Palliative and Supportive Care

cambridge.org/pax

Review Article

Cite this article: Hodson AR, Peacock S, Holtslander L (2019). Family caregiving for persons with advanced heart failure: An integrative review. *Palliative and Supportive Care* **17**, 720–734. https://doi.org/10.1017/S1478951519000245

Received: 9 July 2018
Revised: 6 March 2019
Accepted: 19 March 2019

Keywords:
Advanced heart failure; end of life; caregiver strain; family caregiver; palliative care

Author for correspondence:
Alexandra Rae Hodson, Faculty of Nursing, University of Regina, 111-116 Research Drive, Saskatoon, Saskatchewan, Canada. S7N 3R3.
E-mail: alexandra.hodson@uregina.ca

© Cambridge University Press 2019

CAMBRIDGE UNIVERSITY PRESS

Family caregiving for persons with advanced heart failure: An integrative review

Alexandra Rae Hodson, RN, MN[1], Shelley Peacock, RN, PHD[2] and Lorraine Holtslander, RN, PHD, CHPCN(C)[2,3]

[1]Faculty of Nursing, University of Regina, Saskatoon, Saskatchewan, Canada; [2]College of Nursing, University of Saskatchewan, Saskatoon, Saskatchewan, Canada and [3]University of the Witwatersrand, Johannesburg, South Africa

Abstract

Objective. The unique needs of caregivers of those with advanced heart failure (HF) are not effectively being met, and reports of physical and mental health challenges are common. The objective is to identify the current state of the literature related to family caregivers of persons with advanced HF, ascertain gaps that require further exploration, and provide preliminary practice recommendations based on the results.
Method. Systematic review of quantitative and qualitative literature. A search of CINAHL, Medline, EMBASE, and PubMed identified 24 articles that met inclusion criteria. Data were analyzed using the constant comparison method and coded. Thematic analysis was used to develop themes.
Result. Sixteen qualitative and seven quantitative studies met inclusion criteria. Analysis of these studies identified six key areas: (1) undertaking a journey in a state of flux, (2) gaining strength, (3) forgetting oneself along the way, (4) seeking out sources of support, (5) preparing for end of life, and (6) finding closure.
Significance of results. The healthcare system currently struggles to meet the care demands of patients with chronic conditions such as advanced HF; as such, informal caregivers are undertaking key roles in the management of symptoms and promotion of the health of those with advanced HF. When caregivers are not adequately prepared for their role, both patient and caregiver well-being is compromised; therefore, a deeper understanding of the caregiving experience could assist in identifying the cause of caregiver anxiety and result in the development of strategies to minimize its effects. Overall, this review will also contribute to improving the current practice when working with caregivers of persons with advanced HF and serve as a basis for development of evidence informed interventions in the future.

Introduction

It is estimated that 26 million people worldwide are experiencing life with heart failure (HF) (Ponikowski et al., 2014) and statistics suggest that this number will continue to rise (Heart and Stroke Foundation, 2015). Recent developments in cardiac care have contributed to this increase with new HF treatments, leading to an extension of the advanced stages (Cubbon et al., 2011). Advanced HF is commonly defined in the literature as those who meet classification III or IV of the New York Heart Association or stage D as classified by the American College of Cardiology and American Heart Association (American Heart Association, 2012). Symptoms during this period include fatigue, edema, pain, shortness of breath, and mental health challenges such as anxiety and depression (Adler et al., 2009). Although it is not always clear when a patient enters the advanced stages of HF, key criteria have been identified that indicate a person may be in the advanced period including a noted increase in the frequency of hospitalizations and an inability to relieve symptoms despite appropriate treatments (Glogowska et al., 2016; Hupcey et al., 2016). When a patient enters the advanced period of HF, he or she requires assistance in promotion of health and daily symptom management, a role often performed by the family caregiver (Kitko et al., 2015). In addition, as the healthcare system shifts client care from the hospital to the community setting (Public Health Agency of Canada, 2013), there will be an increased need for family members to take on the role of caregiver; however, this shift in service delivery will be unsustainable if we do not provide support for people undertaking this important role.

In the literature, the voice of the caregiver is often overshadowed by a focus on the needs of the patient. Given the important role that caregivers play in the case of advanced HF, research is needed to understand caregivers' experience. Caregivers of persons living with advanced HF have a challenging role and the literature suggests that the needs of these caregivers are not being met considering the high reports of caregiver burnout and emotional difficulties (Doherty et al., 2016). To develop interventions that effectively meet the needs of caregivers

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

of those with advanced HF, we need to first gain an enhanced understanding of their specific experience. There have been previous meta-syntheses on the topic of caregiving for persons with HF (e.g., Grant, & Graven, 2018; Kang et al., 2011; Molloy et al., 2005); although valuable in their findings, these reviews do not specifically address the advanced stages of the illness where care needs are significant. One previous review did limit focus to caregivers of persons with advanced HF; however, discussion was focused solely on caregiver needs rather than the entire experience of caregiving which is the focus of this review (Doherty et al., 2016). To the best of our knowledge, this is the first review that has focused on understanding the experience of caregiving for individuals with advanced HF, including the end-of-life period through to bereavement. The following will be a discussion of the extent of the knowledge currently available in the literature regarding caregivers of those with advanced HF, including the gaps that require further exploration and preliminary practice recommendations based on findings.

Methods

A rigorous review method was used to synthesize the state of the knowledge related to the experience of caregivers for those with advanced HF from both qualitative and quantitative studies. The structure of this mixed review was based on the integrative review framework presented by Whittemore and Knafl (2005). This framework outlines key areas to address during the research process including (1) problem identification, (2) literature search, (3) data evaluation, (4) data analysis, and (5) presentation. Results generated from an integrative review provide a wider scope of the identified problem area as well as serve to generate new knowledge on the topic (Torraco, 2005; Whittemore & Knafl, 2005). This kind of new knowledge generated by an integrative review is important because existing services are not meeting the needs of caregivers of persons with advanced HF.

Search strategy

The search was conducted in June 2016 and updated in May 2018 (Figure 1). Databases for the search included CINAHL, Medline, EMBASE and PubMed. Search terms were combined using BOOLEAN operators AND/OR. The search strategy included the MESH terms "caregiver" AND "heart failure," both exploded to encompass all subject headings within the term. Key words used were "heart failure" OR "advanced heart failure" OR "cardiac failure" OR "heart decompensation" OR "right sided heart failure" OR "right-sided heart failure" OR "left sided heart failure" OR "left-sided heart failure" OR "myocardial failure" OR "congestive heart failure" AND "caregiv*" OR "family caregiv*" OR "informal caregiv*" OR "spouse" OR "neighbor" OR "friend" OR "carer" OR "daughter" OR "son." The search strategy was developed with assistance of an experienced health science librarian.

Inclusion and exclusion criteria

To meet the aims of the review, inclusion criteria were: (1) family caregivers older than age 18 and including spouse, adult child, friend, and/or neighbor; (2) study indicates patient is palliative, end-of-life, and/or in the advanced stages of HF, class III or IV according of the New York Heart Association (NYHA) and/or stage D; (3) primary research in peer-reviewed journal or unpublished peer-reviewed research such as dissertations and theses; (4) article is in English; and (5) article differentiates between the results of the caregiver and the care receiver. Exclusion criteria were: care recipient has a left ventricular assist device (LVAD) and in the case of mixed population, the results of advanced HF were not reported separately from other population groups. Articles were also not excluded based on date/year of publication. Quality of quantitative articles was assessed using the Quality Assessment Tool for Quantitative Studies, a tool that meets standards for both reliability and validity (National Collaborating Center for Methods and Tools, 2008) and was specifically developed to analyze quality of quantitative articles in the public health sphere. Qualitative articles were assessed using the Critical Appraisal Skills Programme. Studies were not excluded based on quality, but were taken into account during data analysis.

Data analysis

Data extraction was conducted using the process outlined by Pinch (1995), which involved (1) extracting data from each article related to caregivers and creating a summary of each article based on preset categories and (2) analyzing summaries to develop a tentative outline based on common themes (Table 1 provides the completed data extraction table). The constant comparative method of coding developed by Glaser (1965) was used to analyze the data in this study. The first step in this method involved reviewing pertinent data within the studies and assigning meaning to each part of the text through use of codes. As each individual piece of text was coded, it was compared with text within the same category. The purpose of this method is to begin generating comparisons within and between categories to aid in the development of a theoretical explanation of results. The second step involved analyzing each code and group them according to themes.

Results

A total of 24 articles met our inclusion criteria in this integrative review. This included 17 (71%) qualitative and 7 (29%) quantitative research studies. Qualitative research articles used semistructured interviews as their form of data collection. Quantitative research used a mixture of researcher developed questionnaires and established instruments to collect data. The date of publication for the sample ranged between 2000 and 2017, with the majority of research originating from the United States (63%) followed by United Kingdom (17%), Sweden (8%), Netherlands (4%), Canada (4%), and Australia (4%). During the data analysis process, six major themes emerged. Each theme will be discussed in the following section.

Undertaking a journey in a state of flux

A state of flux can be defined as living a life of uncertainty, coupled with not knowing what each day will bring. The stories shared by caregivers reflected a sense of uncertainty regarding the future, "the unpredictability of symptom onset meant that planning activities was impossible" (Aldred et al., 2005, p. 119). Although caregivers reported a desire for routine in an attempt to establish a sense of normality (Braannstrom et al., 2007; Brush et al., 2010; Kitko & Hupcey, 2013; Saunders, 2012; Scott, 2001), there was also a recognition that a normal state did not exist (Aldred et al., 2005; Kitko & Hupcey, 2013; Luttik et al., 2005; Scott, 2001). Loss of the ability to predict future events

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

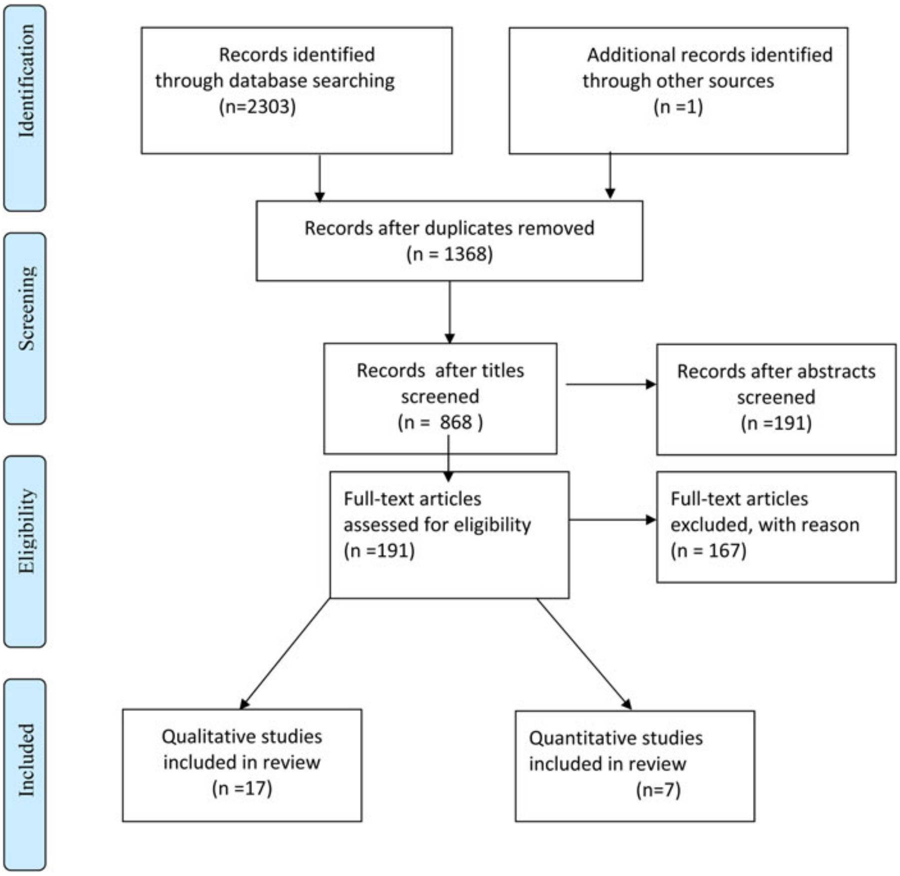

Fig. 1. Prisma flow diagram

resulted in general feelings of discontent (Dracup et al., 2004). The constant state of flux resulted in situations in which caregivers declined invitations to events outside of the home, allowing them to be isolated from a larger social network (Aldred et al., 2005). The state of flux is further revealed through continuous changes to patient care plans and related financial obligations.

Characteristics of this state of flux included frequent changes to medication regimens, introduction of new treatments, and the ongoing need to relearn care strategies (Hupcey et al., 2011; Scott, 2001); for example, one caregiver reported relief in knowing that when the patient started wheezing, he was heading toward a health crisis, alerting the caregiver that they should seek professional support (Kitko & Hupcey, 2013). As the patient neared end of life, he or she no longer exhibited these signs, decreasing the caregiver's ability to predict future health needs. Experienced caregivers recognized that to be successful in their role, they needed to develop skills that allowed them to adapt to new situations when they arise (Scott, 2001). The unpredictable nature of a diagnosis of advanced HF contributed to financial challenges for caregivers (Hupcey et al., 2010, 2011; Kitko & Hupcey, 2013; Scott, 2000). This occurred at a time when it was typical for additional costs to be incurred such as travel to and from hospital, accommodation, meals, payment for medical treatments, and new medication costs (Hupcey et al., 2010, 2011; Kitko & Hupcey, 2013; Scott, 2001).

Gaining strength

The theme of gaining strength encompasses the personal growth that the caregiver attributes to the experience of caregiving. Despite reports of feeling overwhelmed by the caregiving role and concerning themselves with "What if I did something wrong?" several participants reported an increased sense of satisfaction from these additional responsibilities (Scott, 2001, p. 230). Caregivers credited these positive effects of caregiving to the development of new skills and the strengthening of the relationship between caregiver and patient.

Developing new skills

This subtheme includes the development of both cognitive and physical skills. As a result of undertaking the caregiving role, caregivers gained skills in providing physical care (Aldred et al., 2005; Braannstrom et al., 2007; Kitko & Hupcey, 2013; Saunders, 2012). These skills included wound care, patient assessment for symptom deterioration, titration of medication doses based on pertinent clinical data, and administering intravenous medications in the home environment (Hupcey et al., 2011; Scott, 2001). These skills were often equated with the job of a nurse and, although they initially proved to be anxiety provoking, once mastered, these tasks contributed to an increase in caregiver self-esteem (Hupcey et al., 2011; Scott, 2001). Skills gained as caregiver could be transferrable to other areas of life; for example, one caregiver reported using her skills learned as a caregiver to improve her own health status (Buck et al., 2013). Another caregiver reported an increase in her ability to problem solve as a result of the experience of caregiving (Scott, 2001).

Growing together

The subtheme of growing together entailed both negative and positive aspects. It is evident in the literature that caregivers

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

Table 1. Characteristics of articles

Reference	Purpose/problem	Sample	Design	Instrument	Results related to caregivers	Country of origin/quality appraisal score
Aldred, Gott & Gariballa, 2005; Advanced heart failure: impact on older patients and informal carers. *Journal of Advanced Nursing*	To describe the effect of advanced HF on the patient and the caregiver	6 females; 4 males **Age** Mean: 71 Range: 60–77 **Relationship** Spouse: 100%	Qualitative	Interview guide	Negative effect included loss of social network/ feelings of isolation/reduced time with family. Lack of information about diagnosis, healthcare practitioners lacked time to provide support. Caregivers wanted information on the experience of dying but felt uncomfortable talking to patients about their death. Communication issues- unclear who to contact regarding concern. Caregiver provided emotional/ physical support	United Kingdom/ strong
Alonso, Hupcey, and Kitko, 2017; Caregivers' perceptions of illness severity and end of life service utilization in advanced heart failure. *Heart & Lung*	Describe the perceptions of illness and severity of family caregivers of individuals with advanced HF.	64 females, 16 males **Age** Mean: 60 Range: NR **Relationship** Spouse/ partner: 66% Child: 25% Sibling: 5% Friend: 2.5% Parent: 1.25%	Qualitative Descriptive design	Interview guide developed by principle investigator. Seattle Heart Failure Model tool was used to measure patient's predicted time of survival.	Majority of caregivers were unaware of disease severity and the possibility of death in the imminent future.	United States/ moderate
Brannstrom Ekman, Boman, et al., 2007; Being a close relative of a person with severe, chronic heart failure in palliative advanced home care: A comfort but also a strain. *Scandinavian Journal of Caring Sciences*	To gain an understanding of the lived experience of being a relative of an individual with advanced HF (NYHA class III and IV) who receives palliative home care	3 females **Age** Mean: NR Range: 50–75 **Relationship** Spouse: 67% Adult child: 33%	Qualitative Phenomenological hermeneutic interpretation One to two interviews conducted per participant	Open-ended question interview guide	Palliative home care reduces feelings of burden for the close relative, reduces need for medical/hospital visits, and improves quality of life by reducing isolation, improves relative's health status despite support from palliative home care, caregivers experienced emotional and physical burden. Relatives expressed a need to maintain normality (i.e., visiting friends, getting out for a walk)	Sweden/ moderate
Brush, Budge, Alharethi, et al., 2010; End of life	To identify issues that caregivers and patients	20 caregivers (gender NR)		Interview guide	Caregivers participated in end-of-life discussions	United States/ moderate

(*Continued*)

Table 1. (*Continued.*)

Reference	Purpose/problem	Sample	Design	Instrument	Results related to caregivers	Country of origin/quality appraisal score
decision making and implementation in recipients of destination left ventricular assist devices. *The Journal of Heart and Lung Transplantation*	encounter during the end of life period when a patient has a left ventricular assist device.	**Age** Mean: NR Range: NR **Relationship** Spouse: 85% Adult child: 10% Parent: 5%	Qualitative Single interview per participant		regarding discontinuation of the LVAD and at times, initiated the conversation. This discussion occurred with the health care team. Multiple caregivers in the study felt comforted by this conversation. Educational needs included information of experience of dying once pump was turned off and how to manage side effects of pump removal such as anxiety, pain, and shortness of breath	
Buck, Zambroski, Garrison, et al., 2013; Everything they were discussing, we were already doing. Hospice heart failure caregivers reflect on a palliative caregiving intervention. *Journal of Hospice and Palliative Nursing*	To determine if the COPE intervention is effective for caregivers of individuals with advanced HF. COPE intervention involves professional guided support through a series of commonly encountered problem-based scenarios.	5 females, 2 males **Age** Mean: 69 Range: NR **Relationship** Spouse: 57% Adult child: 29% Sibling: 14%	Qualitative descriptive design Single interview per participant	Semistructured interview guide	Intervention not useful for experienced caregivers. Caregivers reporting positive experience with hospice care were less likely to use expert information on symptom management. In some cases, the intervention served to increase caregiver burden. The information presented during the intervention confirmed to multiple caregivers that they were doing a good job in their role.	United States/ moderate
Davidson, Abernethy, Newton, Clark, et al., 2013; The caregiving perspective in heart failure: A population based study. *BMC Health Services Research*	To identify unique characteristics of caregivers of individuals diagnosed with palliative HF.	54 females; 30 males **Age** Mean: 55 Range: NR **Relationship** Spouse: 17% Other: 83%	Quantitative Cross sectional	Data extracted from the South Australian Health Omnibus, a random survey administered in person with telephone follow-up.	HF caregivers with older, less likely to consult with palliative care services before death and less likely to received assistance with hands on care.	Australia/ strong
Dracup et al., 2004; Emotional well-being in spouses of patients with advanced heart failure. *Heart and Lung*	To measure the sense of well-being of spouses of individuals with advanced HF and identify potential factors the influence well-being including how feelings of control influence reported measurements.	52 females, 17 males **Age** Mean: 54 Range: 30–77 **Relationship** Spouse: 100%	Quantitative Cross sectional	Emotional wellbeing measurement using the 36-item short form health survey Perceived control measure using the Control Attitudes Scale-Family Version Caregiver burden- Caregiver Appraisal Tool	Well-being measures were lower than for the average population. **Age** appeared to influence sense of well-being with younger ages reporting lower levels. Feelings of control had a positive influence on well-being whereas perceived	United States/ moderate

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

					caregiver burden had a negative influence on well-being	
Hupcey, Fernstermacher, Kitko, et al., 2010; Achieving medical stability: Wives' experiences with heart failure. *Clinical Nursing Research*	To identify palliative care needs of wives caring for individuals with advanced HF. To present case studies from the perspective of multiple illness trajectories as experienced by wives caring for individuals with palliative HF less than 65 years of age.	26 females **Age** Mean: 55 Range: 27–68 **Relationship** Spouse: 100%	Qualitative Grounded theory Monthly interviews for a 12-month period Time period of study: NR	None identified.	Case 1, sudden death: unexpected shock, reflection needed to process death Case 2, slow decline; gradual increase of responsibilities, feeling loss of previous abilities, increase in financial difficulties Case 3, awaiting heart transplant: fear of the unknown, financial burden, coming to terms Case 4, after device placement: anxiety related to device function, enhanced function with lack of clarity on how long these improvements would last, living in the moment Case 5, slow decline with hospice: sense of peace, period of mourning	United States/ moderate
Hupcey, Fenstermacher, Kitko, et al., 2011; Palliative needs of spousal caregivers of patients with heart failure followed up at specialized heart failure centers. *Journal of Hospice & Palliative Nursing*	To identify the changing needs of caregivers of individuals with advanced heart as the disease progresses through the palliative period.	39 females, 6 males **Age** Mean: 60 Range: 27–76 **Relationship** Spouse: 100%	Qualitative Grounded theory	Interview guide	Needs changed based on the disease trajectory. Informational needs Psychosocial needs Physical needs Unstable: overwhelmed by physical care required to support patient (i.e., medical changes and new devices-tired from multiple roles in addition to caregiving (i.e., work/caring for children/adult parent) Stable: caregivers were able to address their own health needs	United States/ moderate
Kaasalainen, Strachan, Brazil, et al., 2011; Managing palliative care for adults with advanced heart failure. *Canadian Journal of Nursing Research*	An exploration of community services provided to persons dying from HF and barriers that they experience from the perspectives of the patient, caregiver, and healthcare professionals.	8 females, 2 males **Age** Mean: 65 Range 35–85 **Relationship** Spouse: 70% Adult child: 30%	Qualitative	Semi-structured interview guide	Challenges: manage role, accessing resources, transitioning from cardiac care team to palliative team, caring for own physical/ mental health, increased role responsibility, isolation Effective care: interprofessional teams Coping strategies: spiritual, importance of marriage	Canada/strong

(*Continued*)

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

Table 1. (*Continued.*)

Reference	Purpose/problem	Sample	Design	Instrument	Results related to caregivers	Country of origin/quality appraisal score
Kitko & Hupcey, 2013; The work of spousal caregiving of older adults with end-stage heart failure. *Journal of Gerontological Nursing*	To gain an understanding of the work the caregiver of a patient with end-stage HF.	14 females, 6 males **Age** Mean: 67 Range 46–78 **Relationship** Spouse: 100%	Qualitative Grounded theory		Work of the spousal caregiver included providing care (physical and emotional care), navigating the system (medical, financial, government), maintaining self, managing the household (income, compensating for pts previous roles) Vigilance (constantly monitoring patient), Normalcy (organizing daily events around fluctuating health status, developing routines)	United States/ moderate
Luttik, Jaarsma, Veeger, et al., 2005; For better and for worse: Quality of life impaired in HF patients as well as their partners. *European Journal of Cardiovascular Nursing*	To assess the quality of life of patients with NYHA stage III and IV HF and their partners	32 females, 6 males **Age** Mean: 64 Range: NR **Relationship** Spouse: 100%	Quantitative Cross sectional	Cantril Ladder of Life (to assess quality of life)	Informal caregivers of persons with HF had lower quality of life measures than the general population, but better than patient except at times of hospitalization where quality of life measures were lower for caregivers. Little variation in caregiver reported measures between past, present, and future	Netherlands/ weak
MacKenzie, Buck, Meghani, et al., 2016; Unique correlates of heart failure and cancer caregiver satisfaction with hospice care. *Journal of Pain and Symptom Management*	To determine correlates to caregiver satisfaction with hospice care for individuals dying from heart failure in comparison to individuals with cancer.	5,420 females; 1,904 male **Age** Mean: 65 Range: NR **Relationship** NR	Quantitative Retrospective cohort sudy	Family Evaluation of Hospice Care	Care in nursing home was related to reduced caregiver satisfaction Higher caregiver education was correlated with higher overall caregiver satisfaction. Caregivers who perceived that the person with HF was experiencing high levels of dyspnea and pain were less likely to be satisfied with hospice care. 93% reported satisfaction with symptom management in hospice	United States/ weak
Mårtensson, Dracup, and Fridlund, 2001; Decisive situations influencing spouses' support of patient with heart failure: A critical incident technique analysis. *Heart & Lung*	To identify critical incidents that have a positive or negative effect on support that the patient receives from the informal caregiver.	15 females, 8 males **Age** Mean: 75 Range: 62–86 **Relationship** Spouse: 100%	Qualitative Descriptive design	Semistructured interview guide	193 decisive situations identified that were categorized into two main themes (1) Involvement with others (2) Feeling like an outsider	Sweden/ moderate
McIlvennan, Jones, Allen, et al., 2016; Bereaved	To understand the experience of bereaved	6 females, 2 males	Qualitative Descriptive design	Semistructured interview guide	Themes: (1) confusion about the process of death with an	United States/ strong

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

caregiver perspectives on the end-of-life experience of patients with a left ventricular assist device. *JAMA Internal Medicine*	caregivers and patients at the end of life who have a LVAD	**Age** Mean: 64 Range: 54–71 **Relationship** Widow: 63% Mother: 13% Friend: 25%	Single interview per participant		LVAD, (2) confusion about the legal and ethically permissible care of patients approaching death with an LVAD, and (3) confusion about the fragmented integration of palliative and hospice care	
McMillan, Small, Haley, et al., 2013; The COPE intervention for caregivers of patients with heart failure. *Journal of Hospice and Palliative Nursing*	To test the effectiveness of the COPE Intervention for caregivers of patients with HF. COPE is a professionally guided support that teaches caregivers skills for stress and medical management through a series of problem-based scenarios that family caregivers commonly encounter.	28 females, 12 males **Age** Mean: 63 Range: NR **Relationship** Spouse: 43% Adult child: 40% Other: 17%	Quantitative Two-group mixed-methods comparative experimental design with repeated measures	Caregiver Quality of Life Index Caregiver Anxiety and Depression Hospice Quality of Life Index Caregiver Demands Scale Perceived Illness-Related Stressors in Caregivers Caregiver Knowledge Test	No significant differences between groups related to depression scores, caregiver distress, anxiety, quality of life, or knowledge pre- or postintervention.	United States/ strong
Murray, Kendall, Boyd, et al., 2004; Exploring the spiritual needs of people dying of cancer or heart failure: A prospective qualitative study of patients and their caregivers. *Palliative Medicine*	To identify the spiritual needs of patients who are dying from HF or cancer and the needs of their caregivers	20 caregivers (gender NR) **Age** Mean: NR Range: NR **Relationship** NR	Qualitative Interviews at 3-month intervals for up to 1 year	Researcher-developed interview guide	Caregivers have spiritual needs that are not being addressed Potential for spiritual concerns included role conflicts, loneliness, isolation, reliance on others, negative perceptions of situation	United Kingdom/ moderate
Pressler, Gradus-Pizlo, Chubinski, et al., 2013; Family caregivers of patients with heart failure: A longitudinal study. *Journal of Cardiovascular Nursing*	To evaluate the differences between caregiving for individuals with advanced HF and individuals with a lower severity of symptom.	48 females, 15 males **Age** Mean: 69 Range: 24–86 **Relationship** Spouse: 68% Adult child: 21% Other: 11%	Quantitative Longitudinal Baseline, 4-month and 8-month questionnaires	The Oberst Caregiving Burden Scale Control Attitudes Scale The Patient Health Questionnaire-8 Brief Symptom Inventory Anxiety Subscale The Bakas Caregiving Outcomes Scale The Medical Outcomes Study Short- Form The Charlson Comorbidity Index The Family Functioning Assessment Device	Caregivers of stage III and IV patients reported increased time spent on caregiving, higher anxiety, increased difficulty in caregiving tasks. and lower physical health/ quality of life compared with caregivers of persons with HF NYHA class I and II.	United States/ weak
Saunders, 2012; Perspectives from family caregivers receiving home nursing support. *Home Healthcare Nurse*	Exploratory study that discusses the experience of caregivers of individuals with HF who receive support through a home care agency	7 females, 4 males **Age** Mean: 66 Range: NR **Relationship** Spouse: 73%	Qualitative Emergent design	Researcher-developed interview guide	Supportive family, religious practices and home care support are seen as beneficial Mental and physical health is compromised Large amount of time spent on assisting with activities of daily living (i.e., dressing, eating) Hospitalizations were seen as	United States/ strong

(*Continued*)

Table 1. (*Continued.*)

Reference	Purpose/problem	Sample	Design	Instrument	Results related to caregivers	Country of origin/quality appraisal score
		Adult child: 27%			challenging and were avoided -desire for personal time and for patient to regain health	
Scott, 2000; Caregiving and care receiving among a technologically dependent heart failure population. *Advances in Nursing Science*	To determine measures of quality of life for patients with end-stage HF and their caregivers	16 females, 2 males **Age** Mean: 63 Range: 40–80 **Relationship** Spouse: 90% Daughter: 5% Sister: 5%	Quantitative Cross sectional	The eight-item Caregiver Preparedness Scale The Minnesota Living with Heart Failure Questionnaire The 24-item Caregiver Reaction Assessment Mental Health Inventory-5 The Quality of Life Index	Caregivers felt somewhat prepared to handle their role. -most prepared to access and use resources and provide hands on care to patient -least prepared to manage emergency situations, manage stress, and other psychosocial issues such as anxiety. Mental health scores of caregivers were below average −50% reporting anxiety −45% reporting depression and 39% reporting a loss of hope. Other concerns included finances, personal health, lack of time for own interests	United States/ weak
Scott, 2001; Technological caregiving: A qualitative perspective. *Home Health Management and Practice*	To describe the experience of caregiving for an individual with end-stage HF who are dependent on inotropic infusions.	3 females, 1 male **Age** Mean: 71 Range: 62–80 **Relationship** Spouse: 100%	Qualitative Single interview per participant	Interview guide	Positive and challenging experiences reported specifically noted were financial, psychosocial (depression), self-care (lack of sleep, nutrition deficit or overeating), behavioral (changing role patterns) Fear of unknown future/lack of routine, feeling unprepared to fulfill role of “nurse,” obligation to provide care, territorial of patient care provision, socially isolated. increased role responsibilities, anxiety about death of spouse	United States/ moderate
Selman, Harding, Beynon, Hodson, et al., 2007; Improving end-of-life care for patients with chronic heart failure: “Let’s hope it’ll get better, when I know in my heart of hearts it won’t.” *Heart: British Medical Journal*	To develop guidelines for end of life care for individuals with advanced HF	11 caregivers No further data reported for caregivers.	Qualitative Single interview per participant	Semistructured interview guide	Some caregivers felt it would be okay to discontinue active treatment if the patient was having uncontrolled pain, low quality of life, or decline mental function, whereas other caregivers felt that was the decision of the physician or the patient. Discussion between physician	United Kingdom/ moderate

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

					and caregiver around end of life was limited. Anxiety, dread, and guilt were common themes for caregivers.	
Small et al., 2009; Dying, death and bereavement: a qualitative study of the views of carers of people with heart failure in the UK. *BioMed Central (BMC) Palliative Care*	To describe the end of life and bereavement period for caregivers of individuals who died from HF.	17 females, 3 males **Age** Mean: NR Range: 60–70 **Relationship** Spouse: 65% Adult child: 35%	Qualitative Single interview per participant	Interview guide	Lack of discussion about the end-of-life experience before death. Caregivers found support from spiritual beliefs. Sudden death at home preferred over slow decline or death in hospital however this was not the case in all situations. Caregivers recalled unnecessary tests before death and this reduced feelings of peace at end of life. Depression and isolation were common in the bereavement period.	United Kingdom/ strong
Walden, Dracup, Westlake, et al., 2001; Educational needs of patients with advanced heart failure and their caregivers. *The Journal of Heart and Lung Transplantation*	To identify educational needs of patients with advanced HF and their caregivers	55 females, 17 males **Age** Mean: 52 Range: NR **Relationship** Spouse: 100%	Quantitative, cross sectional	Researcher-developed questionnaire	Top three identified caregiver needs: 1. Desire for quality of life 2. Honest explanations from professional members 3. Information about how to react in an emergency situation Least important caregiver needs- 1) patient appearance after transplant surgery 2) employment 3) information regarding sexual activity 4) time on own	United States/ weak

COPE, Creativity, Optimism, Planning, and Expert information; HF, heart failure; LVAD, left ventricular assist device; NYHA, New York Heart Association; NR, not reported.

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

commonly reported experiencing a sense of frustration and resentment when interacting with the care recipient, specifically when they did not attempt to reciprocate care when they had the ability (Hupcey et al., 2011) or when conversation between the patient and the caregiver was limited (Mårtensson et al., 2001). In some cases, caregivers undertook their role from a sense of obligation to the care recipient rather than a desire to provide care (Scott, 2001). Despite these challenges, positive outcomes resulted from the caregiving experience such as the additional time spent with the patient allowed for the development of a deeper relationship (Braannstrom et al., 2007; Scott, 2001). In addition, the psychological support that caregivers provided allowed both the caregiver and patient an opportunity in which time was spent focusing on the positive aspects of life (Aldred et al., 2005; Braannstrom et al., 2007; Kitko & Hupcey, 2013; Scott, 2000). When faced with the inevitability that end of life for the patient may be nearing, the caregiver began to view each additional day with the patient as a gift (Scott, 2001).

Forgetting oneself along the way

The experience of caregiving for persons with advanced HF involved an intense focus on the patient. Caregivers described the experience as "constantly watching thinking something is going to happen with their [the patient's] heart" (Braannstrom et al., 2007, p. 4), which led to caregivers neglecting their own needs in favor of meeting the needs of the patient (Kaasalainen et al., 2011; Walden et al., 2001). Two subthemes emerged from the data: (1) neglect of personal health and (2) making sacrifices.

Neglect of personal health

Caregivers of those with advanced HF experience a higher degree of burden to physical and mental health when compared with caregivers of persons with HF who experience low to moderate symptoms (NYHA class I or II) (Pressler et al., 2013). As additional responsibilities common to end of life were added to the role of the caregivers, it became increasingly difficult for them to address their own personal health needs (Hupcey et al., 2011; Saunders, 2012; Scott, 2000, 2001). The limited emphasis on self-care were in relation to improper diet, poor sleep habits, and failure to make medical appointments for their own health issues (Braannstrom et al., 2007; Kitko & Hupcey, 2013; Scott, 2001).

Caregivers identified that to maintain mental health it was important to participate in activities unrelated to the patient such as watching television, praying, physical activity, or socializing (Aldred et al., 2005; Braannstrom et al., 2007; Kaasalainen et al., 2011; Kitko & Hupcey, 2013; Murray et al., 2004; Scott, 2001); however, caregivers often neglected to take this advice and would only participate in activities outside of the home when the patient's symptoms had been effectively managed (Hupcey et al., 2011; Kitko & Hupcey, 2013). Further, these activities would frequently center on meeting needs of the patient such as obtaining medications (Braannstrom et al., 2007).

Making sacrifices

The experience of caregiving for those with advanced HF involved making sacrifices which can be defined as discontinuing something you enjoy to allow for participation in another thing of value. For example, caregivers reported being unable to travel because it was not recommended for the patient (Aldred et al., 2005; Scott, 2001). This resulted in a large percentage of time being spent in the home setting, which contributed to a sense of isolation from their surrounding community (Aldred et al., 2005; McMillan et al., 2013; Saunders, 2012). Because of the time requirements needed to provide care for a person with advanced HF, many caregivers felt they needed to give up hobbies that they had once enjoyed (Aldred et al., 2005).

Seeking out sources of support

The advanced period of HF is chaotic and, as such, caregivers are required to seek out additional sources of support; however, proclamations such as "I have to support, I have to take care of everything" (Kaasalainen et al., 2011, p. 48) show that caregivers felt alone in their experience. When discussed, identified sources of support included other family members, friends, and professional members of the healthcare team. Caregivers admitted to being hesitant in requesting assistance because they felt others were too busy to provide support and/or they did not want to be seen as a burden (Buck et al., 2013; Hupcey et al., 2011; Murray et al., 2004; Scott, 2001). Support from a palliative care team was seen as an asset (Braannstrom et al., 2007; Hupcey et al., 2010; MacKenzie et al., 2016); however, persons affected by advanced HF were not consistently referred to these sources of support (Alonso et al., 2017; Davidson et al., 2013; Kaasalainen et al., 2011).

The quality of support the caregiver received during the advanced period through to end of life appeared to have a strong influence on whether the experience of caregiving was seen as positive or negative (Buck et al., 2013; Mårtensson et al., 2001). Interventions viewed as supportive included arranging for assistance with physical care, encouraging contact for personal needs rather than solely focusing on the patient, and allowing time for discussion about the caregiving experience using positive language (Mårtensson et al., 2001; Murray et al., 2004). Caregivers also felt supported when they were given straightforward information about the patient's needs and current health status (Hupcey et al., 2011; Walden et al., 2001). A negative experience of caregiving was reported when professionals providing support appeared rushed, when outside support did not provide information to the caregiver, or when communication was lacking between supportive services (Aldred et al., 2005; Braannstrom et al., 2007; Kitko & Hupcey, 2013; Mårtensson et al., 2001; McIlvennan et al., 2016; Saunders, 2012).

Preparing for end of life

Preparation for end of life includes any task that would assist caregivers in the transition from active treatment to acceptance of the possibility of death of the patient. A prime concern of caregivers at end of life was a desire "to receive information about action steps to take in an emergency" (Walden et al., 2001, p.767), illustrating a need to feel equipped for future challenges, although varying degrees of preparedness related to the possibility of death were demonstrated. Areas of preparation reported by caregivers were mainly focused in three areas: (1) mental preparedness, (2) educational concerns, and (3) making difficult decisions.

Mental preparedness

Lack of or delayed discussion about the topic of end of life created a barrier for caregivers to become mentally prepared for the possibility of death of the patient. Caregivers reported knowing that death in the near future was plausible (Aldred et al., 2005;

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

Alonso et al., 2017; Murray et al., 2004; Scott, 2001) but, healthcare providers had not brought the topic up with them and caregivers felt uncomfortable initiating the conversation (Aldred et al., 2005; Alonso et al., 2017; Braannstrom et al., 2007; Murray et al., 2004; Small et al., 2009). Caregivers reported relief when a healthcare professional would broach the subject of end of life because it allowed them to begin to develop a plan for the future (Brush et al., 2010). Reasons cited for avoidance of the topic of death included a wish to maintain a sense of optimism for the patient, feeling uncomfortable about the topic, and/or a lack of knowledge about how to address the matter (Aldred et al., 2005; Small et al., 2009). Once the patient had died, caregivers reported that they had not been mentally prepared for this experience (Alonso et al., 2017; Davidson et al., 2013; Hupcey et al., 2010). Caregivers that received support through palliative care or had access to hospice services were more likely to report being mentally prepared for death or the possibility of death in the future (Hupcey et al., 2010).

Educational concerns

If caregivers were able to acknowledge that HF was a life-limiting illness, they attempted to prepare themselves for end of life by acquiring knowledge. Educational requests included a description of their role when presented with an emergency situation such as when the care recipient's heart stops beating (Braannstrom et al., 2007; Mårtensson et al., 2001; McIlvennan et al., 2016; Selman et al., 2007). Caregivers also reported an eagerness to visualize the end-of-life experience, questioning if pain or anxiety for the patient would be involved (Brush et al., 2010; McIlvennan et al., 2016). These questions commonly remained unanswered, creating a sense of frustration and confusion for caregivers (Aldred et al., 2005; McIlvennan et al., 2016; Small et al., 2009). Caregivers who had already experienced a person dying from HF reported multiple end-of-life scenarios including sudden death, gradual worsening of symptoms, or rapid improvement followed by an unexpected death (Brush et al., 2010; Hupcey et al., 2010; Small et al., 2009). As such, it is difficult to predict which disease trajectory with which the caregiver will be presented.

Making difficult decisions

Because those with advanced HF showed a significant deterioration in health status, caregivers found themselves assisting patients' in making choices that would influence the end-of-life experience. A common decision required of caregivers concerned whether to access palliative resources such as home care or hospice (Alonso et al., 2017; Braannstrom et al., 2007; Hupcey et al., 2011). Other decisions were related to patient hospitalizations, such as the decision whether to bring the patient to the hospital for symptom relief versus staying at home to manage care (Aldred et al., 2005), to decline tests and procedures at end of life that the family deemed unnecessary (Aldred et al., 2005; Small et al., 2009), or to discontinue current life-prolonging treatments including medications and deactivation of an LVAD (Brush et al., 2010; McIlvennan et al., 2016). Caregivers reported that decisions at end of life were based on what would provide the best quality of life for the patient and would result in the lowest degree of pain and anxiety (Selman et al., 2007).

Finding closure

The experience of caregiving does not end once the patient dies. As one participant would describe the experience after death, it is "like falling into a deep pit" (Small et al., 2009, p. 5). The theme of finding closure illustrates the experience of the caregiver during the bereavement period. Findings during this period were conflicted with some caregivers reporting an increase in socialization, whereas others reporting that they remained isolated (Small et al., 2009). All caregivers discussed some level of grief following the death of the person with HF (Davidson et al., 2013; Small et al., 2009), with a high percentage reporting that they were able to eventually resolve their grief (Davidson et al., 2013). Professional support during the bereavement period was seen as beneficial but support services were not commonly accessed by the caregiver (Davidson et al., 2013; Small et al., 2009). Discussion related to the bereavement period was limited to two articles indicating a need for further research in this area.

Discussion

Finding interventions that support the needs of caregivers of persons with advanced HF needs to be a priority. Within this review, only one intervention was tested with caregivers of persons with advanced HF (Table 1) and this intervention was shown to be ineffective (Buck et al., 2013; McMillan et al., 2013). Current guidelines in HF care have identified that incorporating the caregiver into the plan of care is essential (Howlett et al., 2016); however, it does not elaborate on including specific interventions, leaving practitioners with little research evidence to guide their practice in working with caregivers. A review of caregiver interventions for persons with a life-limiting illness identified 12 interventions that have been shown to be effective in improving the caregiver's ability to manage their caregiving role (Candy et al., 2011) with 11 of these interventions being developed specifically for caregivers of persons with cancer. Because of unique differences between each diagnosis, it is not advisable to generalize results from one disease population to another and expect the same outcomes (Molloy et al., 2005). Results generated from this integrative review provide a wider scope of the identified problem area that serves to generate new knowledge on the topic (Torraco, 2005; Whittemore & Knafl, 2005) and can inform development of caregiver interventions. See Table 2 for recommendations for practice based on this research.

Barriers in the accessibility of palliative services was also identified in this review as an issue for caregivers of persons with advanced HF. Patients with chronic obstructive pulmonary disease, a disease with a disease trajectory comparable to HF, encountered limitations with accessing palliative services (Curtis, 2008). Reasons cited for this included a lack of adequate communication about the life-limiting nature of the diagnosis and an inability to predict when end of life will occur, which are identical to the challenges that caregivers of individuals with advanced HF experience. It may be beneficial for key players from both chronic obstructive pulmonary disease and HF to work together to develop a strategy to improve patient services at end of life. In general, there are a multitude of reasons that a caregiver may not have adequate access to support services which are unique to the caregiver (Adelman et al., 2014); therefore, interventions to increase access to support services need to be individualized to the caregiver.

Within this review, caregivers who had experienced the death of the patient commonly expressed that the event had been unanticipated and were therefore not prepared for end of life (Hupcey et al., 2010; McIlvennan et al., 2016; Small et al., 2009). An unexpected death has been shown to increase the caregiver's risk for

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

Table 2. Recommendation for practice based on research findings

Assess the learning needs of the caregiver throughout the entire caregiving experience. Specific needs identified included emergency preparedness in the home, possible end-of-life scenarios, and awareness of the life-limiting nature of HF.
Caregiver support during the bereavement period could be improved through consistent professional follow-up after the person with advanced HF has died.
Not all bereaved caregivers will require support to assist in processing their grief; therefore, to allow for effective use of resources, services should be prioritized based on need, paying particular attention to caregivers of persons with advanced HF who have unexpectedly died from sudden cardiac death.
Encourage caregivers to access respite services to meet their own individual needs and assist in identifying activities if necessary.
Healthcare professionals should receive additional training in the areas of palliative care for persons with life-limiting illnesses to increased confidence with having discussions about end of life.

HF, heart failure.

ineffective coping during bereavement (Shah et al., 2013). Increased referrals to palliative or hospice services for patients living with advanced HF, preferably at the beginning of the disease trajectory, could assist in preparing families for the end-of-life period (Howlett et al., 2010), increasing the likelihood that caregivers will effectively cope with feelings of grief in bereavement. Emotional distress that results from ineffective coping during bereavement can increase the caregiver's risk of mortality (Stroebe et al., 2007). Although it may not be feasible to provide bereavement services to every person who has taken on the role of caregiver for those with advanced HF, by investigating what aspects of the situation place people at an increased risk for prolonged grief and ineffective coping, services can be targeted and those at risk should be offered additional supports when necessary (Ghesquiere et al., 2011).

Within this review, only two articles (Davidson et al., 2013; Small et al., 2009) focused on the caregiving experience following the death of the person with advanced HF. It is not uncommon for this phase of the caregiving journey to be neglected in the literature (Ume & Evans, 2011). In clinical practice, healthcare professionals, such as nurses, providing palliative care state busy schedules do not allow for time to provide support to caregivers in the bereavement period (Johnson, 2015). Not all bereaved caregivers will require support to assist in processing their grief (Faull & Taplin, 2012), and therefore to allow for effective use of resources, services should be prioritized based on need, paying particular attention to caregivers of persons with advanced HF who have unexpectedly died from sudden cardiac death.

Based on the current understanding of the experience of caregiving for persons with advanced HF, it could be argued that this group of caregivers are at an increased risk for complicated grief and failure to cope post death. One reason for this increased risk is related to the frequent reports from caregivers of the lack of effective communication between health care professionals and patients at end of life (Aldred et al., 2005; Braannstrom et al., 2007; Hupcey et al., 2011; Kaasalainen et al., 2011; Kitko & Hupcey, 2013; McIlvennan et al., 2016). Research has shown that ineffective communication with healthcare professionals before the death of the patient limits the caregiver's ability to effectively manage feelings of loss in bereavement (DiGiacomo et al., 2013). Caregivers have a desire for open and honest discussions about death (Thorne et al., 2004). It is also recommended that caregivers are aware that HF is a life-limiting disease and that they receive information on possible end-of-life scenarios.

Limitations of the review

The majority of caregiver participants (86.3%) indicated they were a spouse of the person with advanced HF. The large percentage of spouses within the sample limits the generalizability of the current state of the advanced HF caregiver literature as research has demonstrated that spouses report unique caregiving experiences (Penning & Wu, 2016). When compared with adult children (Pinquart & Sorensen, 2006), siblings, parents, and friends (Penning & Wu, 2016), spouse caregivers report a lower quality of life, increased incidence of depression, and/or financial strain. Therefore, these measures may be overestimated in the results of this review. Same sex couples have also been shown to have individualized needs based on their distinct experiences such as a perceived feeling of discrimination within the healthcare setting (Czaja et al., 2016); however, only one same-sex couple was included in the studies analyzed for this review. In other bodies of caregiver literature, such as research related to caregivers of persons with dementia, an effort has been made to analyze each caregiver relationship in isolation (Day et al., 2014; Lee et al., 2016; Tan & Schneider, 2009). This approach to research development should be replicated in future research related to caregivers of persons with HF as each relationship offers a unique insight into the caregiving experience.

The male perspective is limited within the literature in this review with males constituting 26% of the caregiver sample. The caregiving experience varies between the male and female population (Hammond-Collins et al., 2014). Cultural background has been shown to influence the experience of caregiving. Cho, Ory, and Stevens (2016) found that when compared with Hispanic and African American caregivers, Caucasian caregivers reported fewer positive aspects of caregiving. The majority of caregivers within this review were Caucasian, which could have influenced the reported experiences.

Implications for research

From a research perspective, the current understanding of the caregiving experience for persons with advanced HF needs to be expanded. An enhanced understanding could be achieved by addressing current gaps in the literature that have been identified within this review. As discussed previously, this can include conducting research using participants from different cultural groups, comparing experience by gender, and exploring different relationship structures (such as same-sex marriages). Future research should also avoid solely focusing on the negative aspects of the caregiving experience. Priorities for future research include exploring the experience of bereavement and the development of effective caregiver interventions

Conclusion

The intent of this integrative review was to create a thematic framework for the current state of literature related to informal caregiving of persons with advanced HF from the perspective of the caregiver. To our knowledge, this is the first integrative review that sought to bring together available quantitative and qualitative

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

research specific to the advanced period of caregiving, including end of life and bereavement, for caregivers of persons with HF. Analysis of the included studies identified six key themes: (1) undertaking a journey in a state of flux, (2) gaining strength, (3) forgetting oneself along the way, (4) seeking out sources of support, (5) preparing for end of life, and (6) finding closure.

The understanding of caregiving for people with advanced HF remains incomplete, with multiple gaps identified in the literature. Although it will take time to develop a stronger research base, healthcare professionals working in direct contact with patients with advanced HF can improve the experience of caregiving immediately by implementing small, simple changes into their practice (e.g., taking the time to talk with the caregiver, asking for their feedback, and ensuring that the caregiver is involved in the care planning process). Caregivers play an invaluable role in the care of those with HF and they should be seen as a key member of the health care team.

References

Adelman R, Tmanova L, Delgado D, *et al.* (2014) Caregiver burden: A clinical review. *Journal of the American Medical Association* **311**, 1052.

Adler E, Goldfinger J, Kalman J, *et al.* (2009). Palliative care in the treatment of advanced heart failure. *Journal of American Heart Association* **120**, 2597–2696.

Aldred H, Gott M, Gariballa S (2005) Advanced heart failure: Impact on older patients and informal carers. *Journal of Advanced Nursing* **49**(2), 116–124.

American Heart Association (2012) Decision making in advanced heart failure: A scientific statement from the American Heart Association. *Circulation* **125**, 1928–1952.

Alonso W, Hupcey J, Kitko L (2017) Caregivers' perceptions of illness severity and end of life service utilization in advanced heart failure. *Heart & Lung* **46**, 35–39.

Braannstrom M, Ekman I, Boman K, *et al.* (2007) Being a close relative of a person with severe, chronic heart failure in palliative advanced home care: A comfort but also a strain. *Scandinavian Journal of Caring Science* **21**(3), 338–334.

Brush S, Budge D, Alharethi R, *et al.* (2010) End-of-life decision making and implementation in recipients of a destination left ventricular assist device. *The Journal of Heart and Lung Transplantation* **29**(12), 1337–1341.

Buck H, Zambroski C, Garrison C, *et al.* (2013) Everything they were discussing, we were already doing: Hospice heart failure caregivers reflect on a palliative caregiving intervention. *Journal of Hospice & Palliative Nurses* **15**(4), 218–224.

Candy B, Jones L, Drake R, *et al.* (2011) Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database Systematic Reviews **6**.

Cho J, Ory MG, Stevens AB (2016) Socioecological factors and positive aspects of caregiving: Findings from the REACH II intervention. *Aging Mental Health* **20**(11), 1190–1201.

Cubbon RM, Gale CP, Kearney LC, *et al.* (2011) Changing characteristics and mode of death associated with chronic heart failure caused by left ventricular systolic dysfunction: A study across therapeutic eras. *Circulation Heart Failure* **4**(4), 396–403.

Curtis J (2008) Palliative and end-of-life care for patients with severe COPD. *European Respiratory Journal* **32**(3), 796–803.

Czaja SJ, Sabbag S, Lee CC, *et al.* (2016) Concerns about aging and caregiving among middle-aged and older lesbian and gay adults. *Aging & Mental Health* **20**(11), 1107–1118.

Davidson PM, Abernethy AP, Newton PJ, *et al.* (2013) The caregiving perspective in heart failure: A population based study. *BioMed Central Health Services Research* **13**, 342.

Day JR, Anderson RA, Davis LL (2014) Compassion fatigue in adult daughter caregivers of a parent with dementia. *Issues in Mental Health Nursing* **35** (10), 796–804.

DiGiacomo M, Lewis J, Nolan MT, *et al.* (2013) Transitioning from caregiving to widowhood. *Journal of Pain and Symptom Management* **46**(6), 817–825.

Doherty L, Fitzsimons D, McIlfatrick S (2016) Carers' needs in advanced heart failure: A systematic narrative review. *European Journal of Cardiovascular Nursing* **15**(4), 203–212.

Dracup K, Evangelista L, Doering L, *et al.* (2004) Emotional well-being in spouses of patient with advanced heart failure. *Heart and Lung* **33**(6), 354–361.

Faull C and Taplin S (2012) Adapting to death, dying, and bereavement. In *Handbook of palliative care*, 3rd ed. C Faull, S de Caestecker, A Nicholson, *et al.* (eds.), pp. 81–92. Hoboken, NJ: John Wiley & Sons Inc.

Ghesquiere A, Haidar YM, Shear MK (2011) Risks for complicated grief in family caregivers. *Journal of Social Work End Life Palliative Care* **7**(2–3), 216–240.

Glogowska M, Simmonds R, McLachlan S, *et al.* (2016) "Sometimes we can't fix things": A qualitative study of health care professionals' perceptions of end of life care for patients with heart failure. *BioMed Central Palliative Care* **15**, 3.

Glaser B (1965) The constant comparative method of qualitative analysis. *Social Problems* **12**(4), 436–445.

Grant J and Graven L (2018) Problems experienced by informal caregivers of individuals with heart failure: An integrative review. *International Journal of Nursing Studies* **80**, 41–66.

Hammond-Collins K, Peacock S, Forbes D, *et al.* (2014) In sickness and in health: Comparing the experience of husbands and wives caring for someone with dementia. *Perspectives* **37**(3), 6–13.

Heart and Stroke Foundation (2015) *Heart failure*. Retrieved from http://www.heartandstroke.com/site/c.ikIQLcMWJtE/b.3484065/k.9224/Heart_failure.htm

Howlett J, Chan M, Ezekowitz JA, *et al.* (2016) The Canadian Cardiovascular Society Heart Failure Companion: Bridging guidelines to your practice. *Canadian Journal of Cardiology* **32**, 296–310.

Howlett J, Morrin L, Fortin M, *et al.* (2010) End-of-life planning in heart failure: It should be the end of the beginning. *Canadian Journal of Cardiology* **26**(3), 135–141.

Hupcey J, Fenstermacher J, Kitko L, *et al.* (2010) Achieving medical stability: Wives' experiences with heart failure. *Clinical Nursing Research* **19**(3), 211–229.

Hupcey J, Fenstermacher J, Kitko L, *et al.* (2011) Palliative needs of spousal caregivers of patients with heart failure followed up at specialized heart failure centers. *Journal of Hospice & Palliative Nurse*, **13**(3), 142–150.

Hupcey J, Kitko L, Alonso W (2016) Patients' perceptions of illness severity in advanced heart failure. *Journal of Hospice & Palliative Nursing* **18**(2), 110–114.

Johnson A (2015) Role of district and community nurses in bereavement care: A qualitative study. *British Journal of Community Nursing* **20**(10), 494–501.

Kaasalainen S, Strachan P, Brazil K, *et al.* (2011) Managing palliative care for adults with advanced heart failure. Canadian Journal of Nursing Research **43**(3), 38–57.

Kang X, Li Z, Nolan MT (2011) Informal caregivers' experiences of caring for patients with chronic heart failure: Systematic review and metasynthesis of qualitative studies. *Journal of Cardiovascular Nursing* **26**(5), 386–394.

Kitko LA and Hupcey JE (2013) The work of spousal caregiving of older adults with endstage heart failure. *Journal of Gerontological Nursing* **39**(7), 40–47.

Kitko LA, Hupcey JE, Pinto C, *et al.* (2015) Patient and caregiver incongruence in advanced heart failure. *Clinical Nurse Researcher* **24**(4), 388–400.

Lee J, Sohn BK, Lee H, *et al.* (2016) Impact of behavioral symptoms in dementia patients on depression in daughter and daughter-in-law caregivers. *Journal of Womens Health* **26**, 36–43.

Luttik M, Jaarsma T, Veeger N, *et al.* (2005) For better and for worse: Quality of life impaired in HF patients as well as their partners. *European Journal of Cardiovascular Nursing* **4**, 11–14.

MacKenzie M, Buck H, Meghani S, *et al.* (2016) Unique correlates of heart failure and cancer caregiver satisfaction with hospice care. *Journal of Pain and Symptom Management* **51**, 71–78.

Mårtensson J, Dracup K, and Fridlund B (2001) Decisive situations influencing spouses' support of patients with heart failure: A critical incident technique analysis. *Heart & Lung* **30**(5), 341–350.

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press

McIlvennan C, Jones J, Allen L, *et al.* (2016) Bereaved caregiver perspectives on the end-of-life experience of patients with a left ventricular assist device. *Journal of the American Medical Association: Internal Medicine* **176**(4), 534–538.

McMillan S, Small B, Haley W, *et al.* (2013) The COPE intervention for caregivers of patients with heart failure: An adapted intervention. *Journal of Hospice & Palliative Nursing* **15**(4), 196–206.

Molloy GJ, Johnston DW, Witham MD (2005) Family caregiving and congestive heart failure: Review and analysis. *The European Journal of Heart Failure* **7**(4), 592–603.

Murray S, Kendall M, Boyd K, *et al.* (2004) Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. *Palliative Medicine* **18**, 39–45.

National Collaborating Center for Methods and Tools (2008) *Quality assessment tool for quantitative studies*. Retrieved from http://www.nccmt.ca/resources/search/14

Penning MJ and Wu Z (2016) Caregiver stress and mental health: Impact of caregiving relationship and gender. *Gerontologist* **56**(6), 1102–1113.

Pinch W (1995) Synthesis: Implementing a complex process. *Nurse Educator* **20**, 34–40.

Pinquart M, and Sorensen S (2006) Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *The Journal of Gerontology: Psychological Sciences* **61B**, P33–P45.

Ponikowski P, Anker S, AlHabib K, *et al.* (2014) *Heart failure: Preventing disease and death worldwide*. Retrieved from https://www.escardio.org/static_file/Escardio/Subspecialty/HFA/WHFA-whitepaper-15-May-14.pdf

Pressler SJ, Gradus-Pizlo I, Chubinski SD, *et al.* (2013). Family caregivers of patients with heart failure: A longitudinal study. *Journal of Cardiovascular Nursing* **28**(5), 417–428.

Public Health Agency of Canada (2013) *Preventing chronic disease strategic plan 2013–2016: Canadian living healthier and more productive lives*. Retrieved from http://publications.gc.ca/site/archivee-archived.html?url=http://publications.gc.ca/collections/collection_2014/aspc-phac/HP35-39-2013-eng.pdf

Saunders M (2012) Perspectives from family caregivers receiving home nursing support. *Home Healthcare Nursing* **30**(2):82–90.

Scott L (2000) Caregiving and care receiving among a technologically dependent heart failure population. *Advances in Nursing Science* **23**(2), 82–97.

Scott L (2001) Technological caregiving: A qualitative perspective. *Home Health Care Management & Practice* **13**(3), 227–235.

Selman L, Harding R, Beynon T, *et al.* (2007) Improving end-of-life care for patients with chronic heart failure: "Let's hope it'll get better, when I know in my heart of hearts it won't." *Heart* **93**(8), 963–967.

Shah S, Carey I, Harris T, *et al.* (2013) The effect of unexpected bereavement on mortality in older couples. *American Journal of Public Health* **103**(6), 1140–1145.

Small N, Barnes S, Gott M, *et al.* (2009) Dying, death and bereavement: A qualitative study of the views of carers of people with heart failure in the UK. *BioMed Central Palliative Care* **8**, 6.

Stroebe M, Schut H, and Stroebe W (2007) Health outcomes of bereavement. *Lancet* **370**(9603), 1960–1973.

Tan T and Schneider M (2009) Humor as a coping strategy for adult-child caregivers of individuals with Alzheimer's disease. *Geriatric Nursing* **30** (6), 397–408.

Thorne S, Con A, McGuinness L, *et al.* (2004) Health care communication issues in multiple sclerosis: An interpretive description. *Qualitative Health Research* **14**, 5–22.

Torraco RJ (2005) Writing integrative literature reviews: Guidelines and examples. *Human Resource Development Review* **4**(3), 356–367.

Ume EP and Evans BC (2011) Chaos and uncertainty: The post-caregiving transition. *Geriatric Nursing* **32**(4), 288–293.

Walden J, Dracup K, Westlake C, *et al.* (2001) Educational needs of patients with advanced heart failure and their caregivers. *The Journal of Heart and Lung Transplantation* **20**(7), 766–769.

Whittemore R and Knafl K (2005) The integrative review: Updated methodology. *Journal of Advanced Nursing* **52**(5), 546–553.

https://doi.org/10.1017/S1478951519000245 Published online by Cambridge University Press