

Carers' needs in advanced heart failure: a systematic narrative review

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Abstract

Background: Informal caregivers play a pivotal role in the care of people living with advanced heart failure, however, carers' needs have not been clearly identified.

Aim: The aim of this study is to explore the evidence on palliative care needs expressed by carers of people with heart failure.

Methods: Five electronic databases (CINAHL PLUS, EMBASE, Medline, PsychInfo and SCOPUS) were systematically searched and articles published January 2003 to June 2014, with a qualitative methodology focusing on the palliative care needs of carers of people living with heart failure were included.

Results: Data was systematically extracted from fifteen articles using an inductive methodology for the thematic analysis. Ten broad categories emerged from which three key areas of support needs were identified; psychosocial support to maintain a sense of normalcy; support with daily living; support navigating the healthcare system. The articles were predominantly published in the UK and USA with a total sample size across all articles of two hundred and seventy, the majority of which were older female spouses. Results included a combination of carers, patients and professionals thoughts, however data was extracted for carers only.

Conclusions: Carer's needs initiate when the patient is diagnosed and continue throughout the disease into bereavement. Needs are continuously prioritised and reprioritised depending on the patients' medical stability. A holistic approach is needed to support these carers, incorporating heart failure and palliative care specialties. Further research is warranted to explore different methods of delivering support and information and to evaluate whether these reduce carer burden.

Keywords: Heart failure, palliative care, terminal care, caregivers

Introduction

Heart failure is a major public health issue and given that globally there is an aging population and the prevalence and incidence of heart failure increases with age, the number of people living with heart failure is on the increase¹. In Europe the number of people living with heart failure is thought to be 6.5 million² and its exponential rise puts additional strain on healthcare services. Informal caregivers play a central role in the care of people living with heart failure and often provide long term care at home for an array of complex needs associated with the condition. The physical demands of the caregiving role have been associated with adverse health consequences for the carer, contributing to poor emotional wellbeing³. Furthermore, caregiver's emotional wellbeing has been shown to be associated with the patient's condition⁴. This highlights the need to support both the patient and carer to promote better emotional wellbeing for the dyad and potentially reduce healthcare costs.

The philosophy of palliative care is to achieve the best quality of life, throughout the disease trajectory for the patient and their family, by providing relief and preventing suffering. Historically palliative care services were used predominantly by cancer patients. In more recent years palliative care has been recognised as having an important role for all chronic illnesses including heart failure⁵. This was recognised in a recent statement from the World Health Organisation calling for the early integration of palliative care into health systems at all levels for all conditions⁶.

Heart failure is a chronic life-limiting illness with a very unique disease trajectory and these patients have been identified as a particular group who would benefit from the integration of palliative care services into their care plans^{7, 8}, which in turn has the potential to alleviate carer burden. Research in the UK and Ireland suggests, however, that palliative care services are underused by this group of patients⁹. A long term study of spousal carers of people living

with heart failure, being treated at specialized heart failure centres, indicated carers were not aware of the term “palliative care. Albeit, when introduced to the idea, they were open to the suggestion of integrating palliative care into their family member’s care plan¹⁰. Research has focused on the needs of informal cancer caregivers and an array of needs have been identified such as information, spiritual and emotional needs, social support and practical assistance when caring for a loved at the end of life¹¹⁻¹³. Given that palliative care services have been predominantly used by cancer patients and the differences that exist in the disease trajectory of malignant and non-malignant conditions, research is warranted in the heart failure population to identify their needs in relation to palliative care in order to identify the best way to integrate the two services. To date research has focused on patient needs and more recently carers have been identified as a research priority in end of life care¹⁴, given the central role they play providing care to the patient. This has led to an emerging evidence base focusing solely on caregivers needs. The aim of this review is to explore the evidence on palliative care needs expressed by carers of people with heart failure to inform practice and allow for the development of palliative care services for this non-malignant condition.

Methods

Search strategy

A systematic approach was employed using the Preferred Reporting Items for Systematic Reviews guidelines¹⁵ to generate a narrative review to ensure the maximum number of relevant papers was retrieved. The methodology followed, allows for replication, rigor and transparency to limit bias¹⁶. The literature search was conducted on five electronic databases (CINAHL PLUS, EMBASE, Medline, PsychInfo and SCOPUS). Keywords and search terms were refined through an interactive approach and grouped into three concepts; heart failure;

palliative care and caregivers alongside their associated terms (table 1). Each keyword within a concept were combined using “OR” and the three concepts were grouped using “and”. This identified articles that had used at least one of the keywords/search terms within each concept. Multiple search terms within three concepts were purposefully included to capture as many relevant articles as possible. The results from database searches can be obtained from the researchers on request. The search applied strict eligibility criteria (table 2) for selecting articles for review and articles were included if the following criteria were met: (1) peer-reviewed articles; (2) published between January 2003 and June 2014; (3) English language; (4) original research that explored palliative care needs of caregivers to people living with heart failure using a qualitative methodology. Qualitative research was the preferred method for achieving the objectives of this review, given that exploring individual’s needs, thoughts and desires are not easily translated using quantitative methods.

The search flow illustrated in figure 1 retrieved three hundred and sixteen articles which were screened by one researcher (LCD) in a stepwise manor, initially screening titles followed by abstracts and full text where applicable. Consensus on eligibility was obtained by two researchers (LCD and SMcI) and based on the inclusion and exclusion criteria fifteen articles were deemed suitable for inclusion in the review. The quality of the articles was appraised using the McMaster University critical review form¹⁷ ©. Given that the inclusion criteria stated qualitative methodologies for exploring needs, the McMaster critical review form was selected as they have developed a specific form for qualitative research. No study was excluded from the systematic review based on its critical appraisal, given they were all of high enough quality.

Data analysis

Relevant data was extracted by the researcher (LCD) and an iterative review of each study, using an inductive methodology for the thematic analysis, led to the emergence of ten broad categories. These were examined for common characteristics and relationships between categories which enabled concept mapping to produce three main themes which were discussed and agreed between the research team members: psychosocial support to help maintain a sense of normalcy; support with daily living; support navigating the healthcare system, which are illustrated in table 3.

It was accepted that the emotional, social and spiritual support needs identified from the data extraction process could be adequately summarised using the term “psychosocial support”. Providing support to the carers in these areas could enable them to regain a “sense of normalcy” similar to before their loved one was diagnosed with heart failure. A number of carers mentioned having to deal with role reversal and sacrifice their own healthcare needs, social life, career or hobbies in order to care for their loved one and with this came some financial difficulties, therefore “support with daily living” was deemed a suitable overarching theme for these categories. Additionally, carers expressed the need for more time with professionals as well as communication and information needs; therefore “support navigating the healthcare system” adequately described these issues.

Results

Study characteristics

A summary of the main findings of all the articles included in the review are illustrated in table 4. The UK and US appear to be leading the way in this area of research, with six of the included articles being conducted in the UK and six in the US, while one each was carried out in Sweden, the Netherlands and Canada. Given that the focus of this review is on the

caregivers needs, all studies had a qualitative aspect to its methodology and all used interviews to gather their data. Sample size varied from three¹⁸ to forty-five caregivers¹⁰ and across all articles there was a total sample size of two hundred and seventy carers, the majority of which were older female spouses. Although caregivers needs were the area of exploration in this review, four studies included a combination of patients and carers in their methodology¹⁹⁻²², an additional four sampled patients, carers and professionals²³⁻²⁶, two studies included bereaved caregivers^{26, 27} and seven studies recruited carers only^{10, 18, 27-31}. In the majority of studies the patients identified family members as their informal carer^{10, 18-22, 24, 25, 27-30}, two studies did not specify the relationship between the patient and carer^{23, 26} and one study included family members and a neighbour³¹. However, for the purpose of this review it was the caregiver's needs that was extracted and reviewed.

Psychosocial support to help maintain a sense of normalcy

For the basis of this review, the term psychosocial support encompasses social, emotional and spiritual needs expressed by the carers. For the carers to attempt to maintain a sense of normalcy that they desire, support with these psychosocial needs would be required. They express the need for some time off for themselves, to maintain a social life and a sense of normality^{18, 21, 23, 25, 30}. Carers also expressed the need for family members to take on some caring duties and that they would benefit from the provision of respite care and support groups^{23, 30}. Having a support group to attend would provide not only social support but also emotional support, which was a need identified in this review^{10, 19, 20, 25, 27, 30}. In particular carers would like to have someone to talk to, someone to listen to their fears and worries and to provide companionship, reassurance and validation¹⁹. Some mentioned drawing great comfort from their faith^{10, 21, 24, 30}, particularly carers who had little family support¹⁰. Having counselling services available was suggested^{27, 30} and bereaved caregivers in particular thought they would have benefited from these services both before and after the death of their

loved one, to help them adjust to their death²⁷. A study of bereaved caregivers from the UK felt that the bereavement services they were offered were quite well managed, with the option of counselling and bereavement information available²⁷.

Support with daily living

A number of the carers reported having to sacrifice their own social life due to the demands of caregiving and said they would benefit from support with practical, day-to-day issues such as symptom and medication management and access to physical resources to help assist daily living. Support with these issues on a consistent basis could further enable them to maintain a sense of normalcy²⁹. The majority of carers in the articles included for review were female spouses and role reversal was a common issue that the patient carer dyads needed to adapt to^{10, 21, 22, 25, 29}. In addition to their normal daily duties, carers were required to take on the role of their spouse, increasing carer burden. Often the result was carers having to leave employment to take on the full time role of caregiver, in turn leading to financial difficulty^{10, 29}. Unsurprisingly carers struggled having the time to manage their own medical conditions and identified the need for self-preservation, albeit, needed to wait until the patient was experiencing medical stability before they could prioritise their own health^{10, 18, 24, 25, 29}.

Support navigating the healthcare system

Carers reported the need to have support navigating the healthcare system^{18-21, 24, 25, 29}. Insufficient time with healthcare professionals, in particular heart failure specialists was an issue reported in a number of studies and carers felt they needed more time in order to fully discuss the patient's condition^{22, 26, 30}. Information needs were consistently emphasised in articles reviewed here^{10, 19, 20, 24, 26, 28, 30, 31}. Carers needed more information from specialist teams, regarding the symptoms of the disease, treatment options, what to expect in the future as well as what the term palliative care encompasses and how it could be integrated into the

heart failure care plan. Carers wanted information early in the disease trajectory. There was a need for the information to be tailored to specific groups of carers, depending on the stage of heart failure the patient was at and the information needs to be relevant to patients with multiple co-morbidities²⁸. When healthcare professionals are providing information, carers have highlighted the need for this to be communicated in a way they understand with no use of jargon. In addition to needing improved and more sensitive communication from professionals^{20, 22, 24, 26, 30}, carers have also identified their need for support when communicating with the patient^{18, 20}. However, there is a degree of uncertainty from the carer as to whether communicating end-of-life issues with the patients are beneficial, as illustrated in the following quotes:

“If she could express her concerns to us without worrying about ‘Well I don’t want to worry them’. Worry us! She doesn’t need to keep it all to herself”²⁰.

“It’s really very hard... and I know it will be painful”¹⁸

“I don’t really know if it’s a good idea (talking about death)”¹⁸.

Carers need the support of professionals in deciding when and how to broach the conversation on end of life issues with the patient, otherwise it has the potential to become “the elephant in the room”^{32, 33}.

Discussion

To the best of our knowledge this is the first systematic review focusing on the needs expressed by carers of people living with advanced heart failure. T Data from this systematic review emphasise that carers need psychosocial support to help maintain a sense of normalcy, carers sacrificed their own needs in order to care for their loved one and expressed the need

for support with daily living as well as navigating the healthcare system and communicating effectively.

Overall, caregivers desired support dealing with the caregiving role early in the patient's disease trajectory, highlighting the importance of heart failure specialist's co-ordinating with palliative care teams from diagnosis. Evidence suggests integration of palliative care services for people living with heart failure resulted in an improvement in the dyads overall satisfaction with care³⁴, although uptake to these services is poor⁹. A possible barrier could be a lack of understanding regarding the term palliative care. A study from the UK aimed at formulating palliative care recommendations in heart failure found that some carers interpreted end-of-life preferences as a question about euthanasia or suicide³⁵. Before palliative care can be accepted by patients and families as a method of enhancing quality of life, there needs to be an improved awareness regarding palliative care services and the availability of such services for non-malignant conditions such as heart failure. A study exploring public awareness of palliative care in Northern Ireland found that the phrase palliative care tended to be associated with caring for people who were dying³⁶. Although, in part this is correct, palliative care is much more than this and improving public understanding needs to become an international healthcare priority. McIlfatrick and colleagues suggested media based strategies, involving people who have had a positive experience of palliative care services, to clarify misunderstandings and myths regarding palliative care services³⁶. One study included in this review, reported family carers had barriers to accepting palliative care due to their own fears and not wanting to face the prospect of their loved one dying²⁴. This validates our findings that carers need psychological support and the provision of accessible and well communicated information regarding their options, in order to ease their fears surrounding the future.

There were a number of practical issues raised by the carers and having support when navigating the healthcare system would be a functional way to address these and in turn could alleviate carer burden. There needs to be seamless coordination between heart failure and palliative care specialties and whether this involves providing specialist palliative care training to heart failure nurses or vice a versa, undoubtedly working together is the way forward.

Carers want time to socialise with friends and the opportunity to attend to their own healthcare needs. A number of carers had their own comorbidities and expressed having a lack of time to attend to their own health issues, because of the responsibility of caring for their loved one. Carers need support in this area, possibly in the form of respite care, or a formal carer coming into the home to stay with their loved one. In some situations carers were putting off attending the hospital for medical procedures because there was nobody to stay at home and look after their loved one. Every individual should be able to avail of healthcare when they need it, yet this group of carers are having difficulty maintaining their own self-care due to the responsibility of caring for someone living with heart failure. The result of informal carers neglecting their own healthcare needs could be declining health, potentially leading to stays in hospital. This may well lead to the heart failure patients' health also deteriorating, causing hospitalisation and further increasing healthcare costs. Furthermore, this would increase the psychological stress for both the carer and their loved one. This highlights the importance of addressing both carers' and patients' needs in order to promote better wellbeing for the dyad.

Carers have a number of unmet information needs and given the complex nature of heart failure and the added complexity of the patients' comorbidities, carers continually need more information regarding symptoms, medications and treatment options. Our findings are in concordance with the results of a systematic review of cancer carers, where inadequate

information needs in relation to medication management and disease progression were identified³⁷. Caregiver involvement in disease management programmes has the potential to alleviate stress when caring for the patient at home³¹, particularly during times of ill health. It would be important to have these programs tailored to the patients' disease stage. The carers attending the programs would have the added benefit of psychosocial support from interacting with other carers, giving them the opportunity to build a support network for themselves. However, it is a challenge in itself for carers to find time to attend such programmes. Therefore, in order for these programmes to be successful and for carers to avail of them, caregivers either need access to formal carers to come into their home and care for their loved one or have the option for the patient to attend similar programmes. A number of carers expressed fear being away from their loved one, therefore further research is warranted to determine the most convenient way for carers to access the information they need.

Improvements are needed in communication between dyads and healthcare providers and carers have expressed a need for support communicating sensitive issues with their loved one. Frustrations arise when a breakdown in communication occurs between patients, family and healthcare providers. Family members feel providers lack an understanding of the challenges associated with the caregiving role³⁰. Often, simply acknowledging the continuous role the caregiver plays and the work they undertake is sufficient for the carer to feel valued by healthcare staff. Other studies of cancer populations support this suggestion that healthcare providers need to understand the important role caregiver's plays and that clinicians need to attend to both the patient and caregivers' needs^{38, 39}. It is plausible that the use of jargon leads to misunderstandings and misinterpretations, suggesting that healthcare providers need to provide information and also ensure the carers have understood it so as to empower the caregivers.

The downstream consequence of carers not being able to address their own needs, could be a deterioration in their physical health, increased burden or isolation leading to poorer quality of life . In turn, these factors could play a role in the carer's ability to continue the caregiving role and as a result the heart failure patients' health could be negatively affected leading to more hospitalisation and greater costs. Research is warranted to determine the best way to address the support needs identified by this population of carers and to evaluate the benefits of providing support, to determine whether it has a positive impact on the wellbeing of the patient and carer.

The interpretations of this review may not be generalisable to younger male carers, given the population of carers reviewed here is quite homogenous with the majority being older female spouses. Differences exist in the healthcare structure of different countries and support needs identified in one region may not be lacking in another and so this should be taken into consideration when interpreting the results of this review. When interpreting the findings of this systematic review it is important to remember this is secondary analysis using thematic analysis on qualitative research studies that originally employed thematic analysis. Therefore the themes generated here are based on the interpretations of various other authors.

Conclusion

This review provides some insight into the areas caregivers need support with, when caring for a person living with heart failure. The articles included in this review have highlighted the need for additional psychosocial support in order for the caregivers to continue with normal living and support navigating the healthcare system, particularly until a time when heart failure and palliative care specialties are fully integrated. Palliative care interventions for the heart failure population need to take a holistic approach addressing both the patient's and

carer's needs in order to succeed. Carers should not be suffering disproportionately due to the role they play caring for their loved one. The result of not addressing the dyads needs as one is inevitably increasing healthcare costs and additional strain on an already strained health service.

Implications for practice

- The needs identified in this review; psychosocial support to help maintain a sense of normalcy, support with issues related to daily living and support navigating the healthcare system could form the basis of a practical framework for ensuring the palliative care needs of heart failure caregivers are addressed.
- Caregivers need to be acknowledged by healthcare providers as playing a key role in the care of the heart failure patient and should be included in the development of the heart failure patient's care plan.
- Palliative care offers an innovative model of care that should be applied to the heart failure population, enabling a holistic approach addressing both patient and carer needs.
- Methods of delivering information to carers need to be explored and evaluated to test their ability to ease carer burden.

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Declaration of conflicting interests

The authors declare no conflicting interests.

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Table 1 Search terms and key words grouped by concept

Heart Failure	Palliative care	Caregiver
Heart failure	Palliative care	Caregiver
Systolic heart failure	Terminal care	Carer
Diastolic heart failure	Hospice care	Informal caregiver
Advanced heart failure	End-of-life care	Informal carer
Acute heart failure	Palliative	Family member
	Terminal	Dyad
	Hospice	
	End-of-life	
	Bereavement	
	Grief	
	Death	
	Dying	
	Pain	
	Pain prevention	
	Pain management	
	Psychosocial needs	
	Spiritual needs	
	Emotional needs	
	Quality of life	

Table 2 Inclusion and exclusion criteria for the inclusion of articles in the review

Inclusion criteria	Exclusion criteria
Studies with a qualitative methodology	Grey literature (abstracts, dissertations, editorials, letters)
Studies where the research includes the caregivers needs	Studies that have not focused on the needs of caregivers for heart failure patients
Aim of the research is on palliative care (to include psychosocial/spiritual/emotional needs or quality of life)	Heart failure patients with a left ventricle assisted device
Primary research	
English language	
Peer reviewed article	
Published from January 2003 to June 2014	

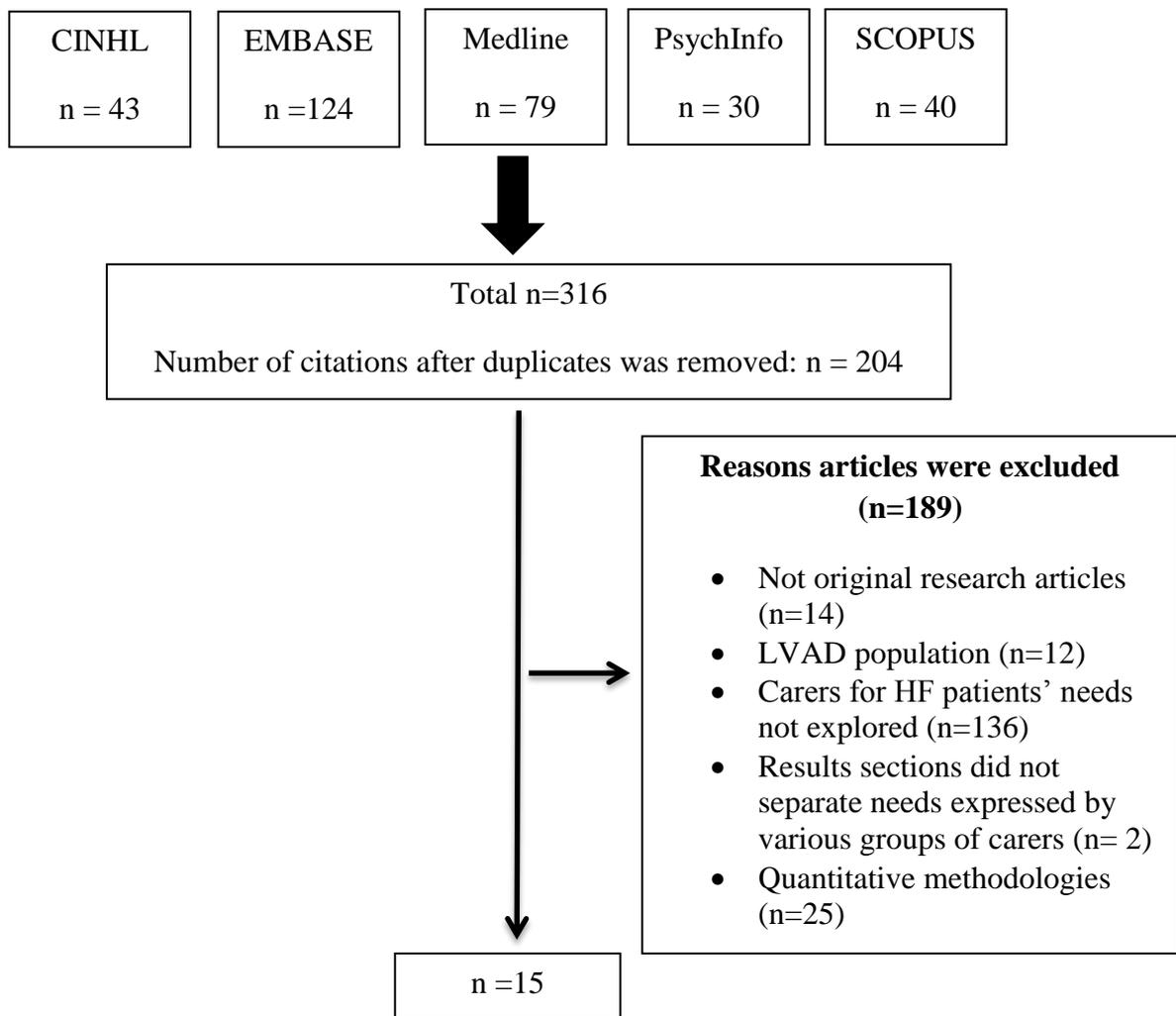


Figure 1 PRISMA flow chart describing the search process

LVAD; Left ventricle assist device, HF; heart failure,

Table 3 An illustration of the key themes identified and the broader support needs within these themes

Themes	Psychosocial support for a sense of normalcy			Support with daily living				Support navigating the healthcare system		
	Social	Emotional	Spiritual	Practical	Role reversal	Financial	Self-care	Information	Communication	Time with professionals
Broad categories										
Small et al. (2007)		*								
Clark et al. (2008)								*		
Buck et al. (2013)								*		
Ross & Austin (2013)	*									
Metzger et al. (2013)		*		*				*		
Boyd et al. (2004)								*	*	*
Luttik et al. (2007)	*			*	*				*	*
Barnes et al. (2006)	*	*		*	*		*			
Brannstrom et al. (2006)	*			*			*		*	
Pattenden et al. (2007)	*		*	*	*					
Bekelman et al. (2011)		*		*				*	*	
Kitko & Hupcey (2013)				*	*	*	*			
Kaasalainen et al. (2011)			*	*			*	*	*	
Imes et al. (2011)	*	*	*					*	*	*
Hupcey et al. (2011)		*	*		*	*	*	*		

Table 4 A summary of the study characteristics and main findings of the articles included in the review

Author & Country	Aim	Study design	Sample size	Gender	Mean age (years)	Main findings
Barnes et al. (2006) UK	To explore the characteristics & views of the family carers of older people with HF	Mixed methods – questionnaire focus groups & Interview	16 family carers (spouse n=14)	6M & 10 F	NS	The necessity to address both the practical & emotional support needs of family carers in older age groups
Bekelman et al. (2011) US	Describe HF patients & their family CGs major concerns & needs. Explore whether, how and when PC programme should be structured	In depth semi structured interviews	20 caregivers (spouse n=9)	2M & 18F	59 ^a	Early integration of practical & emotional support. Information needs and help communicating with the patient & healthcare providers
Boyd et al. (2004) UK	To describe how patients & carers view health & social care in the last year of life	Longitudinal design- focus groups & Interviews	20 informal carers (spouse n=NS)	NS	NS	A more holistic approach to care is needed with service providers taking account of psychosocial, spiritual information and family needs
Brannstrom et al. (2006) Sweden	To illuminate meanings of being a close relative of a person with severe chronic HF in palliative advanced home care	Interviews	3 close relatives (spouse n=2)	3F	NS	Practical & social support is needed to keep everyday life as normal as possible. Help communicating between the dyad & the need for self-care

Buck et al. (2013) US	To examine HF CGs response to a hospice caregiving intervention & elicit the recommendations for future interventions from this panel of novice-to-expert CGs	COPE intervention - semi structured interviews	7 primary caregivers (spouse n=4)	2M & 5F	69	Information needs to be tailored to the dyad & support is needed early in the disease trajectory
Clark et al. (2008) UK	Report of a study to examine the complexities of informal caregiving for people with chronic HF	Semi structured interviews	30 carers (spouse n=24)	7M & 23F	NS	Support for caregivers needs to address both the visible & invisible dimensions of caring
Hupcey JE, et al. (2011) US	To fill the gap in our knowledge about the experiences of spousal CGs over the course of 12-18 months of caring for a patients with HF in order to identify critical variations in PC needs across the HF illness trajectory	open ended interviews	45 spousal caregivers	6M & 39F	60	Information needs, financial issues, psychosocial issues, & physical issues identified. Needs varied depending on medical stability or exacerbation.
Imes et al. (2011) US	To describe the experiences of living with severe HF from the perspectives of the partner	In depth semi structured interviews	14 partners	3M & 11F	65	Social support is needed & information from healthcare providers would be welcomed
Kaasalainen et al. (2011) Canada	To explore the care processes experienced by community dwelling adults dying from advanced HF, their family CGs & their health care providers	Semi structured interviews	10 family caregivers (spouse n=7)	2M & 8F	65	Practical support & more continuity of care with better communication needed. Need for self-care & carers draw comfort from faith
Kitko & Hupcey (2013) US	To describe the types of work in long term spousal caregiving across the progressive course of HF	Longitudinal study -semi structured interviews	20 spousal caregivers	6M & 14F	67	Themes associated with the CG role: providing care, navigating the system, maintaining self, managing the household, vigilance and normalcy.

Luttik et al. (2007)	To explore the explicit experiences of partners of HF patients on the specific factors that influence caregiver well-being & QoL	Semi structured interviews	13 partners	3 M & 10 F	66	Main themes: changes in life, changes in relationship, coping & support
Netherlands						
Metzger et al. (2013)	To describe the patients with HF & their family members experiences with & perceptions of inpatients PC consultations	In depth semi structured interviews	16 family members (spouse n=6)	2M & 14F	54	Emotional support, Information needs & practical support
US						
Pattenden et al. (2007)	To explore how patients with HF & their family carers cope with daily life	Semi structured interviews	20 family caregivers (spouse n=19)	2M & 18F	NS	Physical support to include rehabilitation services & psychosocial support to include respite care
UK						
Ross & Austin (2013)	To identify the spiritual needs & spiritual support preferences of end stage HF patients/carers & develop spiritual support guidelines locally	Semi structured interviews	16 carers (spouse n=NS)	NS	NS	Spiritual support needs were identified & practical support such as respite care & support groups would be welcomed
UK						
Small et al. (2007)	assess carers views on EOL care, the circumstances of the death & bereavement experiences	Longitudinal study –semi structured Interviews	20 bereaved carers (spouse n=13)	NS	NS	Spiritual needs identified & the need for continued support even after death, such as bereavement counselling
UK						

HF; Heart failure, CGs; Caregivers, PC; Palliative care, M; Male, F; Female, NS; Not stated, ^amedian age (years)