; one study reported average years of education as 12.9 ± 2.0 years and six studies reported that 8.3–88.0% of caregivers attended high school or less and five studies reported that 12–91.6% completed some college or higher education. Five studies applied a dyadic approach involving both the patient and caregiver in the intervention, whereas the others focused solely on the caregiver.

Caregiver interventions

As shown in Table 2, there was a range of caregiver intervention designs. Face-to-face nurse-led psycho-educational sessions was the common initial approach (six/eight studies), however, there were variations among studies in approaches to follow-up. These included follow-up face to face sessions [22,24*], home visits [26], telephone calls

Table 2. Caregiver interventions, psychological outcomes, measures, and findings

Study	Intervention	Materials used	Psychological outcomes (instrument measures)	Findings
Ågren <i>et al.</i> [2012] [22]*	Psychoeducational intervention delivered in three modules through nurse-led face-to-face counseling in dyads' homes or heart failure clinic; each session ≈ ≥60 min each.	Computer-based CD-ROM program and written materials	Perceived control (control attitude scale) [31] Health-related quality of life (HRQOL) (short form-36) [32] Depression (beck depression inventory) [33] Caregiver burden (caregiver burden scale) [34]	No significant Δs in perceived control over time No significant Δs in HRQOL over time No significant Δs in depression over time No significant Δs in caregiver burden over time
Chiang <i>et al.</i> [2012] [23]	Nurse-led transitional care combining discharge plans and telehealthcare (remote monitoring + phone counseling)	Written materials + 24-h remote monitoring system	Caregiver burden (caregiver burden inventory) [35] Stress mastery (mastery of stress scale) [36]	Caregiver burden ↓ significantly over time Stress mastery ↑ significantly over time
Etemadifar <i>et al.</i> [2014] [24]*	Supportive educative group intervention: 4 weekly training sessions with nurse of 2 h each	Multimedia training materials	Caregiver burden (Zarit burden interview) [37]	↓ Caregiver burden at 1 month and 3 months
Löfvenmark <i>et al.</i> [2012] [25]	Multiprofessional educational program provided in a group forum format. Group of eight participants met six times for 2 h	Oral and written materials were provided.	Anxiety and depression (hospital anxiety and depression scale) [38] Quality of life (cantril ladder of life) [39]	No significant Δs in anxiety/depression over time No significant Δs in quality of life over time
McMillan <i>et al.</i> [2013] [26]	Psychoeducational intervention (COPE) by a trained nurse over 2–3 intervention visits + 2 phone calls focus on helping caregivers' problem-solve and cope.	Written materials	HRQOL (SWED-QUAL) [40] Anxiety and depression (profile of mood states) [41] Quality of life (caregiver quality-of-life index) [42]	No significant Δs in HRQOL over time No significant Δs in anxiety/depression over time No significant Δs in quality of life over time
Priamriyukul <i>et al.</i> (2013) [27]	Nurse administered coaching session given over 4 telephone sessions that focus on supportive care, problem-solving challenges and teach-back techniques	Written handouts, guide book	Caregiver burden (caregiver burden scale) [34] Confidence in providing heart failure care (confidence subscale of SCHFI) [44] Preparedness in providing heart failure care (one item preparedness scale) [27]	↓ Caregiver burden at 3 months 60% reported improved confidence at 3 months 50% reported improved preparedness at 3 months
Piette <i>et al.</i> [2015] [28]*	Mobile health support which provided dyads with weekly automated structured email report and self-management support calls for 12 months	Written booklet	Caregiver strain (burden) (caregiver strain index) [45] Depressive symptoms (center for epidemiologic studies depression scale) [46]	↓ Caregiver strain at 6 months and 12 months ↓ Depressive symptoms at 6 months and 12 months
Study	Intervention	Materials used	Psychological outcomes (instrument measures)	Findings
Schwarz <i>et al.</i> [2008] [29]	Telemonitoring system was set up in participants' homes; daily weights and symptom reports were transmitted to a central database. Providers were alerted when variances occurred. An advance practice nurse called to follow-up on daily variances.	Written materials	Caregiver mastery (burden) (Philadelphia geriatric center caregiving appraisal scale – mastery subscale) [47]	No significant Δs in caregiver mastery over time

HRQOL, health-related quality of life; SCHFI, Self-Care Index Heart Failure SWED-QUAL, Swedish health-related quality of life survey.

Data for long-term (24 months) outcomes were recently published as a follow-up to the original study; no significant changes in caregiver outcomes were observed [30].

[23,26,28^a], and telemonitoring [23,28^a,29]. Two studies employed a support group format: one was led by a nurse (four sessions) [24^a] whereas the other was led by a member of a multidisciplinary team (six sessions) [25]. The duration of the intervention (including follow-up) for the eight studies ranged from 1 to 12 months.

Efficacy for improving psychological outcomes

Interventions were examined for their reported impact on key caregiver outcomes. Caregiver reported outcomes in the eight studies included caregiver burden ($n=6$), quality of life/health-related quality of life ($n=3$), anxiety ($n=3$), depression/depressive symptoms ($n=4$), perceived control ($n=1$), stress mastery ($n=1$), caregiver confidence and preparedness ($n=1$), and caregiver mastery ($n=1$). Each of the studies used a variety of outcome measures with a range of one and four outcome measures being reported as summarized in Table 2. Four studies reported a statistically significant effect from their caregiver intervention on all outcome measures [23,24^a,27,28^a] whereas the other four studies reported null primary outcome results [22,25,26,29].

Caregiver burden was measured in six studies using the caregiver burden scale [22,26,27], caregiver burden inventory [23], Zarit burden interview [24^a], and caregiver strain index [28^a]. Four of these six studies showed a statistically significant reduction in caregiver burden [23,24^a,27,28^a] whereas two reported no changes [22,26]. Similarly, caregiver quality of life was measured in three studies using various instruments, but none reported significant beneficial effects [22,25,26]. One study measured perceived control over the heart disease at different time points, but did not report statistically significant changes over time [22]. Furthermore, there were no statistically significant changes in anxiety [24^a,26] nor depression/depressive symptoms [22,25,26], except for one study that utilized mobile health support to promote self-management among patient-caregiver dyads and showed a reduction of depressive symptoms in caregivers at 6 months and 12 months [28^a].

Other outcomes included stress mastery, caregiver confidence and preparedness providing heart failure care, and caregiver mastery. Mastery of stress in the caregiving role, defined as the ability of the caregiver to respond to a difficult situation by gaining competence, control, and dominion over stress [36], increased significantly in one study that combined a nurse-led psychoeducational intervention with telehealthcare [23]. Similarly, significant improvements

were reported in caregiver confidence and preparedness in providing care for the patient with heart failure, 3 months following the implementation of a nurse-administered coaching session given over four telephone sessions [27]. However, one study that examined a telemonitoring intervention did not show any improvements in caregiver mastery, defined as a positive view of one's ability to provide care [47], at 90-day follow-up [29].

DISCUSSION

Family caregivers play an essential role in the daily care of persons with heart failure. We identified eight studies of RCTs published between 2005 and 2015 that tested interventions to support family caregivers of patients with heart failure. As a comparison, published reviews of cancer family caregiving identified 49 interventions [48] and of dementia family caregiving identified 62 interventions [49]. Thus, our identification of only eight interventions represents a comparatively small number of studies and reflects the field's need to recognize the importance of intervention development and testing for heart failure family caregiving.

Interventions reviewed in this analysis revealed that the most common intervention approach was face-to-face; nurse led psychoeducational sessions supplemented with additional follow-up, home visits, telephone calls, and telemonitoring. Two studies focused on a supportive educative group intervention. Although this review lends support for the potential promise of interventions to improve psychological outcomes in heart failure caregivers, our findings about what intervention approaches might be most efficacious remain inconclusive because of the mixed results among outcomes of the eight studies. For example, one study using a support group intervention significantly reduced caregiver burden [24^a], however, a similar support group approach in a larger sample showed no significant changes in caregivers' quality of life, anxiety, and depression [25]. Similarly, the four psychoeducational intervention studies showed mixed findings: two studies showed improvements in stress mastery, caregiver burden, and depressive symptoms [22,23,27,28^a] whereas one study reported no significant changes in caregiver mastery over time [29].

Interventions are warranted to support caregivers' ability to support persons with heart failure [50^a,51]; however, additional research is needed to identify those strategies that will optimize outcomes for this understudied and vulnerable population. Comparison among intervention strategies was problematic given the variability in the eight

studies' aims, intervention content, delivery, duration, intensity, overall methodologic rigor, outcome measures, and effects, thus making a meta-synthesis inappropriate given the state of the science. The interventions can also be defined as complex warranting a tailored person-centered approach rather than being completely standardized. Thus, future research in this population would also benefit from evaluation of each intervention both with regard to process and outcomes [52]. Furthermore, recent reports and position statements emphasize several critical areas needed to enhance heart failure care for patients and caregivers that were not consistently integrated into the interventions examined in our integrative review, including interdisciplinary team evaluation and symptom management integrated with psychosocial, functional, and behavioral support; multidimensional assessment to identify, prevent, and alleviate suffering; and early integration of palliative care in patients with heart failure that includes caregivers with updates based on changes in clinical status [53,54]. Although the comprehensive heart failure guidelines [55] advocate for palliative care, symptom management, referral to hospice, and end-of-life support for patients and caregivers suffering with terminal illness, to date, significant gaps constrain the knowledge base to inform such care [5]; an interdisciplinary approach has been relatively slow to reach the care of advanced heart failure because healthcare providers have little tradition and experience with this approach [54].

The review has several limitations. Although a systematic search of the relevant literature was carried out using six electronic databases, a manual search for the related bibliography, and an author search that provided comprehensive coverage of key nursing, medical, and health-affiliated journals, published in English, publication bias may have been present, as studies with null results often go unpublished. Because these studies were conducted exclusively in affluent, Western countries, generalizability is also limited. It should be noted that none of the studies focused on an ethnically diverse group, hence future studies need to include racially and ethnically diverse samples. Many studies had issues with recruitment and are likely to have included selected groups of caregivers which also may limit generalizability. Most of them had a fairly small sample size, except the study by Piette *et al.* [28], and there may be power issues.

Our findings confirm the need for and potential benefits of interventions that directly support caregivers of patients with heart failure [56]. The participation principle contends that successful caregiver interventions depend on involving people

in defining their needs, setting their priorities, planning their care, and evaluating their progress. In providing family-centered care, healthcare providers should include caregivers in plans of care so that they can foster adaptation, motivation, and lifestyle change in patients with heart failure [6]. Thus, the caregiver's coping skills and behaviors are important influences that must be considered when helping patients adjust to heart failure [57]. Research indicates that increased caregiver participation and collaboration result in increased patient satisfaction with care, feelings of control over health and well-being and better self-care [56]. Caregiver involvement in patient care can be enhanced by providing them information about what to expect and about opportunities for them to become knowledgeable about care routines [6]. The evidence also suggests that dyadic interventions that focus on promoting dyadic coping skills might be most promising in reducing psychological distress of patients and caregivers in response to a stressful situation like advanced heart failure [56].

CONCLUSION

The heterogeneity in aim, intervention content, delivery methods, duration, and intensity of the studied interventions demonstrates that defining best caregiver support is not possible given the limited number of studies published at present with their heterogeneous nature and social and cultural selectivity. Thus, research priority is strongly warranted for intervention development and testing to enhance heart failure caregiver support and education and to develop an evidence base for interventions that have proven psychological and clinical benefits and can be scaled to reach a global population of caregivers of patients with heart failure.

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Conflicts of interest

There are no conflicts of interest.

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