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Permalink
https://escholarship.org/uc/item/8bk9p6bz

Journal
CURRENT OPINION IN SUPPORTIVE AND PALLIATIVE CARE, 10(1)

ISSN
1751-4258

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Publication Date
2016-03-01

DOI
10.1097/SPC.0000000000000182

Peer reviewed
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...
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 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 published between January 2005 and September 2015. As depicted in Fig. 1, electronic databases searched

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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.

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MeSH terms: ‘Heart failure or congestive heart failure’ and ‘caregiving burden or caregiving or informal carers’ and ‘intervention or support or education’


Search results: 30 articles

Inclusion criteria: Randomized controlled trial, caregivers of patients with heart failure, english

Studies excluded

Duplicate articles: 2 No caregiver data: 4 No published results: 2 Review article: 10 Surgical/ LVAD: 4

Studies included: 8

Intervention involved patients and caregiver-5 Intervention involved caregiver only-3

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**FIGURE 1.** Search strategy and eligibility criteria.
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 caregivers. Caregivers’ mean ages were 61.7 years, and were mostly women (73.5%). Educational level was reported in seven studies; one study reported average years of education as 12.9 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 psychoeducational 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

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

*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]^*.
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 \([23,24*,27,28*]\) 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 \([24*]\), and caregiver strain index \([28*]\). Four of these six studies showed a statistically significant reduction in caregiver burden \([23,24*,27,28*]\) whereas two reported no changes \([22,26,26]\). 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 \([24*,26]\) 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 \([28*]\).

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 \([24*]\), 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 \([22,23,27,28*]\) 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 \([50*,51]\); 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
Cardiac and circulatory problems

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.

Acknowledgements

None.

Financial support and sponsorship

The authors would like to acknowledge funding from the National Heart, Lung, and Blood Institute (1R01HL093466–05) and from the Swedish Research Council for Medicine and Health and the Swedish Research Council for Health, Working Life and Welfare. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Heart, Lung, and Blood Institute – National Institutes of Health or the Swedish Research Councils.
Interventions to improve psychological outcomes Evangelista et al.

Conflicts of interest
There are no conflicts of interest.

REFERENCES AND RECOMMENDED READING

Papers of particular interest, published within the annual period of review, have been highlighted as:
◦ of special interest
□ of outstanding interest


29. The new study describing the effects of a mobile health support on caregiver outcomes.


32. The new study describing the long-term effects of a psychoeducational intervention on patient and caregiver outcomes.


37. An important review on burden of caring in caregivers of patients with advanced heart failure.


39. The new study describing the effects of a psychoeducational intervention on caregiving tasks and caregiver burden in caregivers of patients with heart failure requiring surgery.


