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Exploring carers' experiences of supporting a patient with advanced heart failure: a mixed methods study

by

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Abstract

Heart failure (HF) is a life-limiting condition with a poor prognosis and unpredictable trajectory. As the prevalence of HF increases so do the numbers of informal carers. This study explored negative and positive factors influential to carers' perceptions of caring, appropriateness of a Carer Support Plan (CSP) initiative and examined the impact of caring on quality of life (QOL) of informal carers.

A qualitative dominant mixed methods design followed two phases. Phase 1 was a self-completion the Family Quality of Life (FAMQOL) survey of 57 carers of HF patients recruited by community-based heart failure nurses (HFNs). For Phase 2, semi-structured interviews were carried out with 14 carers recruited from Phase 1, and data were analysed using Interpretive Phenomenological Analysis.

Findings from Phase 1 showed living arrangements and how long the person had been caring was statistically significant on overall QOL, physical wellbeing and psychological wellbeing. Working status showed statistical significance; carers who had previously worked reported better overall QOL, physical health and social wellbeing. Spousal carers had significant lower social wellbeing scores than non-spousal carers. 40% of carers reported caring added purpose to their lives.

Three superordinate themes emerged from the Phase 2 qualitative analysis: Emotional Impact of Caring, Living as a Carer and Carer Experience of Support. Carers experienced fragmentation in access to information and support, feelings of uncertainty and social isolation. HFNs were valued in offering support and information, and validating the role the carer provided. Younger carers faced differing challenges; they desired information and support tailored to meet their needs. The Carer Support Plan initiative was viewed as a positive means to increase awareness about supportive services. Relationships with the person cared for and formal care services influenced carer positivity.

The study adds to understanding of the lived experience of carers of patients with HF. Findings point to a need for further exploration of new initiatives, for example the Carer Support Worker role and Carer Support Plan, to complement current health and social care provision.

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List of abbreviations

| | |
|---|--------|
| British Heart Foundation | BHF |
| Carer Burden Scale | CBS |
| Carer Support Plan | CSP |
| Carer Support Worker | CSW |
| Dutch Objective Burden Inventory | DOBI |
| Family Quality of Life instrument | FAMQOL |
| General practitioner | GP |
| Gold Standards Framework | GSF |
| Heart failure | HF |
| Heart failure nurse | HFN |
| Health related quality of life | HRQOL |
| Interpretive Phenomenological Analysis | IPA |
| Mixed Methods | MM |
| New York Heart Association | NYHA |
| National Institute for Health and Care Excellence | NICE |
| Quality of Life | QOL |

Publications

Barnes, S. and Whittingham, K. (2017) *International Handbook on Positive Ageing: Heart Failure Chapter*. Oxon: Routledge.

Whittingham, K., Barnes, S. and Dawson, J.G. (2017) Exploring Carers' Experiences of Supporting a Person With Palliative Heart Failure: Positives and Pitfalls of a Mixed-Methods Study *SAGE Research Methods Cases Part 2*. Available at: <http://dx.doi.org/10.4135/9781526419699>

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Whittingham, K., Barnes, S. and Gardiner, C. (2013) Tools to measure quality of life and carer burden in informal carers of heart failure patients. A narrative review. *Palliative Medicine* 27(7), 596-607.

Conferences

Whittingham, K. (2017) *Exploring carers' experience of supporting a person with heart failure*. Oral conference presentation. Madrid: European Association of Palliative Care Conference.

Whittingham, K. (2015) *Reflections on challenges of a research study exploring carers' experiences of supporting a person with palliative heart failure*. Conference presentation. Copenhagen: European Association of Palliative Care Conference

Chapter One: Introduction to the thesis

This mixed methods (MM) thesis aimed to explore factors influential to carers' perceptions of caring, appropriateness of a Carer Support Plan (CSP) initiative and examine how caring affects quality of life (QOL) in carers supporting a patient with advanced HF.

When I embarked on the study, my interest was founded in experience working as a community heart failure nurse (HFN). Criteria for referral to the HFN service are patients with symptomatic HF and/or complex needs; as such patients on the case load can be considered to be living with advanced HF. For the purpose of the thesis the term HF will refer to patients with advanced HF and associated palliative care needs.

Whilst community HFN services were established to support patients in their own homes, with the aim being to reduce the numbers of unplanned emergency admissions, clinical experience led me to recognise the role the HFN offered in supporting carers. I became interested in how carers coped, how this was different for each individual and what, if any, were positive aspects of caring. Since commencing the research, the issue of unpaid carers and associated challenges with supporting the increasing numbers of people living with complex long-term conditions has become a prominent topic of debate in relation to health and social care provision. Therefore the research findings are timely in adding to the understanding of this carer population. The findings demonstrate that carers' experiences show how day-to-day life in the context of caring is an individual and unique experience influenced by the societal context in which care takes place. There are factors within this societal context which are integral to the life-limiting condition of HF thus making this carer population's experiences different to other carer groups.

Chapter two of the thesis presents the background prevalence of HF and associated challenges for carers supporting people living with advanced HF. This is followed by chapter three, which outlines underpinning conceptual definitions of carers and caring. Chapter four presents a narrative literature

review, critically examining evidence-based instruments used to measure carer QOL and the impact of caring.

Chapter five presents the research aims and objectives of the thesis, and chapter six, the methods chapter, outlines the rationale for the mixed methods (MM) approach followed by the underpinning theoretical principles of the quantitative instrument and the qualitative methodology, namely Interpretative Phenomenological Analysis. A detailed presentation of the two phases of the study, including recruitment and associated challenges, data collection, analysis and ethical considerations, is provided in this chapter.

Chapter seven presents the study findings from phase one: the quantitative phase of the study. Chapter eight provides an overview of the study participants and briefly sets out the qualitative themes. Chapters nine, ten and eleven present findings from the dominant qualitative phase of the study. From the in-depth analysis it was clear that participants experienced challenges, many of which had caused emotional distress. However, alongside these challenges carers also described a sense of achievement that helped them sustain their caring role. Several sub themes emerged from the analysis relating to the emotional impact of caring such as control, unpredictability, social isolation, loss of independence, coping with the challenges of caring, facing the future and rewarding aspects of caring.

Chapter twelve, the discussion, outlines the contribution the findings add to the theoretical understanding of carers of people with advanced HF and presents considerations for innovative ways of working to meet the needs of this population. Methodological challenges of conducting research with this study population are critically considered including strengths and limitations of the thesis.

The thesis concludes with reflections on my experience and learning whilst undertaking the study alongside thoughts for future research to improve the caring experience for this population.

Chapter Two: Heart failure prevalence, symptoms and prognosis

2.1 Prevalence

HF is a life-limiting condition associated with debilitating symptoms resulting in poor QOL. HF presents a major challenge for health care delivery as numbers of people living with the condition are increasing. Figures for the United Kingdom (UK) indicate over 900,000 people are living with HF, and globally it is estimated that 23 million people are living with the disease (British Heart Foundation, 2015; Roger, 2013; National Institute for Health and Care Excellence (NICE), 2010). The prevalence of HF increases with age; the estimate in an adult population is approximately 2%, which increases to between 5 and 9% for people aged over 65 years (van Riet et al., 2016). Additionally, the older HF population presents not only the challenge of managing the condition but also the need to address the complexities associated with existing comorbidities and psychosocial issues. The condition is associated with frequent readmission to hospitalisation. In the UK, HF is the most common cause of medical admission to hospital in patients, and readmission rates are high when post-discharge care in the community is limited (Cowie, 2010).

2.1.2 Symptoms

NICE guidelines define HF as “a complex clinical syndrome of symptoms and signs that suggest the efficiency of the heart as a pump is impaired. It is caused by structural or functional abnormalities of the heart” (NICE, 2010 p 5). The three main categories of HF are left ventricular systolic dysfunction (LVSD), HF with preserved ejection fraction and HF caused by diseased or damaged heart valves. For the majority of cases, HF does not have a single cause; rather, there are a number of other conditions that increase the chances of developing it. These can include high blood pressure (hypertension); coronary heart disease, which may cause angina or a heart attack; heart muscle weakness

(cardiomyopathy); heart rhythm disturbance (atrial fibrillation); anaemia; or an overactive thyroid gland (NICE, 2010).

The main signs and symptoms associated with HF are breathlessness (dyspnoea), fatigue, and swelling in the lower limbs (oedema). Additional symptoms include palpitations, chest pain, memory loss, and sleeplessness. Symptoms such as breathlessness and fatigue can significantly limit the extent of daily physical activities. Depressive symptoms also predict greater mortality in HF patients, and negative mood is associated with exacerbated physical symptoms (Woltz et al., 2012).

The New York Heart Association (NYHA) classification, devised by the Criteria Committee of the American Heart Association (1994), is internationally recognised as the measure of how the condition impacts on the patients' day-to-day life and is categorised as shown in Box 1 (NICE, 2010).

Box 1 NYHA Classification table (Criteria Committee of the American Heart Association 1994)

| | |
|----------------|--|
| Class 1 | No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation or dyspnoea. |
| Class 2 | Slight limitation of physical activity. Comfortable at rest but ordinary physical activity results in fatigue, palpitation or dyspnoea. |
| Class 3 | Marked limitation of physical activity. Comfortable at rest but less than ordinary activity results in fatigue, palpitation or dyspnoea. |
| Class 4 | Unable to carry out any physical activity without discomfort. Symptoms at rest. If any physical activity is undertaken, discomfort is increased. |

2.1.3 Prognosis

HF has a poor prognosis; following the initial diagnosis, survival rates are 50% at five years and 10% at ten years (Roger, 2013). Dying from HF is unpredictable. In up to 50% of patients, death can be sudden and at any stage of the disease trajectory; for the remaining patients, the disease process is progressive with frequent distressing decompensations which can result in episodic and prolonged hospitalisation (Connolly et al., 2010). Thus there are considerable difficulties in meeting the palliative care needs of this patient population, which are critiqued in the following section.

2.2 Palliative care service provision for heart failure patients

Whilst mortality rates of HF are similar to breast and prostate cancer, it is the variability in the disease trajectory that brings additional challenges both physically and emotionally for the patient and carer population (O'Leary et al., 2009; Gott et al., 2007). The requirement to consider the palliative care needs of this patient and carer population has been reflected in recent UK strategies which acknowledge the necessity to shift the focus of palliative care and end-of-life service provision beyond the traditional remit of cancer diagnoses (Connolly et al., 2010). The Gold Standards Framework (GSF) (2006) is an example of an instrument advocated by the End of Life Care Strategy for England (Department of Health, 2008) that aims to identify patients in the last year of life with a focus on seven key principles: communication, coordination of care, control of symptoms, continuity of care, continued learning, carer support and care of the dying. The GSF recommends at least two of the following indicators act as a trigger to predict if an HF patient is in the last year of life:

- NYHA stage 3 or 4 (NICE, 2010) – shortness of breath at rest or minimal exertion
- Patient thought to be in the last year of life by the care team – the ‘surprise’ question, which refers to would the practitioner be surprised if the person died in the next 12 months (GSF, 2006)
- Repeated hospital admissions with symptoms of HF
- Difficult physical or psychological symptoms despite optimal tolerated therapy.

Despite the guidance and an acknowledgement of a pressing need to provide supportive and palliative care inclusive of HF patients and their families, the National Heart Failure Audit highlighted high rates of unmet needs with only 6% of patients dying of heart failure being referred to palliative care services (NHS Information Centre, 2016).

Chattoo and Atkin (2009) explored the practical tensions of implementing initiatives in the UK which are aimed at improving palliative care in HF, such as the GSF. They undertook a qualitative study across three sites in North and Central England over a period of eighteen months to explore professional boundaries in the context of palliative care. Interviews were conducted with twenty seven professionals including cardiologists, HFNs, consultants in palliative medicine, palliative care nurses and district nurses. A key finding was that, whilst cardiologists felt comfortable discussing with patients and carers that HF is a progressive disease and that it could be controlled with medication, they did not disclose that it was a life-limiting condition. This was associated with the unpredictability of the disease trajectory in which patients are at risk of sudden death or conversely could be alive five to ten years later. Cardiologists felt that this unpredictability led to difficulties in knowing when to involve palliative care services. There was also concern that they did not want to appear to be negative about the prognosis when the patients may not die in the near future (Green et al., 2010; Chattoo and Atkin, 2009).

It appears that there needs to be clarity over what is meant by palliative care in relation to HF and an emphasis that it is not only for patients whose death is perceived to be imminent. The World Health Organization (2002) considers palliative care to be an ethos of care that focuses on improving QOL of patients

and their families facing problems associated with life-threatening illness by preventing and relieving suffering through early identification and comprehensive assessment and treatment of pain and other physical, psychosocial and spiritual issues. This is arguably a philosophy integral to palliative care in HF. A predominant finding in the literature, however, relating to palliative care suggests that some professionals continue to think of it as an approach solely applicable to those close to end of life (Bekelman et al., 2008). There is a plethora of evidence indicating that the shift from active treatment to treatment focusing on comfort and QOL in the cancer trajectory has, in most cases, got distinct clinical indicators (Connolly et al., 2010; Hupcey et al., 2009; Goldstein and Lyn, 2006). Traditional models of palliative care reflect this predictable disease trajectory. Conversely HF patients experience long-term life-limiting symptoms, frequent decompensations and may have uncontrolled symptoms towards end of life making the traditional model difficult to apply as illustrated in Figure 1. (Murray and Sheikh, 2008; Goldstein and Lyn, 2006).

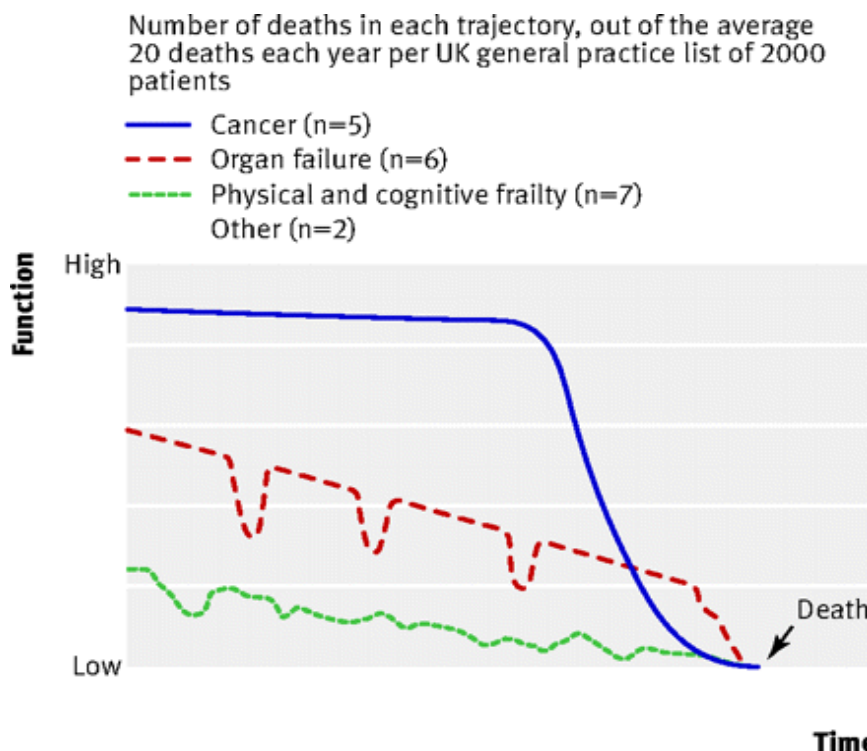


Figure 1 The three main trajectories of decline at the end of life (Murray and Sheikh, 2008).

Hupcey et al. (2009) describe two studies exploring the palliative care needs of families of HF patients. Carers demonstrated limited understanding of what was meant by palliative care with a common theme being that it was associated with care at end of life. When the researchers outlined a definition of palliative care, all the carers believed that the services would be valuable to them. There was discrepancy about when these services would be most helpful; however, half of the carers supporting patients who were symptomatic identified that the support of the services would be most useful if it was available from point of diagnosis.

Recognising an overarching philosophy of palliative care as integral to caring for HF patients leads to consideration of the positive implications for carers.

Bekelman et al. (2008) view palliative care as being patient and family centred with focus on anticipatory care. It is this focus on anticipating and proactively managing complex issues that can be extremely beneficial to carers when considering the physical and psychological impact of being a carer for a patient with advanced HF.

Bekelman et al. (2008) propose that a palliative care approach recognises carers as part of the unit of care by considering their psychosocial care and including them in the patient's treatment plan. The approach acknowledges that information and effective communication is essential to support the carers to be aware of the prognosis and its implications. Goodlin (2009) advocates that the life-limiting nature of the condition and the associated risk of sudden cardiac death is discussed with patients and carers as part of education at point of diagnosis. In this way Goodlin (2009) argues that this honest dialogue may limit the shock for carers if and when the patient deteriorates.

Hupcey et al. (2009) call for a shift in thinking from palliative care as associated with specific service provision to rather as a philosophy of care needs. These authors present a model of palliative care that has been developed to meet the needs of HF patients throughout the disease trajectory in the United States. Importantly, they call for acknowledgement that the services should be available for patients who may not be diagnosed as dying but who will greatly benefit from comprehensive holistic care throughout the illness/death trajectory. The authors argue that whilst at the early stage of the disease the aim of intervention is life-prolonging therapies and there may not be the necessity of

palliative care service provision, the philosophy of the approach should underpin care delivery to HF patients. This model mirrors the recommendations of Boyd and Murray (2010) of introducing palliative interventions at point of diagnosis with the level of these interventions being adjusted accordingly to patients' and carers' physical and psychosocial needs. Two narrative reviews examining the integration of HF and palliative care (Dionne-Odom et al., 2017; Gelfman et al., 2017) recommended that based on the current evidence base, further research is needed to develop and test service models that assess and meet the needs of carers; patients and carers should be involved in the development of these models; and a pragmatic approach is needed to integrate a palliative care ethos into service delivery for HF patients and their carers. By doing so, future care delivery should reflect a 'person-centred approach' by recognising dignity, compassion and respect, and offering personalised care, support or treatment (Health Foundation, 2014).

2.3 Chapter summary

From the evidence presented, it is evident that HF has high prevalence across an older population, and similar mortality rates to breast cancer and prostate cancer. However, evidence critically discussed in this chapter indicates that effective palliative care services for this population are lacking, which can have a negative impact on those caring for HF patients. The following chapter will provide an overview of theoretical models of care and caring with application to the present study. Carers in the context of this thesis will be defined and the complexities of caring and HF will be considered.

Chapter Three: Review of the caring literature

3.1 Defining caring and informal carers

The present study uses the term informal carers as referring to family members, friends and neighbours, and a detailed description is provided in section 3.2 of this chapter. Over the last twenty years, there has been an increasing research interest in the profile of family carers in relation to the support they provide to people living with chronic diseases. It could be argued that a catalyst for this interest is a shift in health and social care policy which has led to more care being focused in the community (Payne and Ellis-Hill, 2001). The number of family carers is steadily increasing. Figures indicate that 12% of the UK adult population are carers; this is 10% higher than in 2001 (Milne and Larkin, 2015). Consequently, policy makers and service providers are increasingly acknowledging that it is necessary to understand the meaning of the term 'carer' and 'caring'.

An exploration of literature relating to the concepts of carers, caring and carer support was undertaken focusing on literature emerging from 1980 onwards. The rationale for this was that this was the time period when community-focused 'care' evolved as a pressing issue to be addressed by health and social care policy. The following databases were searched: CINAHL, EMBASE, MEDLINE, Scopus, Cochrane and PyscINFO. The search terms used were carer, caregiver, family carer, informal carer and carer support. A further refined search combined the initial results with chronic disease and HF. Whilst it is acknowledged that this was not an exhaustive, systematic review, findings considered applicable to the research aim are critiqued below.

Historically, understanding of caring relates to providers of care and the undertakings that caring involves (Bond, 1992). Explorations of caring may be concerned with formal care associated with professional organisations and informal carers. In the context of the thesis the focus of the research related to the experiences of informal carers and therefore the concepts associated with informal caring are presented.

Abrams (1989) proposed formal care is conducted in structured, rigid and bureaucratic organisations. Caregiving exists in professional frameworks with the associated accountability. Conversely informal care is concerned with the attachment of caregivers to the recipient of the care and not just a commitment to tasks. This stance leads to consideration of the distinction of 'care' and 'caring about' (Ungerson and Kember, 1997). The former views instrumental activities being the dominant concern, a task orientated approach; 'caring about' differs in that it is not tangible, rather fundamentally it is about being concerned. Abrams (1989) asserted that it is this personally driven concern about another person that is the essence of informal care and as such offers a unique quality in the relationship between the caregiver and the recipient of care which structured, formal care could not replicate.

A feminist perspective of caring considers social and familial caring relationships, irrespective of whether they are embarked on in a voluntary capacity, and convey certain duties and responsibilities (Kittay, 2001). Early feminist researchers proposed caring relies on and reinforces the sexual division of labour. Women are primarily responsible for the day to day unpaid caring roles associated with families and communities (Finch and Groves., 1983, Graham, 1991., Gilligan, 1993). These perspectives are intrinsically linked to community and therefore it could be proposed reinforce the principle of communitarianism, a social philosophy that emphasises the importance of society in articulating 'good' (Etzioni, 2015). Traditionally feminists have been seen to oppose the stance of communitarians due to an association with restricting opportunities for women, in that roles are driven by societal expectations, with limited choices other than wife and mother. Friedman (1993) advocates for the women to have the freedom to move away from their '*communities of place*', those in which there are perceived roles and duties, to '*communities of choice*'. However whilst there are limitations of communitarianism as regards predefined gender roles, feminist writers have acknowledged that it offers the notion of community which enables a route to situate the concepts of social responsibility, interdependency obligations and identity (Friedman, 1993., Kittay, 2001). Indeed a principle communitarian proponent, Selznick (1992) asserts that if individuals do not need each other,

and nothing is grown from sharing of benefits and through cooperation for a common purpose, then the notion of community will struggle to flourish.

Neediness and an ability to respond to those in need is central to our communities. Kittay (2001) highlights that throughout life people benefit from the investment of care provided by another person. Furthermore if a person is worthy of care then it follows that the carer is also worthy of care when they are in need. This perspective moves beyond that of communitarianism and related assumptions regarding traditional caring roles. Need and how we respond to need is embodied in our fundamental relationships and those with whom we have close attachments. The attachments that form through such relationships are commonly those which we hold in high esteem (Kittay, 2001).

Thus whilst a feminist perspective of caring could consider that a decision to care is driven by '*community of place*', focusing on gender expectations, I propose the concept of caring embodies deeper complexities than just a desire to fulfil duty driven by gender. As such I support the perspective of Graham (Graham, 1991) that informal care is based not only on service but also affection and as such there is a need for further exploration of caring as a '*community of choice*'.

Undeniably the feminist perspective of caring and associated research highlighted the profile of the unpaid work of caring for both the able bodied and dependant and aimed to influence social policy with a focus on gender inequality (Graham, 1991). Bond (1992) suggests however it is equally necessary to address wider issues including class and age to deepen understanding of informal caring relationships. Furthermore Sevenhuijsen (2003) argues care is evolving, albeit progressively, as regards gender with increasing numbers of men contributing to daily care of family members. There are rising numbers of people who require care; people with complex conditions are living longer and care is increasingly provided in communities. As a consequence the profile of carers and supporting carers, both formal and informal, is increasingly acknowledged as a priority for health and social care policy. Twigg (1989) proposes that informal care is commonly characterised by relationships of reciprocity, is founded in daily experiences and is likely something people will experience at some stage in life. Thus awareness of the

intricacies of informal caring necessitates acquiring knowledge of persons and places of caring. To address this evolving profile of caring the conceptual model, an ethic of care, aims to remove divisive boundaries; rather considering caring as solely a gender issue care ethicists view care as a normal aspect of human existence (Barnes, 2012). We will all need care and commitment as a stage in our lives at differing degrees and importantly everyone is capable of giving care; this is the embodiment of an ethic of care which is presented below.

The concept of an ethic of care deepens our understanding of caring with a focus on the particularities of day-to-day interactions and understanding of care being given and received (Barnes, 2012). Essentially an ethic of care considers caring is fundamental to human nature; through our life course we will face situations when it is likely that we will experience episodes of illness, physical or emotional, during which we will need the support and help of others. Thus negative and positive aspects of caring are encapsulated and care is considered as part of everyday life (Barnes, 2012).

Tronto (1993) considers that the four principles of attentiveness, responsibility, competence and responsiveness are encompassed in the concept. To these earlier principles Sevenhuijsen (1998) added trust, and Engster (2007) advocated respect was considered central within the principles.

In showing attentiveness, Tronto (1993) proposed it is necessary to acknowledge the needs of others. To demonstrate attentiveness the person must have capacity to suspend their own life plans, '*put things on hold*' to attend to the needs of another. At its core, attentiveness is people responding when others seek help, whether that be family, friends or at a wider societal level.

Responsibility refers to acceptance that action is required (Tronto, 1993). Notably, responsibility differs from obligation, in that responsibility is not a pre-determined expectation; rather it is grounded in the special relationships with family and friends. Additionally, it is inclusive of those we share social relationships with or unexpected situations that require we take on a responsibility (Engster, 2007).

It is important to acknowledge that in order for carers to take on caring responsibilities a capacity to understand and to be in a position to respond to

the needs of the individual must be evident. Thus competence is an integral principle within the moral considerations of an ethical care conceptual model. Competence is essential in that the care being provided is delivered in a safe and competent manner; in essence it is not adequate to accept responsibility for caring if the care provided is not quality care (Tronto, 1994).

Barnes (2012) describes responsiveness as the understanding of how the care is received and what it means for the person receiving the care; it aims to acknowledge the vulnerability the cared-for person may feel and to limit the inequity in the relationship. To build on the principle of the responsiveness, Sevenhuijsen (1998) advocates the addition of trust that recognises the vulnerability of the person being cared for and requires the need for open dialogue between the carer and cared for. To further enhance trust, Engster (2007) argues that respect for people being cared for is essential to facilitate high quality of care.

Predominantly, initial health care research with carers has been inclined to focus on the 'care', namely the practical tasks such as washing, dressing, feeding and toileting. In this way, caring is measured by the number of tasks, and the impact of these tasks was commonly associated with caring burden (Payne and Ellis-Hill, 2001). Whilst it is essential that empirical understanding of the practicalities of caring is developed, it is necessary to additionally capture the less visible '*caring about*' to truly deepen knowledge and understanding of the meaning of being a carer and in particular consider the positive aspects of caring.

Nolan developed previous work by Bowers (cited in Nolan et al., 1996) eight conceptual categories of caring have been presented. Anticipatory care focuses on anticipating future needs and adjusting aspects of day-to-day life in the caring dyad to proactively address what may occur in the future, examples of which may include moving house, or reducing working hours. Preventative care does not involve direct visible support, but rather an 'arm's length' monitoring of the person being cared for is beginning to occur. Examples can include overseeing medication and dietary requirements. The person being cared for may not necessarily be aware of the role the carer is fulfilling; the support is subtle. Supervisory care is a stage when the cared-for person is aware of the

monitoring and the carer offers increased assistance, an example of which is actually administering medications as prescribed regularly and on a daily basis. The fourth category, instrumental care, occurs when the person cared for is aware of the intervention of the carer; the carer is visibly undertaking tasks whilst endeavouring to maintain reciprocity in the relationship. Underpinning all these categories is protective care, the aim of which is to maintain the dignity of the person being cared for by promoting their independence. Often it is this principle carers find difficult to address, and conflict can arise with the juxtaposition of having to offer instrumental care whilst maintaining the independence of the person being cared for. Nolan et al. (1996) further developed the original conceptual model of Bowers. Following their own research with carers of people living with dementia, they identified protective care, preservative care and reconstructive care. Protective care, although intuitive, may be counterproductive as the dynamic in the patient-carer dyad is unbalanced; whose best interests are being addressed may be unclear. Thus Nolan (1996) advocates that preservative care should be the preferred strategy; there is an equality in the dyad preserving the dignity, hope and control of the person being cared for. Finally, reconstructive care builds on existing relationship to create a new dynamic to recognise the new roles required.

Considering these categories of caring, Nolan et al. (2003) propose research endeavours to not only consider the measurable aspects of caring but also portray the positivity associated with caring. As identified by Nolan et al. (1996), carers can consider the new reconstructed focus within their relationship with the person they are caring for as something which engenders reciprocity and congruence. Hence research conducted with family carers of people with dementia and learning disabilities by Nolan et al. (2003) explored the satisfactions and rewards of caring. Findings indicated the importance of the nature and quality of the relationships in the patient-carer dyad and how this correlated to carers' satisfaction rather than the numbers of practical tasks undertaken.

It is essential that 'care' inclusive of the practical tasks provided by increasing numbers of unpaid carers is visible and acknowledged by service providers. Health and social care policy that does not reflect the voices of the carer and the cared for lacks understanding of the importance of the relationship and how

individuals construct meanings from their circumstances (Henderson and Forbat, 2002). Considering 'care' in this manner in isolation of deeper understanding of 'caring for' offers limited insight into the experiences of carers in everyday life and does not facilitate carers to voice their needs. Barnes (2006) argues that to fully understand caring relationships the narrative of the individual and shared biographies of carers must be heard. In doing so, the personal, social and cultural context is captured inclusive of reciprocity and negotiations occurring in complex caring relationships.

The conceptual models of caring presented offer an insight into the complexities of truly capturing people's experiences of living as an informal carer. An element of the research interest is the positive aspects of caring and the dimensions that carers may feel are rewarding or offer value. Therefore whilst reflecting on the influencing sociological perspectives of caring, the present study predominantly considers the application of an ethic of care (Barnes, 2012) and Nolan's (1996) perspective of caring relationships as these conceptual models offer the opportunity to explore positive attributes in caring relationships.

3.2 Definition of informal carer used in this thesis

The present study embeds an ethos of caring as presented by Nolan et al. (1996) and Barnes (2006) and used a research methodology that reflected the complexity of the carer population. The measurable aspects of caring, both positive and negative, were empirically investigated followed by an in-depth qualitative exploration of the lived experience of a group of carers supporting a person with advanced HF.

At the outset of the present study it was necessary to reflect on a definition of carer in the context of the study population. The language of caring and carers evolved from professional perspectives of what the role involves, has been primarily task focused and initially referred to family members who provided unpaid physical care. Increasingly people are receiving complex care, up to and including end-of-life care at home, with the support of unpaid carers. In order to meet these needs and to address changing demographics in family structure, the term carer now encompasses both families and wider social networks including friends and neighbours. A systematic review examining interventions for supporting informal caregivers of patients in the terminal phase of a disease conducted by Candy et al. (2011) defines carers as an unpaid person that provides practical and/or emotional care to a relative or friend. Whilst seeking a singular definition does not illustrate the complexity of being a carer as described in the underpinning conceptual models presented, it was necessary to have a perspective of what the present study means by the term carer. A decision was therefore made to use the definition as identified by Candy et al. (2011) for the thesis. Additionally, it is recognised that the conceptual models refer to the '*cared for*' rather than patient. However, for clarity in presenting the study findings, it was agreed that for the purpose of the thesis the person being cared for will be referred to as the patient.

3.3 Caring in heart failure

Whilst carers of HF patients report similar issues to those caring for patients with other chronic conditions, HF presents the additional challenge of coping with frequent changes in patient symptoms. This is alongside the responsibility of managing and administering medication, emergency admissions to hospital and difficulties associated with prognostication. Evidence indicates these challenges can impact on carer physical and psychosocial wellbeing (Dracup et al., 2004).

Carers have reported that the physical requirements of the role impact on their own health, which they can neglect due to focusing on meeting the needs of the patient. A study by Pressler et al. (2009) reported older carers frequently forgetting to take their own medications leading to poor control of their own health conditions. The physical aspects of caring can also affect psychosocial wellbeing with carers feeling high levels of responsibility associated with the role. A sense of helplessness when patients are symptomatic, particularly when they are struggling to breathe, can cause carer distress. Carers may also experience reduced social activities or a change in working patterns. By having reduced contact with friends, family or work colleagues, the impact of caring can be increased; carers can become isolated and have no one to share their concerns with (Usher and Cammarata, 2009). Carers can express concerns about leaving the patient alone to pursue their own social interests, and this may be related to lack of access to or poor quality respite care services.

Carers can experience restrictions, day to day, as a result of the physical limitations the patients experience when living with symptomatic HF. In a study conducted by Pihl et al. (2010), carers of HF patients described missing the daily life experiences they used to share with their partner before they became unwell. They spoke about lacking mutual experiences and shared interests as they are no longer able to participate in activities together. Lack of intimacy both physically and mentally with the patient can enhance feelings of loneliness.

A particular difficulty associated with HF is dealing with frequent unpredictable symptoms and the subsequent responsibility carers have for managing and administering medication (Dracup et al., 2004). Carers are often responsible for altering the dosages of diuretic medication according to symptoms, and this

requires assessment of the patient on a daily basis, alongside the management of supplies to ensure adequate stock if medication is increased.

Conversely, evidence suggests that carers who feel well supported and have a sense that a network could help them if or when they needed it cope better with the demands of caring (Andreu et al., 2015; Kitko and Hupcey, 2013; Agren et al., 2010). This network can be a family member or health care professionals and can offer great reassurance and engenders a feeling of shared responsibility of caring. The manner in which health care professionals who are involved in the care of the patient respond when carers ask for help or if, when visiting the patient, they ask how the carer is coping is an important means of making the carer feel a priority (Strömberg, 2013). Being seen and being heard allows carers to feel that their needs are recognised as important, and this can be enhanced when health care professionals acknowledge the struggles that informal carers face and offer proactive support. The support of family and friends is also important to help carers maintain a positive outlook. Carers who have limited social support have been shown to find the role more demanding and have increased carer burden (Hwang et al., 2011). It is therefore important that health care professionals involved in the patient's care assess the availability of wider social support.

Carers who report a good understanding of the condition have been shown to display lower levels of anxiety and better emotional wellbeing (Bakas et al., 2006b). Evidence indicates that partners of HF patients desire more information from health care providers, particularly in relation to the treatment of symptoms (Imes et al., 2011). Providing basic information can show positive benefits to the carer in a short period of time (Harding et al., 2004). Spouses of HF patients who had information provided by a health care professional felt more prepared to help the patient; in particular, advice around medication assisted in their understanding of the condition and its management (Mårtensson et al., 2001). Carers commonly report a need to have open and honest dialogue with health professionals to promote understanding of the disease progression (Aldred et al., 2005). Whilst carers acknowledge that HF is a serious medical condition, there is limited understanding of it being a chronic, incurable disease (Clark et al., 2008).

An evidence review conducted by Hooker et al. (2015) indicates that, where patients and carers have strong emotional relationships and effective communication, patients' experience improved health status and carers report feeling less burdened and distressed in relation to the demands of the role. This highlights the importance of nurturing quality relationships, accompanied by effective and structured health and social support, to enable both patients and carers to engage positively with the challenges and complexities of living with HF.

3.4 Initiatives to support carers

Hanson et al. (2006) developed the Carers Outcome Agreement Tool (COAT) to promote a new model of working with carers that focused on partnerships between carers, practitioners and service providers. The approach required a shift from the predominant focus being carer burden and stress to consider the positive aspects of caring and quality relationships. COAT viewed the carer as a co-expert; carers and practitioners worked together to agree goals and outcomes and the support needed to achieve them. An important aspect was to ensure that the support offered was of a good quality as the carers were often concerned about the poor quality of services they had received in the past, which could lead to reluctance in accepting help (Brereton and Nolan, 2003).

A further initiative, Carer Support Needs Assessment Tool (CSNAT), was intended to enable carers to identify and prioritise the domains in which they felt they needed more support and what they would find helpful to assist them (Grande et al., 2015). A MM trial of the CSNAT conducted with six palliative home care services indicated that there were favourable effects of the intervention but differences were small between carers who had been assessed using the instrument and those who were not assessed. Carers who were asked their support needs using the CSNAT were not more likely to feel that their needs had been met (Grande et al., 2015). The authors asserted that this result could be associated to data indicating that the CSNAT was only distributed to one-third of carers and that it was only completed in a minority of cases. Additionally, the practitioners in the study did not perceive the value of the CSNAT and had concerns about how it impacted on their workload (Grande et al., 2015).

Further to the CSNAT, Knighting et al. (2015) examined the effectiveness of the Carer Alert Thermometer (CAT), which differed in that it was a shorter assessment used to identify carers at risk and in need of a formal assessment. The pilot of the CAT showed that it was well received by carers and professionals and was a useful means to regularly review carers' needs. Interestingly, the carers and professionals highlighted that asking questions on specific topics could raise carers' expectations that they could have access to support to assist them with that issue but there may be no service provision. Carers suggested open questions with a checklist would enable carers to talk about what was important to them with follow up questions to prompt the professional completing the CAT (Knighting et al., 2015).

3.4.1 Community-based heart failure nurse services

In recent years, community-based HFN services have been established in the UK to meet rising numbers of patients living with heart failure. The service offers a case management approach to nursing care in that patients and their carers are supported from point of referral to end of life in partnership with general medical practitioners (GPs) and secondary care services, to support patients living with symptomatic HF. The objectives of the service include clinical assessment; education relating to medications and self-management to patients, carers and other health care professionals; reducing unnecessary admissions and readmissions to hospital; and improving QOL for patients. Referral criteria to the service are patients with symptomatic and complex needs.

The model of community-based HFN services was developed based on the findings of a randomised controlled trial (RCT) examining the intervention on patient outcomes (Blue et al., 2001). A review of multi-professional services for frail HF patients indicated that the most effective programmes were inclusive of home visits (Holland et al., 2005). In a multi-centre study comparing clinic versus home-based HF services, Stewart et al. (2012) found that, although there was no difference in service delivery as regards hospitalisation or death of patients, in the home-based services patients had fewer days in hospital. The

authors concluded that this outcome could be related to home-based programmes offering better involvement of carers in disease management.

A further systematic review (Takeda et al., 2012) indicated that a case management model of care led and delivered by a specialist HFN reduced HF-related admissions at 12 months follow-up, all-cause readmissions and all-cause mortality. By offering an integrated pathway of care, utilising multi-professional interventions, the HFN nurse-led model of care has been established as cost-effective and proactive in increasing collaboration between primary and secondary care (BHF, 2015; Takeda et al., 2012; Jolly, 2002).

As regards patient perceptions of the HFN service, Jolly (2002) proposes that patients value the HFN as they coordinate person-centred focused care; the patients consider the nurse as accessible, consider them to be their advocate and appreciate the continuity through the disease trajectory. This is supported by the findings of Banerjee et al. (2010), who conducted a survey of patients' perspectives of the diagnosis and prognosis of HF. The results of the survey showed that, in relation to information, patients did not know enough about their condition and would like more information. Notably, the HFN was considered to play an important role in relation to increasing knowledge of the condition; by managing HF in the community, they were able to spend more time with patients and could assist to resolve concerns and provide information as necessary (Banerjee et al., 2010). Additionally, patients described how they felt more able to talk to the HFN when they were at home as they were more at ease and felt they had time to ask more questions. By being visited at home, the informality of the social setting allowed for open dialogue and recognition of the social context of the patient-carer dyad.

Yet despite the strong evidence base for HFN services, the current financial climate in UK health care provision places such specialist roles under scrutiny which has already led to some areas decommissioning the service due to financial constraints (BHF, 2015).

3.5 Rationale for the research

It is clear from the plethora of literature that there are particular struggles for carers supporting patients with advanced HF. Initiatives such as the CSNAT and the CAT aimed at assisting carers have demonstrated varying effectiveness. To date there remains limited research exploring positive aspects of caring in the context of HF and, although the introduction of the HFN role demonstrates a reduction in numbers of inpatient days, increased knowledge and support for patients, there is limited research exploring the impact of the role for carers. The present study aimed to address these gaps in the knowledge relating to the HF carer population. Utilising the conceptual models of caring as presented in this chapter, the study investigated positive and negative aspects of caring using an MM methodology. At the core of the present study was recognition that caring may bring burdensome challenges but additionally may offer rewards. Hearing the carer voice offers opportunity not only to recognise the widely documented difficulties of caring but also to portray positivity.

3.6 Chapter summary

This chapter has presented the conceptual understanding of caring in the context of the present study, and the consequences of being a carer for a person with advanced HF have been outlined with consideration to both the negative and positive impacts of caring. Some recent initiatives to support carers of HF patients have also been outlined. The following chapter provides a narrative review of the evidence-based instruments measuring the impact of caring on carer QOL and carer burden.

Chapter Four: Narrative review of the instruments to measure the impact of caring

To ensure an appropriate instrument was selected to capture measurable data about the impact of caring on QOL inclusive of negative and positive aspects of being a carer, it was necessary to critique the current evidence-based instruments available for use in the study population of carers of patients with HF. This chapter presents a narrative literature review of the instruments alongside a rationale for the instrument that was finally selected for use in the present study.

4.1 Instruments to measure the impact of caring

Harkness and Tranmer (2007) conducted a review of instruments to measure the caregiving experience in carers of HF patients. The review concluded that whilst measurement of the caregiving experience had been conducted in several studies there were no instruments which specifically addressed the particular and complex issues of the HF carer population. The authors highlighted a need for further research to consider measurement instruments that not only address the negative aspects of caring in HF but also effectively capture the positive aspects of being a carer and give consideration to the particular dimensions that can contribute to the positive experience.

During the PhD process, I published a narrative literature review critiquing the instruments and examining the literature relating to both the negative and positive aspects of being an informal carer of a person with advanced HF. This review was published in *Palliative Medicine* in 2012 (Whittingham et al., 2013) and was updated in 2017 for inclusion in this thesis.

The review follows the processes recommended for a narrative review as outlined by Hawker et al. (2002). It synthesises evidence from quantitative and qualitative research studies and literature reviews undertaken to explore means

of measuring QOL and/or carer burden in carers of HF patients. The development of the narrative review follows these stages:

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

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

Caregiver burden is described as the physical, emotional and financial challenges of providing care (Makdessi et al., 2011).

QOL – burden measures are widely used as a predictor of emotional distress and QOL outcomes in carers (Molloy et al., 2008).

Carer is an unpaid person providing physical, practical and/or emotional care and support to a relative or friend (Candy, 2011).

4.2 Search strategy

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

Search terms:

Heart failure terms

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

Carer terms

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

Quality of life terms

Quality of life, life qualities, life quality

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

MEDLINE, CINAHL, EMBASE, ASSIA, PsycINFO and Cochrane for literature published until July 2017.

The inclusion and exclusion criteria are listed in Box 2.

Box 2 Inclusion and exclusion criteria

| Inclusion criteria | Exclusion criteria |
|---|---|
| Written in the English language | Written in languages other than English |
| Papers focusing on informal carers of HF patients | Papers focusing on carers of patients with Left Ventricular Assist Devices or pre/post heart transplant, other long-term conditions |
| Studies that measure caregiver burden or QOL | |
| Empirical studies, literature reviews | Editorials, commentaries, letters |
| International sources | |
| Adult carers (over 18 years) | Papers focusing on children or young carers |
| Unpaid carers | Papers focusing on paid carers or formal carers |

4.3 Assessment of relevance

Studies identified from the search were selected systematically in the following manner: consideration to the title, abstract and full text. This process is illustrated by the Prisma flow chart shown in Figure 2.

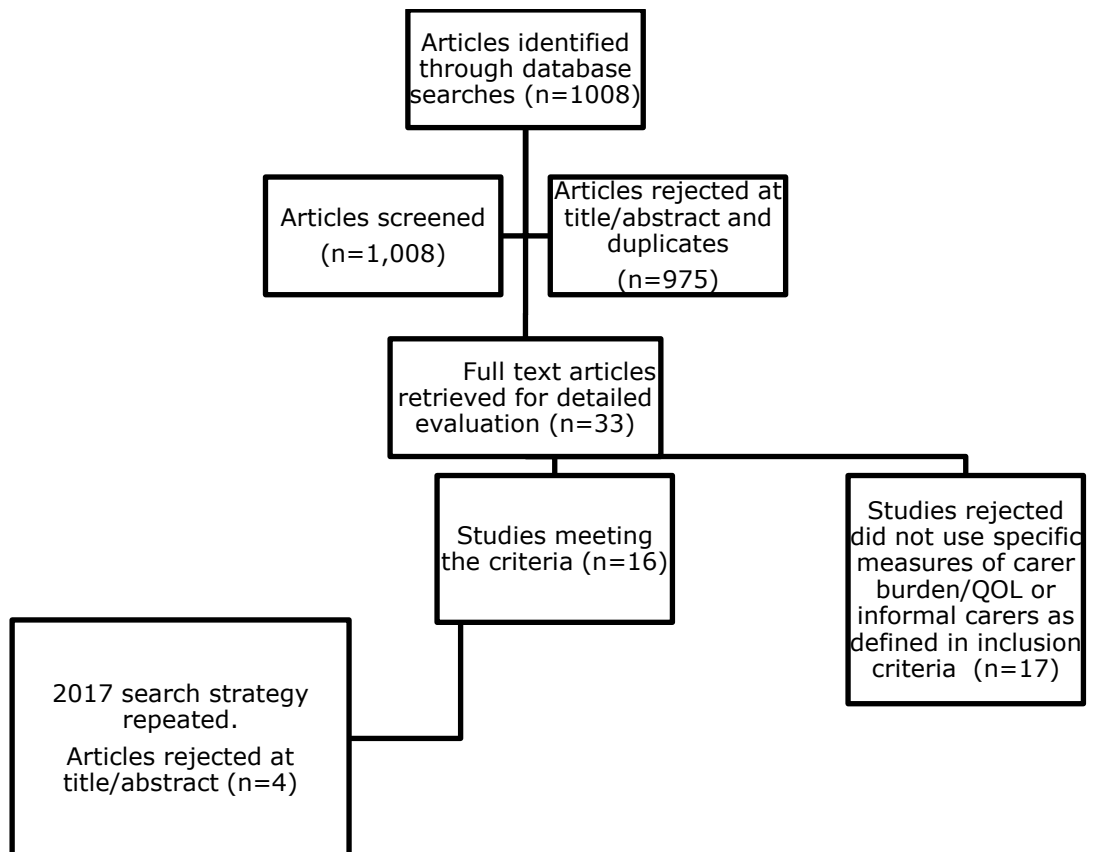


Figure 2 Prisma flow chart indicating study selection criteria

4.4 Data extraction, appraisal and synthesis

The initial search conducted in 2013 of the identified databases using the listed search terms resulted in a total of 1,008 studies. A sift of the titles and abstracts resulted in 975 studies being rejected as they did not meet the specified inclusion criteria. Following extraction of duplicated articles, a total of 33 full text articles were retrieved and screened for eligibility, of which 16 studies met the inclusion criteria. An updated search following the same search strategy conducted in 2017 resulted in a further four studies, but none of these met the specified inclusion criteria. The final studies included in the narrative review combined a range of research methodologies, and it was therefore fitting to conduct the synthesis utilising a thematic analysis (Hawker et al., 2002). This approach allowed for systematic data extraction and appraisal and considered the following key aspects: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, findings/results, transferability/generalisability, implications and usefulness. As recommended by Hawker et al. (2002), each of these aspects was rated as good, fair, poor or very poor and conclusions drawn as to the rigour of the studies critiqued. I initially undertook the review process, and following this, the quality of the studies selected was further reviewed by the supervisory team. The studies included in the systematic narrative literature review are summarised in a matrix (Appendix One).

4.5 Results

The 16 studies in the review are predominantly from the USA and Canada (13) with the remaining studies being European (UK 2, Sweden 2, Netherlands 1). The majority of the study designs were descriptive correlational cross sectional (13); one study was a RCT, one study used an experimental exploratory design, one study was a cohort study and two studies were comparative prospective designs. All studies were conducted with an HF population; studies were inclusive of patient-carer dyads and carers. The studies all used at least one

ratified instrument to measure carer burden and/or QOL. Study settings were acute and primary care.

The quality assessment of the studies was conducted using the range of quality indicators identified by Hawker et al. (2002), following which a thematic synthesis was undertaken and the following themes identified:

- perceived carer control
- depression and anxiety
- types and frequency of caregiving tasks
- impact of age/gender/demographic factors
- impact of patient's physical condition
- positive aspects of caregiving.

4.5.1 Perceived carer control

Four studies included in the review used the Control Attitudes Scale instrument to identify measures of dimensions of carer control and how this linked to increased levels of burden (Hwang et al., 2011; Agren et al., 2010; Bakas et al., 2006a; Dracup et al., 2004). The studies illustrated how perceived control was a contributory factor to caregiver burden. Carers who perceived they had less control had greater anxiety and poorer mental health. Spouses perceiving high levels of control demonstrated lower levels of anxiety, depression and hostility to the caring role (Bakas, 2006b). A sense of control experienced by the carers in relation to a patient's health has particular importance in determining a carer's emotional wellbeing (Dracup et al., 2004). Low levels of control alongside less social support were linked to a negative impact on the carers' physical and emotional health. A further study exploring control and its effects on carer burden was conducted by Molloy et al. (2008); this study implemented an instrument commonly used to examine job strain, namely Care Work Strain Scale (Karasek and Theorell, 1990). The research supported the previous studies with the results indicating that control was the strongest predictor of

carer burden. Additionally, Molloy et al. (2008) used the model to identify associations between demand and satisfaction, but the findings did not achieve statistical significance. Hwang et al. (2011) argued that this lack of positivity about the caring role may be associated with the patient population; commonly HF patients have complex comorbid conditions that decrease the carer's positive feelings about supporting and caring for the patient.

A partner-centred approach using education and support for carers is advocated to aim to assist the carer in feeling prepared and supported for the complex challenges throughout the disease trajectory in order to facilitate a sense of control over the situation (Agren et al., 2010; Dracup et al., 2004).

4.5.2 Mental and emotional wellbeing

Many of the studies identified the negative effects of being a carer on emotional wellbeing. A wide range of instruments were used to measure emotional and mental wellbeing including the Beck Depression Inventory (Beck et al., 1988), the SF-36 (Linds and Martin, 2016), the Zarit Burden Inventory (Bedard et al., 2001), the European Quality of Life survey (van Reenen and Janssen, 2015), Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983), Cantril's Ladder of Life (Cantril, 1995), Brief Symptom Inventory (Derogatis and Melisaratos, 1983) and the Centre for Epidemiological Studies Short Depression Scale (Lewinsohn et al., 1997).

Several studies indicated a strong correlation between the physical condition and QOL of patients and levels of depression in the carer population (Agren et al., 2010; Iqbal et al., 2010; Chung et al., 2009; Luttik et al., 2009; Hooley et al., 2005). Carers' depressive symptoms and anxiety negatively impacted on patient QOL (Chung et al., 2009; Hooley et al., 2005). Whilst QOL of carers was commonly self-reported as being higher than that of the patients, QOL of carers did correlate with the QOL of patients (Chung et al., 2009). In patients reporting lower levels of QOL, carers also had lower QOL (Iqbal et al., 2010; Chung et al., 2009;). Additionally, several studies indicated that QOL was lower in female carers than male carers, and younger carers report higher levels of depression

and anxiety (Hwang et al., 2011; Iqbal et al., 2010; Luttik et al., 2009; Bakas et al., 2006b; Dracup et al., 2004).

Levels of depression were influenced by the carers' physical and mental wellbeing when undertaking the role of carer (Pressler et al., 2009; Saunders, 2008). Poor physical and emotional wellbeing at the onset of undertaking the caring role are more likely to demonstrate depressive symptoms and poor QOL over time; Pressler et al. (2009) found carers with poor emotional and physical wellbeing at the beginning of the study showed progressive deterioration at four and eight months.

The study by Dracup et al. (2004) indicated lower levels of mental health and health perception scores in the SF36 of carers than the mean scores of the general population.

Conversely, two studies demonstrated the positive effects of being a carer on emotional wellbeing (Fried et al., 2005; Evangelista et al., 2002). Emotional wellbeing was significantly higher than that of the patients they were caring for, and the overall emotional burden was reported by carers as being low. The authors proposed that these are significant findings that demonstrated the positive aspects of caring. Carers may have increased self-esteem by undertaking activities and responsibilities to support the patient, which positively improve mental wellbeing.

4.5.3 Types and impact of caregiving tasks

The type and frequency of tasks that carers undertake are significant in how they cope with the role and its impact on their physical and mental wellbeing. Instruments that were utilised to measure the tasks and their effects included the Bakas Caregiving Outcomes Scale (Bakas et al., 2006a), the Zarit Burden Interview (Bedard et al., 2001), the Dutch Objective Burden Inventory (Makdessi et al., 2011) and the Oberst Caregiving Burden Scale (Oberst, 1990).

Two studies demonstrated that younger carers, for example aged under 60 years, found day-to-day household tasks difficult to manage (Hwang et al., 2011; Bakas et al., 2006b). These tasks included cleaning; managing the finances, bills and forms relating to the patient's illness; and transport issues. A

greater perceived difficulty with tasks led to increased burden in the carers. A reason as to why younger caregivers found particular difficulty with these tasks was the fact that many were working full or part time alongside being a carer for the patient; in the study conducted by Hwang et al. (2011), over half of the carers were employed full or part time.

Further studies explored how spousal carers and older carers managed tasks associated with a caring role (Makdessi et al., 2011; Pressler et al., 2009). The study by Makdessi et al. (2011) involved carers with a mean age of 63 who were predominantly female spouses; in the Pressler et al. (2009) study, carers had a mean age of 59 and again were predominantly female spouses.

Spouses performed more caregiving tasks than adult child carers, and female carers provided more emotional support than male (Makdessi et al., 2011).

Particularly challenging tasks for spousal carers included dealing with the behavioural problems of the patients such as moodiness and giving emotional support, managing dietary needs, monitoring signs and symptoms and obtaining health information from health care providers (Pressler et al., 2009).

Two studies indicated that younger spouses report higher levels of carer burden and younger carers perceive tasks to be more difficult and their mental health to be worse than older carers (Bakas et al., 2006b; Dracup et al., 2004). Reasons linked to these higher levels of burden include additional responsibility of continuing to maintain a job, childcare and a household.

An impact of the responsibility of delivering caregiving tasks is reduced opportunity for social activity for carers. This is a change in their life that carers perceived to be negative and results in loss of contact with friends and reduced social activities. This negative perception resulted in the caring role being less enjoyable or rewarding (Bakas et al., 2006b). The strongest variable associated with carer burden was a need for increased support with daily tasks and social support (Garlo et al., 2010).

4.5.4 Impact of patient's physical condition

A range of instruments were used to assess the severity of the patient's HF including the NYHA, the Minnesota Living with Heart Failure Questionnaire (MLHFQ) (Rector et al., 1987) and the Charlson Comorbidity Index (Charlson et al., 1987).

The MLHFQ is a validated instrument to assess QOL in HF patients and to examine the effects of different interventions. The Charlson Comorbidity Index is an instrument to classify conditions that can influence patients' mortality and captures those conditions that will impact on overall disease severity.

Three studies indicated that a higher degree of carer burden was related to worse physical function of the patients (Hwang et al., 2011; Agren et al., 2010; Hooley et al., 2005). NYHA score was a significant indicator of risk of carer burden; higher NYHA class correlated with lower QOL in carers (Iqbal et al., 2010). Hwang et al. (2011) demonstrated that a higher NYHA score was associated with the sense of less support for caregiving and overall a higher NYHA score, indicating severe disease, led to greater disruption to the carers' lives.

A further study by Hooley et al. (2005) showed increased carer burden is linked to the advanced disease of patients. Interestingly the findings of Hooley et al. (2005) indicated that the patient's poor QOL related to the number of medications that they were prescribed; the authors concluded that medications are likely to be a surrogate for disease burden.

4.5.5 Impact of age/gender/demographic factors

Two studies indicated that younger spouses report higher levels of carer burden and younger carers perceive their mental health to be worse than older carers (Bakas et al., 2006b; Dracup et al., 2004). Reasons linked to these higher levels of burden include additional responsibility of continuing to maintain a job, childcare and a household. Dracup et al. (2004) propose that older carers may derive more satisfaction in their role as carers and describe this as finding a new purpose in life. The findings illustrate the importance of clinicians being

alert to the needs of younger spouses who may be at higher risk for impaired emotional wellbeing.

A differing perspective as regards the effect of employment was found by Saunders (2008); in a study of 50 carers, carers who were not employed had greater levels of burden. The author concurred, however, that older carers were less likely to be employed than younger carers and that age may be an additional correlation in this finding.

There is an established link between spousal carers' emotional distress and patient's QOL, with poorer QOL leading to increased distress (Chung et al., 2009), but non-spousal carers were shown to receive less support from family members than those that were the spouse of the patient (Hwang et al., 2011). Non-spousal carers may also have additional responsibility to other family members; caring for HF patients and other relatives has higher levels of perceived burden (Saunders, 2008). However, Saunders (2008) also indicated that adult child carers had greater levels of self-esteem than spousal carers. Carer burden is shown to be less in those carers that are sharing the responsibility with another family member (Saunders, 2008).

An instrument used to measure economic status of carers and its influences on carer burden and QOL was the Scottish Index of Multiple Deprivation (Iqbal et al., 2010). The study by Iqbal et al. (2010) indicated QOL in carers is lower in those with poor socio-economic status.

Two studies showed interesting findings regarding the gender of carers. Luttik et al. (2009) found that a partner's illness was associated with lower wellbeing and a negative change in perceived health in women but not in men. The study showed differences in mental health in relation to gender; female participants reported poorer mental health than male. Female carers also reported more difficulty with the tasks required of them as a carer. In contrast, male partners did not appear to suffer the same stress in taking care of women. The authors proposed that this finding could not be explained by gender differences in the numbers of caregiving tasks performed. Rather, they argue that in the study male partners performed more personal care tasks for female patients compared to female partners of male patients. They concluded that the gender differences may be associated with role identity; taking care of the family,

partner and children is traditionally seen as the domain of the woman and therefore the additional stress of being a carer to a patient may have a stronger effect on female carers.

Iqbal et al. (2010) support the evidence that QOL is lower in female carers and advocate further research is undertaken to explore this issue.

4.5.6 Positive aspects of caring

A limited number of instruments considered the positive effects of being a carer; these include the Oberst Appraisal of Caregiving Scale (Oberst, 1990) and the Caregiver Reaction Assessment (Qualls and Kenny, 2008). These instruments aim to capture dimensions such as satisfaction, mastery and ideology associated with being a carer.

For certain carers, the new role and responsibilities are linked to a positive effect on their wellbeing (Hwang et al., 2011; Agren et al., 2010; Fried et al., 2005; Evangelista et al., 2002). Carers can feel rewarded by being able to provide care for a family member. Interestingly Hwang et al. (2011) showed that non-white carers and those carers whose family member had fewer emergency admissions perceived the role as more enjoyable and rewarding. The ethnic influence was also demonstrated by Saunders (2008), who found carer burden to be less in non-Caucasian carers. Saunders (2008) proposed that feelings of negativity in relation to admission to emergency care may be a result of the carers feeling they have failed in their role. The study also re-emphasises the importance of social support with evidence that increased social support both formally and informally from other family members increased the positive attitude to caring

4.6 Summary of the literature

There is clear evidence from the narrative review that carers supporting patients with advanced HF face many challenges impacting on their physical and mental wellbeing. The studies included provide an insight into the individual dimensions which make a carer particularly vulnerable, namely younger carers, female carers and carers with existing physical and emotional health issues.

Additionally, there are external influences that increase risk of burden including the NYHA status of the patient; if the patient has had recent emergency admissions or has been discharged home; and level of social support available to the carer. It therefore seems appropriate that carers should be screened for such issues so that vulnerable carers will be proactively identified in order for timely interventions to be instigated.

A further finding from conducting the review is that there are still limited measures of the positive aspects of caregiving. A study conducted by Janssen et al. (2012) of caregiving to a range of patients with advanced organ failure concluded that insight into positive aspects of being a carer remains scarce. Two studies in the review recommended that further investigation be conducted into the dimensions of dyads that may positively influence the caregiving experience (Agren et al., 2010; Chung et al., 2009). These studies propose that it is necessary to explore the effect of marital quality on the relationship between emotional distress and quality of life and how the marital quality may affect these variables.

4.7 Rationale for choice of instrument for the present study

Previous studies of HF carers have used generic measures and evaluated a single dimension of QOL such as physical or mental health, which may not fully represent the carer experience. Interestingly studies of cancer carers found that a disease-specific instrument was more effective to describe carer mental health than the SF-36 (Nauser et al., 2011).

A review of self-report instruments to measure burden, needs and quality of life of carers (Deeken et al., 2003) identified that there is content overlap in the domains. The authors proposed that there needs to be recognition as to the

domains that all the instruments include and recommended consideration be given to the development of one instrument that is inclusive of the domains to capture both the impact of being a carer on quality of life and burden experienced by carers. A further review of health-related quality of life conceptual models conducted by Bakas et al. (2012) identified the most commonly used theoretical models used in association with health related quality of life (HRQOL) and assessed these models for relevance to research and practice. The authors proposed that differing conceptualisations of HRQOL lead to difficulty in the development of coherent evidence when examining the effectiveness of interventions aimed at improving HRQOL. However, whilst Bakas et al. (2012) concluded by advocating the use of one of the global models, there was recognition that on occasions a disease-specific model is appropriate.

The instruments shown in table 1 provide an overview of the domains in instruments that have been used in previous studies with HF carers, as presented in the systematic narrative literature review above. Of these instruments only the Bakas Caregiving Outcomes Scale, originally developed for carers of stroke patients, offered the opportunity to report positive aspects of caring, but it was not developed specifically for HF carers.

Reflecting on the recommendations of Bakas et al. (2012) the present study explored the feasibility of using a disease-specific measure developed specifically for the carers of patients with advanced HF. The FAMQOL was chosen because it met the research aim of measuring carers' perspective of wellbeing in relation to physical, psychological, social and spiritual dimensions. It is a validated instrument developed specifically for a HF carer population that was inclusive of all the relevant domains and allowed for positive aspects of caring to be measured.

Table 1 Overview of instruments to measure carer QOL and carer burden

| Measure | Source | #of items | Domains assessed | Item response | Reliability | Validity | Description |
|---|---|-----------|--|---|-------------|---|--|
| Zarit Caregiver Burden scale | Zarit et al.(1980) Bédard et al.(2001) | 4 | Physical, social psychological | 5-point scale, responses include: "never," "rarely," "sometimes," "quite frequently," and "nearly always" | .78 | Tested in caregivers of adults with dementia Correlations between the screening and full versions: 0.83 - 0.93 | Designed for use as a screening tool for the assessment of caregiver burden, this scale includes items such as: "Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?" |
| General Health Survey Questionnaire, Short Form 12 (SF-12) | Ware et al.(1993, 1996) | 12 | Physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional wellbeing, social functioning, pain, general health | 2-point, 3-point, 5-point, and 6-point scales with multiple response options (see General Health Survey Questionnaire, Short Form 36 [SF-36]) | .63-.91 | Not caregiver specific, tested in a wide variety of populations Construct, content | This scale is comprised from a subset of items from SF-36 that measure the same 8 domains of health. Items assess the degree to which the respondent feels: "limited because of physical health," [they've] "accomplished less because of emotional problems." |
| General Health Survey Questionnaire, Short Form 36 (SF-36) | Ware et al.(1993,1996) | 36 | Physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional wellbeing, social functioning, pain, general health | 2-point, 3-point, 5-point, and 6-point scales with multiple response options including: "not at all" to "extremely"; "much better now" to "much worse now"; "definitely true" to "definitely false" | .67-.94 | Not caregiver specific, tested in a wide variety of populations Construct, content | Measures each of 8 domains of health: physical functioning; role limitations due to physical health problems; bodily pain; general health; vitality; social functioning; role limitations due to emotional problems; and mental health. |

| Measure | Source | #of items | Domains assessed | Item response | Reliability | Validity | Description |
|--|-----------------------|-----------|--|---|-------------|--|---|
| Beck Depression Inventory (BDI) | Beck et al.(1988) | 21 | Psychological | 4-point scale, scores range from: 0 (absence of depression) to 3 (maximal depression severity) | .58-.93 | Not a caregiver specific tool, tested in a wide variety of populations Concurrent | Measures depression by asking the respondent to choose the response that best fits him/her "over the past week, including today", for example: from (0) "I do not feel sad" to (3) "I am so sad or unhappy I cannot stand it." |
| Oberst Caregiving Burden Scale, | Oberst (1990) | 15 | Social, psychological | 5 point scale rating 15 different time for caregiving tasks ranging from no time, to a great deal of time | .913 | Tested in caregivers of patients following a stroke Construct | Measures burden in relation to caregiving tasks based on the perceived time and difficulty associated with the task. |
| Bakas Caregiving Outcomes Scale | Bakas et al.(2006a) | 10 | Social functioning, subjective wellbeing, physical wellbeing Unidimensional | 7-point scale, responses range from: "changed for the worst" to "changed for the best" | .77 | Tested in caregivers of patients following a stroke Criterion | Measures life changes that result from caregiving as experienced by the caregiver with regard to: emotional wellbeing, ability to cope with stress, self-esteem, relationship with friends and with family, physical health, time for social and family activities, future outlook, and relationship with care recipient. |
| Dutch Objective Burden Inventory, Medical Outcomes Study (DOBI) | Makdessi et al.(2011) | 7 | Personal care, practical care, motivational support, emotional support | 7 point scale measuring objective caregiver burden in relation to caring tasks. | .80 | Tested in caregivers for people with HF Construct | Disease specific. Responses to the DOBI provided new insight into frequency of caregiving tasks. Study recommended further research into the psychometric properties of the tool. Measures burden with no measure of positive aspects. |
| Caregiver Reaction Assessment | Given et al.(1992) | 4 | Physical, psychological | 5-point scale, responses range from: "strongly agree" to "strongly disagree" | .80 | Tested in informal carers of older people Construct, content | Measures the caregiver's physical capability and energy to provide care. It further assesses the caregiver's health in relation to the caregiving role. |

| Measure | Source | #of items | Domains assessed | Item response | Reliability | Validity | Description |
|--|----------------------|-----------|---------------------------------------|--|-------------|---|---|
| Control Attitudes Scale – Family Version, | Agren et al.(2010) | 4 | Multidimensional control helplessness | 7-point response scale ranging from 1 (“not at all in control”) to 7 (“very much in control”) The CAS-R is scored by adding the item scores- each item is rated on a scale from 1 (totally disagree) to 5 (totally agree). | .62 | Tested in cardiac patients and their families Poor validity for the family version | Measures level of perceived control and helplessness in patients and their families' cardiac problems The CAS-R consists of 8 items from the original Control Attitudes Scale (and 6 items from the Cardiac Attitudes Index). |
| Centre for Epidemiological Studies – Depression Scale (CES-D Short Version) | Kohout et al.(1993) | 11 | Psychological | 2-point:yes or not | .94 | Not caregiver-specific, tested in a wide variety of populations Construct | A general measure of depressive symptoms often used in caregiver studies. Respondents are asked if they have felt a particular way with items such as: “did you feel that people dislike you?” and “did you feel lonely?” |

4.7.1 FAMQOL instrument development

The FAMQOL (Appendix Two) was designed to measure QOL as an adaptational outcome representing the culmination of carers' stress experience to capture discrete but important changes in QOL (Nauser et al., 2011). The FAMQOL domains were developed to embed the transactional theory of stress associated with personal control, stress and coping (Folkman et al., 1986). A brief overview of this theory in the context of the FAMQOL instrument is briefly presented below.

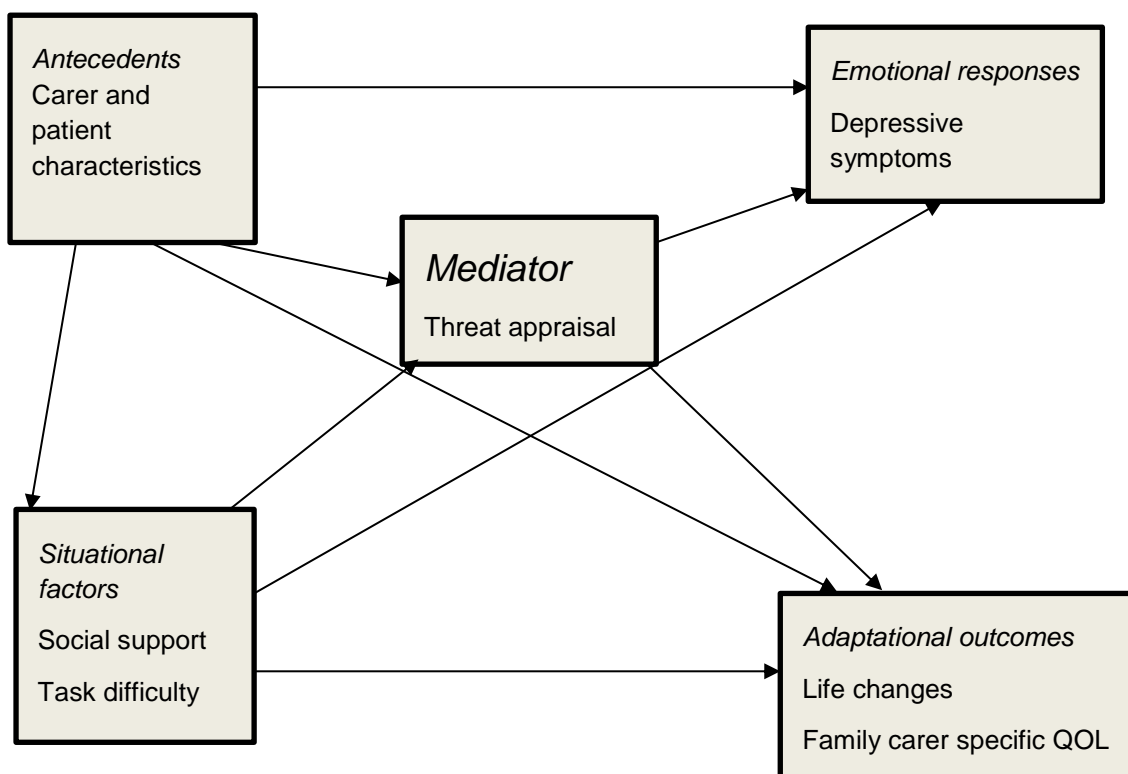
Folkman et al. (1986) proposed that stress is not a property associated with the person or the environment or a stimulus or response to a given situation; rather it is a complex relationship between the person and their lived environment. The person and the environment are a dynamic relationship that is constantly changing and evolving; the relationship is two directional in that the person and the environment influence each other and involves primary and secondary appraisal.

During primary appraisal the person makes the judgement that the situation is not significant to their wellbeing and that it does not necessarily exceed their capacity to manage the situation and indeed may signify positive consequences for the person. Appraisals are made in relation to harm/loss, threat and challenge. Challenge is of particular interest in regard to the HF carer population as it refers to opportunities for growth and mastery or gain. The perception of carers who see the role as having positive consequences may be linked to their positive response to the challenge of developing new skills and knowledge as part of the caring role. Primary appraisal additionally involves the person considering the stakes: the commitments involved with the situation. This theoretical principle is of consequence to carers of HF patients. Folkman (1984) illustrates that the more serious or extensive the commitment and the more at stake for the carer in relation to these commitments, the more meaningful controllability becomes.

Secondary appraisal evaluates the coping resources and options available to manage the situation. Coping resources in this context can be physical, social, psychological and material assets. Physical resources can be the person's

current health status and its impact on energy to physically sustain the situation. Social assets include the person's family, friends and wider social networks from which tangible assistance and emotional support can be gained. Psychological resources include the person's beliefs which help them sustain hope, self-esteem and morale. Nauser et al. (2011) modified the Lazarus and Folkman (Folkman, 1984) transactional theory of stress to present a conceptual model for the psychometric testing of the FAMQOL (Figure 3).

Figure 3 Conceptual model of carer stress



Content validity for each QOL domain was reviewed by a team of experts including doctoral trained nurses with clinical experience in HF or family carer research, an adult child carer and a spousal carer. Internal consistency reliability was evaluated using Cronbach's alpha, which was re-examined for the individual domains. Multiple regression using eight additional measures (Cognitive Status Scale, Medical Outcomes Survey, Caregiver Burden Scale, Uncertainty in Illness Scale, Appraisal of Caregiving Scale, Hospital Anxiety and Depression Scale, Bakas Caregiving Outcomes Scale, SF36), factor analysis and hierarchal multiple regression were undertaken. Criterion validity was calculated using Pearson r correlations computed between the FAMQOL with

individual domains and the criterion variables from Bakas Scale, SF-36 and Mental Health subscales. Analysis of the instrument demonstrated that the overall FAMQOL and each of the four wellbeing domains demonstrated satisfactory tests-retest reliability and internal consistency reliability (Nauser et al., 2011).

Based on an existing definition of family caregiver specific QOL developed by Ferrell et al (2001) for cancer family caregivers, a collective of 58 potential items was developed for the FAMQOL instrument. Nauser et al (p 53, 2011) defined family caregiver specific QOL as “the caregivers perceptions of how caring impacted on their wellbeing relating to physical, psychological, social and spiritual domains”. In creating the instrument domains, two content experts who were also carers for patients with HF suggested the items ‘ *I feel selfish when considering my own needs*’ and ‘ *I am overwhelmed*’. The instrument additionally reflected issues raised in the literature review (Whittingham et al., 2014) relating to caring in HF. To measure QOL as a multidimensional concept, items were incorporated for the following four domains: physical, psychological, social and spiritual wellbeing (Nauser et al., 2011).

The finalised pool of items were peer reviewed, to establish content validity, by five research nurses with HF experience, family caregivers including an adult child HF carer and a spousal HF carer. From the original 58 items, 34 items had minimum content validity. Therefore a total of 46 items remained on the scale for psychometric evaluation.

A further three measures were used to evaluate criterion validity: The 15 item Bakas Caregiving Outcomes Scale (Bakas et al., 2006), SF-36 General Health Scale (Ware et al., 1996) and the Mental Health subscale in the SF-36 (Ware et al., 1996).

Nauser et al (2011) considered a strength of the instrument was that each domain was represented equally with 4 items each. Criterion-related validity of the overall FAMQOL and the 4 subscales was supported. However whilst the spiritual wellbeing subscale did correlate significantly with the Bakas Caregiving Outcomes Scale and the SF-36, it did not correlate as a single spiritual wellbeing overall item. Nauser et al (2011) concluded that this related to the difficulty in defining spiritual wellbeing in the sample population. Items in the

spiritual wellbeing domain referred to the positive aspects that may be derived from caring, namely purpose/mission, inner strength, inner peace and meaning. Nauser et al (2011) proposed that despite the difficulties in capturing spiritual wellbeing within the domain of the FAMQOL this is an important aspect for consideration in the carer experience and is worthy of investigation. Demographic questions were added to the existing FAMQOL for the quantitative phase of the present study.

Although FAMQOL was originally developed to be administered over the telephone Nauser et al (2011) recommended that the instrument could be self-administered and was therefore fitting to use in the present study. Additionally when considering the study population the FAMQOL contains only 16 items facilitating ease of administration.

Nauser et al. (2011) concluded that the use of a disease-specific instrument has the capacity to offer more accuracy in the discrete measurements of the positive and negative aspects of the carer experience in relation to caring for HF patients. The FAMQOL shows evidence of reliability and validity in measuring positive and negative impacts of caregiving. The instrument was considered beneficial in the present study as it was designed specifically for the HF carer population and as demonstrated in table 1, unlike the other instruments listed, captures multidimensional concepts of physical, psychological, social and spiritual wellbeing. The rationale for the present research study was that the measure could be implemented alongside a qualitative investigation exploring the holistic lived experience of caring, including positive elements. The present study therefore selected the FAMQOL instrument to pilot in a UK HF carer population.

4.8 Chapter summary

This chapter presented the narrative review of the evidence-based instruments to measure carer QOL and carer burden; a critical perspective of the current instruments was offered including limited measures of the positive aspects of caring. The underpinning theoretical principles in the development of the FAMQOL instrument were presented alongside a rationale for using it in the present study. The following chapter outlines the research question, aims and objectives for the present study.

Chapter Five: Research aims and objectives

As outlined in chapters three and four, evidence indicates the complexities of caring for HF patients and limited use of disease-specific instruments to measure the carer experience in the context of HF. Additionally, measures have tended to focus primarily on the negative aspects of caring on quality of life. Research with this carer population predominantly emphasises the difficulties associated with caring with limited consideration to the positive aspects caring may offer. Initiatives focused on helping carers have had varying effectiveness to date; the present study therefore aimed to add to the evidence base relating to the HF carer population by investigating both positive and negative aspects of caring.

The research interest of the present study evolved from clinical experience working with HF patients and their carers in a community setting. As an HFN, a tacit awareness existed that the manner in which carers embarked on and sustained the requirements of caring was influenced by particular dimensions and how some carers embraced the role from a positive perspective. To affirm this tacit, inferred perception the present study set out to examine the literature relating to the impact of being a carer for a patient with HF, the instruments used to measure the impact of caring in this population and current evidence-based initiatives to support carers.

Additionally, the present study was interested in carers' perceptions of the usefulness of a Carer Support Plan (CSP) (Appendix Three). The intention when using the CSP is to offer carers the opportunity to discuss the types of help they would prefer from a range of options available locally. The CSP differs from the CSNAT and the CAT outlined in section 3.4 in that it does not endeavour to assess carers' needs; it is intended as an instrument to create conversations about what carers would find helpful and to ensure the available support networks are outlined to them. It is envisaged that the CSP can be completed by health and/or social care providers that are in contact with the carer; with carer consent, the information will be shared with the carer's GP, HFN and other formal care providers involved in the patient care.

5.1 Research aim

The aim of this study was to use a MM approach to explore factors influential to carers' perceptions of caring, appropriateness of a Carer Support Plan (CSP) initiative and examine how caring affects QOL in carers supporting a patient with advanced HF. The research questions were as follows:

1. What are the levels of physical, psychological, social and spiritual wellbeing for carers of patients with advanced heart failure?
2. How do levels of wellbeing vary by types of carer?
3. What are carers' perceptions of supporting a patient with advanced heart failure?
4. What are positive and negative influences on carers' QOL?
5. Is a Carer Support Plan an acceptable and feasible tool to provide information to this carer population?

5.2 Research objectives

1. to measure positive and negative aspects of caring (physical, social, psychological and spiritual wellbeing) using a structured survey
2. to explore carers' experiences of supporting a patient with advanced HF
3. to elicit the views of carers in relation to positive and negative aspects of being a carer
4. to elicit the views of carers regarding the CSP initiative in relation to acceptability and feasibility
5. to analyse and integrate the findings from the 2 phases of the study in order to provide recommendations for health and social care providers regarding appropriate support to meet the needs of the HF carer population

5.3 Chapter summary

This chapter draws together evidence presented in the previous chapters on the HF carer research literature to provide a rationale for the present study. The research aims and objectives for the two phases of the study are presented. The following chapter outlines the study methods and rationale for the selection of a methodology that addressed the research questions and aims in an appropriate manner.

Chapter Six: Methodology

This chapter outlines the rationale for selecting a MM approach and presents the methods used to meet the aims of the research. The philosophical foundations of MM are introduced and considered in relation to the theoretical issues of the study population: informal carers of HF patients. The two phases of the research design including sampling strategy, recruitment process, data collection and analysis are detailed. Methodological concerns relating to the quantitative data collection are critically reviewed with justification for use in the present study. The choice of the qualitative method, namely Interpretive Phenomenological Analysis, is presented in detail with reference to the quality and rigour in the analysis. Ethical concerns and researcher reflexivity before embarking on the study in view of the study populations are outlined with the necessary actions taken.

6.1 Mixed methods methodology

MM research requires a broad-based and logical approach to an inquiry which guides the selection of specific methods; the methodology is informed by a range rather than a singular conceptual position (Teddlie and Tashakkori, 2009). When embarking on an MM study, it is important that there is a clear stance of the research paradigm influencing the inquiry. Teddlie and Tashakkori (2009) propose that the methodology has three features which are interlinked: conceptual positioning, issues regarding methods and methodology, and applications of MM research findings in contemporary practice.

MM researchers should be able to offer a knowledgeable insight of the key debates surrounding this approach and develop a reasoned and justifiable argument as to why the approach is the best fit for their research. By presenting a reasoned argument, the researcher should endeavour to ensure that it is clear that it is the correct choice without reducing their capacity to be innovative in order to produce robust research that addresses the needs of their research population (Cameron, 2011). Thus there is a need for clear reasoning and rationale as to why this methodology has been selected that demonstrates that

the quantitative and qualitative aspects of the study are interconnected and the approach maximises the strengths and weaknesses of both types of methodology. Cameron (2011) advocates consideration is given to the appropriateness of the method/s selected to answer the research questions; principally, does the use of mixed methods deepen the understanding of the research population?

When embarking on the present study, an exploration of literature critiquing MM research identified that it is an approach commonly implemented in health care research (Östlund et al., 2011). It is proposed that this is because the methodology allows the researcher to draw on the strengths and perspectives of each method (Östlund et al., 2011; Connelly, 2009). When considering this suggestion in the context of HF carers, the approach creates opportunities for the researcher to recognise the practical influences (quantitative element) as well as the importance of reality and influence of human experience (qualitative element); in doing so, it gives understanding of the complexities of the phenomenon being studied (Östlund et al., 2011). Giddings (2006) argues that MM research allows diverse solutions for diverse problems. Giddings (2006) further advocates MM research should be considered as a multi-methodological co-operative inquiry that has relevance in examining and exploring the needs of diverse communities (Giddings, 2006).

When considering potential MM study designs, Cameron (2011) recommends the use of exemplars to add robustness to the rationale for choosing an MM methodology and the study design. Reflecting on this recommendation, reviewing the MM research literature led to the critique of several research papers from which knowledge was ascertained that was applicable to the present study design.

Shipman et al. (2008) conducted an evaluation of a national palliative care educational intervention. The study was sequential: quantitative data was obtained using pre- and post-education questionnaires; qualitative interviews and one focus group were used to explore the impact of the intervention. The authors concluded that it was necessary to use the three methods of data collection to contextualise the quantitative findings from the study. Importantly there was a clear implicit theoretical stance that the educational programme

would increase the knowledge and confidence of practitioners, and this evidence was supported by the empirical data gleaned from the questionnaires. Thus the qualitative themes complemented the quantitative findings.

A sequential longitudinal study conducted by Lukkarinen (2005) aimed to describe, explain and understand Health-Related QOL in a population with heart disease. Interestingly, in a review of MM research Östlund et al. (2011) argued that this was of the few studies that clearly stated its theoretical position was to obtain rich quantitative data about the average QOL in a population with heart disease supported by findings relating to the study population's own individual and unique life experiences. Methodologically the quantitative approach provided information about changes in quality of life and correlations in background factors relating to QOL. The qualitative information gave an insight into the impact of QOL on the individual's life situation, life course and long-term rehabilitation. Importantly a phenomenological method using in-depth interviews provided an insight into the participants' lived experience and perceptions of QOL that would not have been obtained by solely using a quantitative questionnaire.

Shipman et al. (2008) and Lukkarinen (2005) both used a sequential explanatory design; quantitative data collection and analysis was followed by qualitative data collection and analysis. In MM research it is fundamental to the study design that the research is a fluid, connected piece of work rather than two or three distinct studies. Historically, MM studies have been criticised for not adequately demonstrating methodological and data integration (O'Cathain et al., 2009). To highlight transparency in the interconnected nature of the methods being implemented, the researcher must be clear about which approach has dominance (Connelly, 2009). The most common sequential explanatory design is one in which the quantitative component is the dominant part of the study, with the qualitative results used to assist in explaining the findings of a predominately focused quantitative study (Teddlie and Tashakkori, 2009). However, Plano Clark and Creswell (2008) propose a variation on the sequential explanatory design in which the qualitative data collection and analysis is the dominant focus of the study. For a study following this design, the quantitative phase of the study is used to identify participants in relation to the research aim. The quantitative results can be used to provide measurable

data and guide purposeful sampling of participants for a predominantly qualitative study. Findings from a sequential explanatory design can be presented in two separate stages and be drawn together in the discussion, and this design, as recommended by Plano Clark and Creswell (2008), was implemented in the present study.

As identified in chapter three and chapter four, there are multi-faceted and complex influences on being a carer for a patient with advanced HF. Disparities continue to exist in the knowledge relating to the level of care provided by carers of advanced HF patients and how the experience of caring is viewed by the carer population. Whilst measurable quantitative data can provide valuable information, to fully understand caring relationships it is necessary to enrich this data with in-depth dialogues from an HF carer population.

It was the complexities associated with the study population that was the underpinning theoretical principle when considering the most appropriate research design to address the research questions. By conducting an MM study, the aim was to examine and explore similarities and differences of the phenomenon of being a carer. In this way it was recognised that the community, namely carers and the impact of caring, consisted of multiple dimensions which may overlap and causative effects which could be fluid from one dimension to another.

The study proposal had three key elements:

- A validated instrument developed specifically for this carer population was used to measure the impact of being a carer for a patient with advanced HF on carer QOL.
- A qualitative exploration was undertaken with carers in relation to factors influential to the carer's perception of caring.
- A qualitative exploration was conducted to explore the appropriateness of a CSP as an initiative to support carers of HF patients in the caring role.

Drawing on a pragmatic philosophy as a researcher, a methodological approach which aimed to answer these three aspects of the study was utilised. The

FAMQOL instrument (see section 4.7.1) obtained quantitative data about the impact of being a carer on quality of life; furthermore, the quantitative phase allowed for a sample to be obtained for the qualitative phase of the study. This quantitative phase was the supplemental phase of the study. The dominant component of the research process was the second qualitative phase, in which carers were asked to participate in semi-structured interviews. Based on evidence from the literature presented in chapters three and four, and the quantitative survey results, emerging ideas of what aspects to explore in the qualitative phase of the study were developed. The lines of questioning considered in the interview focused on participant's experiences both positive and negative and the dimensions that the carer perceived to influence this experience. This qualitative data was intended to add depth to the quantitative findings; it provided an understanding of individual carers' experiences and the dimensions of their lives associated with how they perceived their experience of caring. An interpretation and integration of the findings was conducted at the final stage of the study. Thus the study used methodological triangulation (Appendix Four) to develop comprehensive theoretical understanding of the phenomenon of caring (Ostund et al., 2011).

Denscombe (2008) proposes that research paradigms mirror the communities they are studying and use methodologies that address a common purpose but may implement diverse methods to achieve this. Reflecting on the complexities of the study population led to the premise that MM was the most fitting research design.

The present study used a sequential explanatory MM design as described in section 6.2. Phase one (quantitative) of the study was a self-completion survey using the FAMQOL instrument; phase two (qualitative) comprised semi-structured interviews with carers. The first phase of the study informed the sampling and interview schedule for the second phase. The quantitative phase of the study was the supplemental component of the study; the dominant component of the research process was the second qualitative phase (see Figure 4).

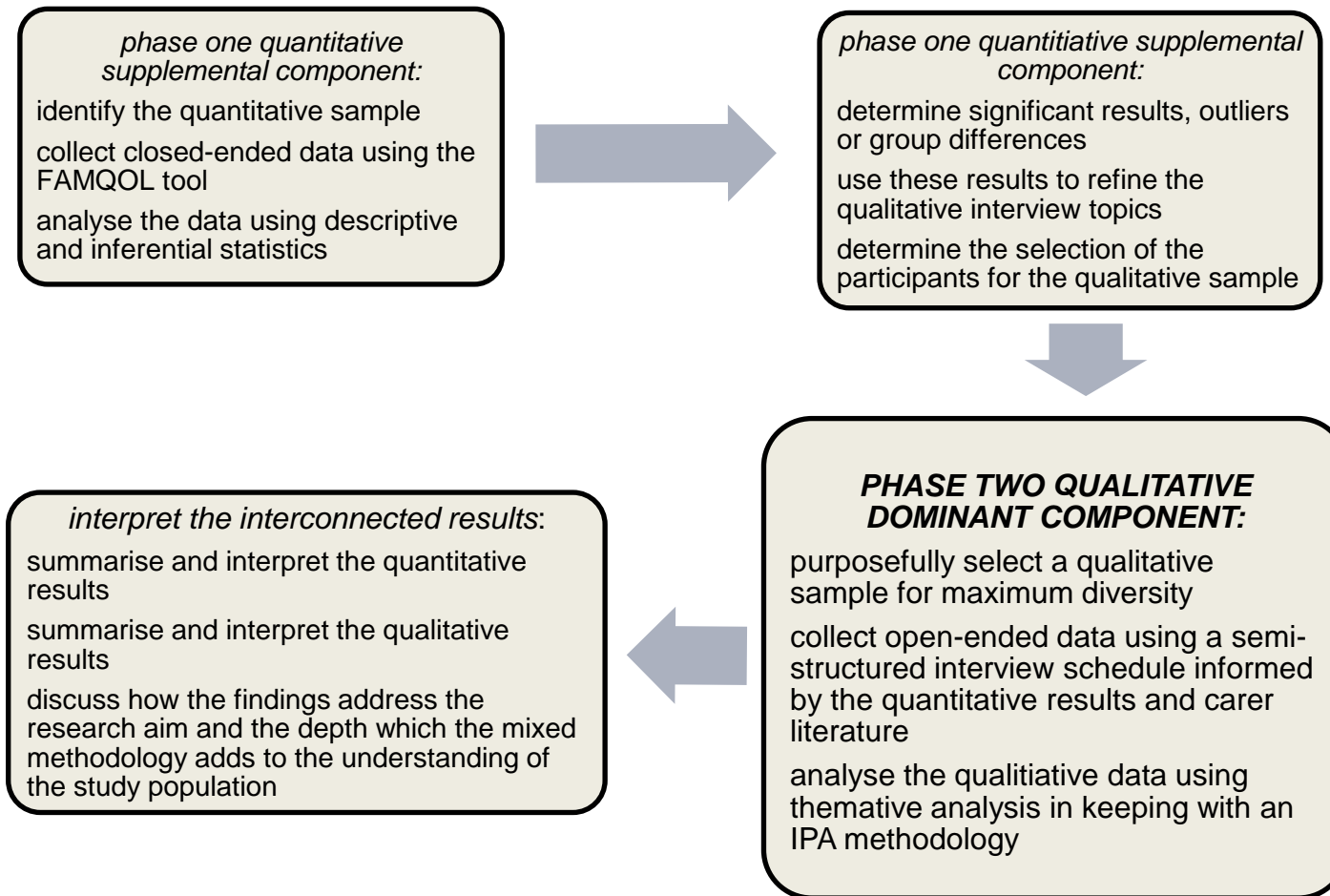


Figure 4 Flow chart of the implementation of an explanatory design (Creswell and Plano Clark, 2011)

6.2 Study setting

Phase one and phase two of the present study were both conducted in Nottingham City and Nottinghamshire County using the HFN service. The background to community based HFN services is presented in section 3.4.1. The population estimate of Nottingham City in 2010 was 306,700 with 16% of the population in the age range between 60 and 90 years old (SEPHO, 2011). The population estimate of Nottinghamshire County in 2010 was 668,100 with 25% in the age range between 60 and 90 years old (SEPHO, 2011).

In 2010/11, the emergency admission rate for HF in Nottingham City was 79.9 per 100,000. This is higher than England (SEPHO, 2011). In 2010/11, the emergency admission rate for HF, all persons, in Nottinghamshire County was 61.4 per 100,000 (747 admissions). This again is higher than England (59.8 per 100,000).

Forty-four per cent of deaths from HF in Nottingham City occurred in the usual place of residence, which is a lower proportion than the national average (SEPHO, 2011). Seventy per cent of deaths from HF occurred in the usual place of residence in Nottinghamshire County, which conversely is a higher proportion than the national average (SEPHO, 2011).

6.3 Phase one methodology

The quantitative phase of the study used the self-completed FAMQOL questionnaire to measure positive and negative aspects of caring (physical, social, psychological and spiritual wellbeing) using a structured survey in a population of carers of patients with advanced HF. Variance in levels of wellbeing by types of carer were examined.

6.3.1 Survey as a method of data collection

Surveys are commonly used to develop an understanding of views, experiences and attitudes and are effective instruments to gain self-reported data on

abstract concepts such as wellbeing and quality of life (Walker and Almond, 2010; Watson et al., 2008).

Surveys can be administered face-to-face with an interviewer asking the survey questions, through telephone interviews or in a self-report questionnaire which can be posted, given to the respondent directly or carried out via the internet (Addington-Hall et al., 2011). Addington-Hall et al. (2011) recommend that it is imperative that consideration is given to the method of the data collection when using surveys in research, and in particular in research with palliative patients and their carers. The authors propose that no one method shows evidence of being more effective than others, with each type of data collection method having strengths and weaknesses. Consideration needs to be given to the study context, study participants and setting and the resources available to administer the questionnaires (Addington-Hall, 2011).

To address the study objectives 1 and 3 measuring physical, psychological, social and spiritual domains in relation to carer QOL and positive and negative dimensions of caring, a survey was conducted using the FAMQOL instrument with a sample of carers for patients with advanced HF. As previously stated the instrument was considered beneficial in the present study as it was specific to the HF carer population and captures multidimensional concepts of physical, psychological, social and spiritual wellbeing.

6.3.2 Cross sectional design

Following the recommendations of Addington-Hall (2011), the present study used a cross-sectional survey to give a profile of the study population at a given time (Liamputtong, 2010). The rationale for using a cross-sectional design related to the study population and the sequential design of the present study. Attrition can be an issue when undertaking research with carers due to their challenging, changing personal circumstances (Penrod et al., 2011). Additionally, the survey did not aim to measure change or causality, and therefore there was no rationale for the added difficulty and expense of a longitudinal survey.

A review of the literature relating to research priorities with family carers conducted by Hudson et al. (2011) indicated significant gaps in this area of research and highlighted particular issues with accessing carers to participate in studies and issues with determining who the main caregiver for the patient is. Consequently, as a research population, carers present a range of issues that need to be addressed in order to facilitate their participation in research. A systematic review undertaken by Bonevski et al. (2014) advocated specific strategies can be incorporated into the study design to improve access to hard-to-reach populations. Miller et al. (2003) further recommends that positive interpersonal relationships between the research participants and the people recruiting into the study are essential in maximising participant recruitment. Participants' sense of respecting, liking and trusting the person recruiting has been demonstrated to improve accrual and retention throughout the research process (Miller et al., 2003). When considering carers of HF patients as a hard-to-reach study population, the use of gatekeepers was considered as a positive recruitment strategy in the present study, and it was decided that the survey should be administered via the HFN service. The community-based HFN service was an organisation that had access to and an established rapport with the study population.

6.3.3 Quantitative sampling strategy

The present study implemented use of a two stage sampling strategy for phase one. Initially a convenience sample was used in that carers were accessed through the HFNs in Nottingham and Nottinghamshire where I could readily access the nurses working in this service.

The aim at the outset of the study was that all carers of patients receiving the HFN service in Nottinghamshire were to be invited to complete the FAMQOL. As the intention was for each HFN to recruit all carers they had contact with during the data collection period the second part of the sampling strategy was considered to be a census sample. A census sample is used when data is collected from all individuals in the population of interest, in the context of the present study, carers of patients with advanced HF (Bryman, 2008). Therefore phase one of the study used a multi-stage sampling strategy. A convenience sample and census sample of participants was recruited to complete the

FAMQOL questionnaire. Carers of patients on the caseloads of eight HFNs throughout Nottinghamshire were contacted by the HFNs and asked to complete the questionnaire.

Although the quantitative phase of the study was using an exploratory approach based on the figures of carers known to the HFN services in Nottinghamshire, 82 carers would be sufficient to detect a moderate correlation of 0.30 with 80% power. Therefore, aiming for 100 carers would give sufficient power to allow for some incomplete data and offer reasonable precision in the estimates in the data. If a larger sample were achieved, it would also allow for some multiple regression analysis to examine the joint effect of different factors on quality of life. The unit of analysis was the carer.

The inclusion criteria of the sample were as follows:

- The carer must be an unpaid person providing physical, practical and/or emotional care and support to a relative or friend in the patient's home.
- Due to practical implications (limited availability of translation services and the study timescale), the carer must be able to read, write and speak English.

The exclusion criterion was as follows:

- Family members of HF patients residing in an extended care facility or nursing home as they are receiving formal care.

6.3.4 Strengths and weakness of the sampling strategy

A positive aspect of a convenience sample is that it can be obtained through an organisation with good access to the target population. Bonevski et al. (2014) acknowledge that this approach has limitations but argue that it presents a pragmatic advantage for sampling a hard-to-reach group. Convenience sampling is nonprobability sampling and aims to obtain information from participants that are easily accessible. The advantages of this sampling method include ease of recruitment, retention of sample members, often good response rates, and affordability and practicality (Etikan et al., 2016., Bowling, 2009). However, a disadvantage of convenience sampling is the risk of bias in that the sample is not representative of the whole study population. Bowling (2009)

recommends that the researcher considers the degree to which the study population differs from the wider population of interest. The researcher needs to consider an estimation of the extent to which the population of interest included in the study differs in significant ways from the wider population of interest not included in the study. Whilst the study was conducted in a sample population from Nottingham and Nottinghamshire this population does not have not distinct differences as compared with England as a whole. Therefore although representativeness cannot be assured, there is no rationale as to why the study population would be considered unrepresentative.

A positive aspect of using a census sample is that the whole population of interest is covered and thus there is no sampling bias. However, as with the convenience sample, there is the issue of non-response bias.

In the present study there were two types of non-response bias to be considered. Firstly related to the possibility of the HFNs deciding not distribute the questionnaires to some carers. Secondly amongst those to whom the questionnaires were distributed the types of carers who may be less likely to respond e.g. older carers, carers with their own health issues.

A sampling strategy that may have addressed the limitations highlighted would be to conduct the study across a wider geographical region. To overcome the non-response bias would have necessitated a costly follow-up mechanism or for the questionnaires to have been distributed by myself; neither of these strategies would be considered viable within the scope of the present study due to the associated costs and time.

Therefore it was considered that, despite the limitations, the use of a convenience sample, followed by a census sample was an effective sampling strategy in relation to the study participants. A strength of the sampling method in the present study was that sampling was conducted with an entire HFN service covering Nottingham City and Nottinghamshire; all HFNs working in the service were used to recruit carers. The sample therefore was unlikely to suffer from systematic bias and, whilst there may have been a level of non-response bias, this was considered to be no more likely than non-response bias in a representative random sample. Thus it is proposed that the present study used a robust approach to the chosen sampling strategy.

6.3.5 Quantitative data collection

The FAMQOL asked carers to respond to questions in relation to physical, psychological, social and spiritual dimensions using a numerical scale, where 1 represented strongly agree, 5 represented strongly disagree. Additionally demographic data was collected in the following categories: age, gender, relationship, ethnicity, working status, living arrangements, children, living arrangements, health issues and time spent caring.

All HFNs in the study locality, eight in total, were approached and asked to disseminate the FAMQOL questionnaire. The phase one data collection period was between January and March 2014. Each HFN was given an information pack containing 20 questionnaires for distribution. All carers who were seen by the HFN during the recruitment time frame were invited to participate in the study. If the HFN distributed the 20 questionnaires during the recruitment time frame, they were requested to contact the researcher to be provided with a further supply of questionnaires and continue to distribute them accordingly.

An information sheet (Appendix Five) about the research and its purpose was given to participants with the questionnaire by the HFN. The information sheet included the following information: outline of the aim of the research, requirements of participants and confidentiality of the responses. The questionnaire was self-administered (carers completed the questions themselves, in their own time). Participants were asked to return the questionnaire by a given date in a prepaid envelope to the researcher. A reminder was sent out to non-responders after three-week period.

Each HFN was contacted after two months to ascertain how many questionnaires had been distributed.

6.3.6 Quantitative data analysis

The quantitative analysis involved descriptive statistical analyses to generate means, standard deviations and percentage scores on key variables.

Relationships between overall FAMQOL score, the four domains and the following variables were analysed using one way analysis of variance (ANOVA): working status, level of support provided, length of time known to the patient and how long supporting the patient. Relationships between overall FAMQOL score, the four domains and the following two category data were examined using t-tests : gender, living arrangements, relationship to the patient, children and health problems.

Additionally correlations were to be used to measure the strength of relationships between two variables in that as the score on one variable changes, a change in the score on the other variable would be observed (Walker and Almond, 2010). In the present study this could establish, for example, a correlation between carers' physical health and feelings of being overwhelmed

The quantitative data analysis and subsequent findings were fed into the development of the topics for the qualitative semi-structured interview schedule as indicated in section 6.5.6 to allow for in-depth exploration.

6.4 Phase two methodology

Reflecting on the aims and objectives associated with the qualitative phase of the research and in recognition of my own position as a researcher within the qualitative paradigm, an exploration of various stances within this methodological approach was undertaken to find the best fit for the research.

Bryman (2008) categorises five main qualitative approaches to investigation. It is necessary to state that this is not an exhaustive list but includes approaches that could be considered fitting to address the qualitative aim and objectives of the present study: narrative research and case study, ethnography, grounded theory and phenomenology. The rationale for the choice of phenomenology is briefly presented.

Narrative research and case study design

Narrative research methodology alludes to text or discourse focusing on stories told by individuals. It is mainly used with one or two individuals, reporting and chronologically ordering the meaning of their experiences. A case study design

reports detailed and intensive analysis of a single case; a 'case' can refer to a location, a community, an organisation or a family. Such an approach is fitting where there are clear boundaries of the case being studied and a need for in depth understanding. Therefore I felt that narrative research and case study design were not appropriate methodologies for the present study, which seeks to understand the experiences of a larger group of people, and look for similarities and/or differences underlying the individual experiences.

Ethnography

Ethnography involves the researcher being immersed in the study population and the associated social setting for an extensive episode of time; making regular observations of the members of the population; listening to and engaging in conversations and developing an understanding of the cultures and behaviours of people's behaviour. The qualitative research aim in the present study focused on deepening understanding of similarities and/or differences between individual's experiences, rather than how people interact with each other. Additionally conducting an ethnographic study with the study population would raise ethical concerns as regards the vulnerability of the participants.

Grounded theory

Grounded theory seeks to identify and contextualise social processes. It allows concepts and categories to emerge from data without preconceptions; assumes social events and process have an objective reality and can be observed by the researcher. The researcher acts as a witness; must be careful not to import their own preconceptions into the process. Theory evolves from the emergent data, with no predefined theory, and data emerges without 'theoretical blinkers'. As a researcher with previous nursing experience working with carers of HF patients and theoretical knowledge generated from the quantitative phase of the present study I propose that it was not applicable to implement a grounded theory approach as it was not feasible to remove theoretical blinkers.

Phenomenology

In contrast to the qualitative approaches outlined, phenomenology is concerned with individual experiences, derived from each person's accounts, understanding and interpreting the meanings. I wanted to explore peoples' lived experience and consider how the theoretical underpinnings of my study were affirmed or diverged from existing literature.

Many studies in nursing utilise a phenomenological approach; nursing values the whole person and values their experiences. The essence of nursing concerns itself with the nature of being, becoming existence and/or reality, all of which are subjective and embedded in the lived experience (Moxham and Patterson, 2017).

The qualitative aim of this study was to develop and enhance knowledge of a specific human experience, namely caring. In doing so, it was hoped that the findings would lead to recommendations for new and innovative initiatives to improve carers' experience. To develop this new perspective, I implemented Interpretive Phenomenological Analysis (IPA) to deepen understanding rather than seeking explanations. This approach is commonly utilised in nursing research as it allows for research to be undertaken with participants to gain understanding of experiences of being in the world and in doing so emphasises the importance of meanings (Flood, 2010; Mackey, 2005).

6.4.1 Theoretical underpinnings of Interpretive Phenomenological Analysis (IPA)

IPA is founded in the philosophical principles of hermeneutic interpretive phenomenology originally proposed by Heidegger (Rapport and Wainwright, 2006, Crist and Tanner, 2003). In order to understand the philosophical underpinnings of hermeneutic interpretive phenomenology, it is necessary to distinguish hermeneutic interpretive phenomenology from the classical descriptive phenomenology, namely Husserlian phenomenology (Rapport and Wainwright, 2006).

For Husserl, the aim of phenomenology was a description of how the world and associated experiences are constituted through the human consciousness (Draucker, 1999). He proposed that subjective information is a vital part of understanding human actions and motivation, and to gain this understanding a scientific approach is needed to identify the essential components of the lived experiences specific to groups of people (Flood, 2010). It is also necessary for the researcher to shed prior personal knowledge and experience to prevent preconceptions and biases influencing the researcher's perspective; this process is known as bracketing (LeVasseur, 2003). Husserl advocated that researchers withhold assumptions concerning knowledge to enable clarifying of the essence of cognition (Rapport and Wainwright, 2006).

In the context of this study I would argue that the process of bracketing was not feasible on two counts. Firstly, as a MM study there was an existing knowledge, albeit empirical, from the first phase of the study about the impact of being a carer for a person with HF. Indeed, the study methodology stated that the findings from phase one of the study would be used to affirm and develop the topics for the semi-structured interview schedule in phase two of the study. This process was in keeping with an MM methodological stance in that the two phases should be clearly integrated.

Secondly, I believe that the previous knowledge and experience I had relating to the study population from both engagement with a wide range of literature and past clinical experience influenced the interpretation of the qualitative findings and was valuable to guide the inquiry (Tuohy et al., 2013).

6.4.2 Core concepts in IPA

A hermeneutic phenomenologist explores the meanings of an individual's 'Dasein', namely the situated meaning of a human in the world. In Heidegger's view, 'Dasein' means we are already embedded in a world of meaning (van Manen, 1990). Since hermeneutic interpretive phenomenology explores the lived experience, the relationship between the world in which people live and the influence this has on their reality needs to be understood within the research process.

Heidegger referred to the term 'life world' for the concept that an individual's reality is influenced by the world in which they live (Lopez and Willis, 2004). Existential life world themes are important to gain an understanding as to how people experience the world which is through lived space, lived time, lived body and lived human relations (van Manen, 1990).

Lived space places a person in a location with which they may have positive or negative feelings, for example home or institutions such as work or care settings. Lived time is subjective time; how we interpret specific events occurring at particular times in our lives and if these events have positive associations. Lived time may speed up if we are happy or slow down if we are experiencing difficult life events. Lived body refers to embodiment; we are always in our body and demonstrate feelings through a range of body language. Lived human relations are the relations we maintain with others in interpersonal space we share. It is through relationships we experience the world and influence and are influenced by others (van Manen, 1990). Clearly the meanings associated with the life world hold importance in the context of the present study and would influence the individual interpretations of the meanings of being a carer.

An important distinction between descriptive and interpretive phenomenology is Heidegger's stance that presuppositions or expert knowledge cannot and indeed should not be suspended as part of the research process (Flood, 2010; Draucker, 1999). Heidegger argued that it is impossible to exclude the background personal understandings of the topic that the researcher brings and which ultimately have led the researcher to consider the topic area to be one of importance and necessary to deepen understanding through the research process (Koch, 1995). Thus personal knowledge is viewed as useful and integral to the research process (Geanellos, 2000).

The researcher is seen as an active participant in the interpretive process; meanings from narrative dialogue from participants is merged with those of the researcher and put in context. This process is described as the co-constitution of data (Flood, 2010; Draucker, 1999). Gadamer (1975) referred to this process as a fusion of horizons. Understanding is influenced by a personal horizon of experiences and meanings, and in this way interpretation is embedded by the

separate, intersecting horizons of researcher and participants (Geanellos, 2000).

Heidegger argued that interpretation of meanings is a cyclical process moving between the parts and wholes of the paradigm (Mackey, 2005). The researcher moves back and forth within the dialogue with the participants, questioning in order to develop an expanding circle of ideas, namely the hermeneutic circle (Tuohy et al., 2013). Understanding deepens when the researcher and participants meet through open and honest dialogue. Patricia Benner, a prolific phenomenological nurse researcher, proposes that interpretation can be facilitated with the use of exemplars and paradigm cases (Benner, 1994). Exemplars are important as they are defined, clear visualisations that provide distinctions within and between themes and thus enable the cyclical process of understanding, interpretation and reflective critique (Benner, 1994).

Thus the study implemented the philosophical stance proposed by Heidegger (Finlay, 2009). Heidegger argued against Husserl's phenomenological philosophy being purely descriptive. He proposed that any description of 'being' without interpretation was not possible. Heidegger's view of phenomenology was one in which we seek to uncover understanding of 'being'; he believed that humans live hermeneutically in that we try to find significance and meaning in the world, and thus this view of phenomenology is that the process involved is interpretative rather than descriptive (Mackey, 2005; Draucker, 1999). The aim of interpretive phenomenology is therefore to increase understanding of the meanings of human experiences; it seeks to find out what it means to be a person in the world. It has been described as the science of interpreting human meaning (Gadamar, 1975). Daily acts of living are accessed by narrative dialogue to explore the meanings and experiences of being in the world for participants experiencing a particular phenomenon (Crist and Tanner, 2003).

Van Manen (1990) advocates the use of hermeneutic writing during this process; by writing and rewriting, the researcher seeks to clarify, reflect and illustrate the deeper meaning of the phenomenon. This involves the researcher reading and listening to the data to fully engage with the participant's dialogue; sections of the transcripts are highlighted, notes are made about the meanings

of the text and questions developed by the researcher to propose meanings and consider what is absent. A key part of this whole process in hermeneutic writing is reflection; the researcher must step back and look at what is revealed about the phenomenon. Only when this process is completed can the themes be developed through analysis and synthesis (Mackey, 2005).

Research utilising IPA as a methodology seeks to understand and interpret individuals' experiences and meanings associated with experiences, and in this manner views human experience as a valuable source of knowledge (Mackey, 2005). Phenomenological research which embraces the Heideggerian philosophy emphasises the value of the richness of the everyday experience and how this is interpreted to deepen understanding of what the essence of the phenomenon means for the individual.

IPA follows the principles developed by Heidegger in that it is concerned with examining how a phenomenon appears (Smith et al., 2011). Additionally, IPA encompasses ideography, a concern with the particular. This is twofold; firstly, there is a commitment to the particular in relation to details and therefore the depth of analysis. Secondly IPA encompasses understanding of how a particular phenomenon is understood from the perspective of particular people in a particular context (Smith et al., 2011). It seeks to understand the uniqueness of individuals' experiences and the meanings associated with a particular phenomenon and focuses on an individual's personal experience of a certain situation (Clarke, 2009; Watson et al., 2008). IPA recognises the importance of the rich narrative dialogue from which key themes can be analysed (Brocki and Wearden, 2006). It follows the double hermeneutic principle of empathy and questioning. In the context of this study, this relates to trying to explore and empathise with what it is like to be a carer for a person with HF but additionally analyse this experience and make sense of the experience within the wider theoretical concepts of caring.

When considering the theoretical principles of fore-structure and the hermeneutic circle, IPA acknowledges that access to the participants' unique experiences is complex and is influenced by the researcher's own conceptions; thus the process of IPA involves joint reflections from both participant and

researcher accounts (Pringle et al., 2011a Brocki and Wearden, 2006;). This interconnectivity is dependent on the participants' ability to articulate their experiences and the researcher's capacity to reflect and analyse this dialogue to capture the true essence of the phenomenon.

Pringle et al. (2011a) advocate that this approach is necessary in order for researchers to reach, hear, understand and access participants' experiences. Thus IPA is a blended phenomenology and an evolving dynamic activity rather than a collection of scholarly ideas. Quotes and metaphors from participant narratives are central to and embedded in the themes within the analysis; this is a particularly poignant means to give vulnerable and hard-to-reach groups a voice in the research process.

6.4.3 Sampling strategy in IPA

As identified, an important feature of IPA is the centrality of the individuals' narrative in the analysis. Thus the selection of the sample focuses on recruiting participants for whom the research question has relevance and meaning (Smith et al., 2011). It is the depth of narrative dialogue rather than numbers of participants needed to substantiate theory, as seen in grounded theory that is the driver when sampling. Whilst smaller sample sizes may be argued as being a weakness of this methodology, Smith and Osborn (2008) propose that the approach creates opportunities to engage in a deeper level of analysis which may be diluted if the sample is too large. This deeper analysis requires the researcher to 'go beyond' what is immediately apparent in the dialogue.

Whilst there is no definitive sample size, IPA requires the sample to be homogenous, and sampling therefore tends to be purposive. Brocki and Wearden (2006) propose that this is necessary to provide adequate contextualisation to the perspective being explored. Smith et al. (2011) argue that the homogeneity of the sample is essential for the researcher to be able to draw out these differences and explore the variability of each individual's experiences of the same phenomenon. Thus the analysis explores convergence and divergence in the participant's narrative. The sample size can be

considered to be adequate when the interpretation and analysis of the participants' narrative reveals no new findings (Crist and Tanner, 2003). Additionally, the sampling method is influenced by pragmatics and practicalities. Smith et al. (2011) advocate that researchers consider which people are in the situation under investigation, how can they be contacted easily and what the researcher's contacts are that could facilitate this process

The sample for the qualitative phase of the study was drawn from respondents to the FAMQOL questionnaires. Participant returning reply slips were purposively sampled and approached to take part in an interview. As the quantitative phase of the study recruited from HFN caseloads the qualitative sampling strategy strived for homogeneity in the study participants. It is important to note, however, that whilst the sample was homogenous the aim was not to have a group of individuals in the sample that were treated as identical; rather it was to have a sample of individuals who had commonality of the phenomenon being explored but differing experiences.

6.4.4 Semi-structured interviews

Semi-structured interviews are deemed the gold standard for data collection in IPA research (Smith and Osborn, 2008). A critical evaluation of the use of IPA research in health psychology undertaken by Brocki and Wearden (2006) found that the majority of IPA studies included in the evaluation used face-to-face interviews with a semi-structured interview schedule. This method of data collection was considered to be a means to facilitate the participants to tell their own story in their words. The interview schedule allows the researcher to use prompt questions to facilitate disclosure, and the schedule enables the researcher to prepare the likely interview content and sets out the order in which the issues may be addressed (Smith et al., 2011). There should be recognition that whilst this can guide the interview, each interview experience will differ and it will be necessary for the research to adapt accordingly once each interview commences. Smith and Osborn (2008) emphasise that the

participant should have a strong role in the interview process and the use of prompts should be kept to a minimum.

The interview schedule may be based on theoretical research or previous interview questions. In the present study, the interview schedule built on the dimensions and initial findings of the FAMQOL questionnaire alongside the wider literature and previous interview schedules.

Interview schedule

The interview schedule (Appendix Six) was informed by relevant literature and the ideas emerging from the findings of the FAMQOL questionnaire analysis. Based on the initial quantitative analysis the following questions were added to the interview schedule to deepen the exploration:

Has caring for your husband/wife impacted on your social life?

Do you think there is anything that would improve your caring experience?

I aimed to draw out the carers' perspectives regarding their experiences of being a carer, and feelings regarding the CSP initiative and support offered during the interview. There was also opportunity to explore how support services address carer needs, issues regarding coordination and communication, and any gaps they felt there may be in support.

The interview schedule began with a broad area of questioning about being a carer and then focused more directly on specific issues relating to caring. In doing so, my aim was to establish a rapport with the participant before addressing aspects of caring that the participant may feel difficult to talk about. Using semi-structured interviews enabled me to steer the interview with prepared questions whilst still allowing a level of spontaneity and opportunity for interviewees to elaborate on their answers.

Consultation was undertaken with the Carer Support Group (Appendix Seven) for HF carers to ask for their opinions on the appropriateness and acceptability of the interview questions and schedules prior to phase two of the study commencing. Four carers were shown the interview schedule, and they felt that the questions were acceptable to ask and did not identify any changes that should be made.

The interviews

The semi-structured interviews were conducted with carers who had identified that they would be willing to participate in an interview. Using the contact details provided on the return slip, each participant was contacted, and a date and time was set to conduct the interview which was convenient for them. Prior to the interview date, the participant was sent a second version of the study information sheet (Appendix Eight).

Interviews lasted between 30 and 60 minutes. Due to the social context of the study, interviews took place with carers in their own home, reducing inconvenience for participants and assisting in making them feel at ease. This method of data collection was fitting when considering the potential difficulties of recruiting to a research setting away from the home due to the caring responsibility of the participants. Interviews were conducted without the patient present but the participant was reassured that the interview could be suspended for them to attend to the patient if necessary. This was to facilitate participants to talk openly about their experiences.

Prior to the interview commencing, the aim of the research study was reiterated, the carer was asked to reread the information sheet and any queries that the carer may have had were answered. If they were willing to proceed, they were asked to read and sign a Consent Form (Appendix Nine).

6.4.5 Data analysis in IPA research

Central to the analysis is the interpretation of the narrative and the emerging themes. The transcript of the participant's narrative should be read and reread, and it is advisable to listen to the audiotape of the interview whilst reading the transcript (Smith et al., 2011).

Hearing the dialogue helps to remind the interviewer of each individual participant rather than focusing on text alone; the aim is to keep the person central to the process of analysis. The researcher can choose to record their

own recollections of the interview and make observational notes about the transcript to be referred to at a later date. It is crucial at this first stage that the researcher has an open mind about the analysis.

The founding theoretical and philosophical principles of IPA centre on a desire to deepen understanding of personal experience and to interpret the meanings associated with the experience from the perspective of individuals. IPA is increasingly being recognised as a qualitative methodology that is fitting to explore complex concepts (Brocki and Wearden, 2006). As illustrated in the literature review, caring for a person with advanced HF is complex, and therefore IPA was considered to be a fitting methodology to explore the carer experience.

Whilst it is recognised that the analysis was an iterative process with researcher reflexivity and the need for a level of fluidity in analysing the transcripts, Smith et al. (2011) advocate following some structured steps to ensure the analysis is auditable and systematic rather than rigid and prescriptive.

These steps are as follows:

- Reading and rereading
- Initial noting
- Development of emergent themes
- Exploring of connection between themes
- Moving on to the next participant transcript
- Looking for patterns across participants' transcripts (Smith et al., 2011).

Smith and Osborn (2008) recommend the following strategies to demonstrate rigour in IPA: clear rationale for design; where possible, ensure the data analysis is checked and agreed by participants; peer review of transcripts; and presentation of findings to reflect representation.

When presenting findings, Liamputtong (2010) recommends consideration is given to the following: credibility of the findings, i.e. whether the findings can be

applied to other contexts and therefore show transferability; dependability of the process, i.e. whether the findings fit with the data collected, if the process is traceable, logical and documented; and transparency of researcher consideration of their own values and how these may influence the interpretation of the findings in any way.

A criticism of IPA analysis is that, due to the manner in which each participant's experience is considered a unique experience, it is then difficult to propose generalisability of the findings as a result of subjectivity. Searle (2000) calls for a focus on commonality rather than generalisability; thus the qualitative analysis explored themes that showed commonality amongst carers of people with advanced HF. The manner in which the study sample was selected also enhanced the commonality. By selecting a homogenous sample, it was possible to contextualise the findings to the study setting in which the research was conducted (Smith et al., 2011). This was applicable to the present study; all carers were supporting a person with advanced HF and were receiving the services of HFNs.

Importantly, IPA is driven by the exploration of the essence of a phenomenon or experience; it does not aim to claim generalisability of findings but rather to produce narratives that resonate with readers of the research (Pringle et al., 2011a; Liamputtong, 2010).

In the present study each interview was transcribed verbatim, following which the transcripts were read and reread to gain familiarity with commonality, patterns and emerging themes (Smith et al., 2011). The lead supervisor and I independently read and drafted a coding framework from a sample of transcripts. Following critical discussion, the coding framework was refined, and to facilitate the process of in-depth analysis the Computer Assisted Qualitative Analysis Software package NVivo was used. In the present study, NVivo was a positive means to organise the interview transcripts, create annotations on the individual transcripts, create nodes for themes emerging and to explore for commonality.

IPA analysis recognises the centrality of the researcher in making sense of the participant's experiences, and in this way it differs from a more descriptive

phenomenological analysis (Pringle et al., 2011a). The interpretation of participants' dialogue was twofold. I considered the participants' beliefs and descriptive dialogues of being a carer; this was followed by an interpretation of how the participant makes sense of being a carer and how it places them in a societal context. The process was idiographic in that I considered the wholeness and uniqueness of the individual experience; each carer's experience was discrete to their own situation and circumstances. To illustrate the idiographic nature of the analysis, themes that emerged are supported by direct quotes from the participants' dialogue to substantiate the themes. To further anchor the participants' experience in the research analysis, Pringle et al. (2011a) advocate drawing themes and titles from quotes from and metaphors used by participants, and this approach was demonstrated in the present research study.

In keeping with the philosophical stance of IPA, coding was an inductive process from initial analysis of the transcripts. Analysis was iterative and cyclical with the aim of improving and refining by revisiting the transcripts to check the fit of the developing themes with the theoretical concepts and participants' dialogue (Watson, 2010). Themes demonstrated synergy between the descriptive accounts of the participants' experiences and my interpretation of these accounts in which the theoretical concepts were embedded (Pringle et al., 2011a). Transcribed data was organised for clarity in the process of analysis from initial commentary on the written transcripts to the development of themes and structuring of themes, which is outlined below (Smith et al., 2011).

1. Reading and rereading:

To immerse myself in the data, I read and reread the transcript and revisited my accompanying interview notes. This process facilitated an awareness of my own initial perceptions and thoughts which may have influenced my interpretations of the data; by re-engaging with the data, I was able to develop familiarity with each of the participant's experiences

2. Initial noting:

Each typed transcript was uploaded to the NVivo database. I then began looking at the descriptive, linguistic and conceptual comments in each

transcript. This was achieved using the annotations function in NVivo. Examples of different types of notes are shown below:

Descriptive comments: the services received were good but it is the proactive support that is lacking – the ‘pop in’ visit

Linguistic comments: sense of need to be persistent to get things sorted, implies frustration and need to push to get things sorted. When asked about support and help, she describes this as needing to use threats to get help – this a very emotive way to gain help, anger, frustration.

Conceptual comments: links to theories of uncertainty and practical implications of caring. Metaphor of falling to her knees, very visual way to describe the impact on her physical and mental health that caring has caused – not able to think straight, poor cognition due to exhaustion; this is worrying as she is dealing with the complex care needs of her husband including his medications. Use of the word shattered, broken into pieces, links to comments on relating to be in different pieces to meet the varying demands of caring.

3. Developing emergent themes:

To refine the data, I began to explore the emerging themes in each individual transcript and began to create initial nodes in NVivo. Examples of tentative themes included *activities of caring, adapting to the caring role, dealing with differing demands*. Where feasible, I tried to use the language of the participants for the themes.

4. Searching for connections across emergent themes:

Revisiting the nodes in NVivo and reviewing the annotations relating to the nodes, relationships within the themes were explored for each of the individual transcripts to deepen the level of the analysis. Moving on to the next case:

Steps 1- 4 were undertaken for each of the transcripts. Importantly, in keeping with the IPA methodology, each transcript was viewed individually before moving on to the next case. This was to ensure each participant’s experiences were analysed for uniqueness before considering commonality across all participants’ experiences.

5. Looking for patterns across cases:

This stage involves drawing together the cases to explore for connections and emerging themes. To facilitate this process, typed themes were listed in chronological order and a report was run in NVivo highlighting the coding summary by node. I then viewed the themes and wrote a draft of how the themes could be merged together for discussion with the supervisory team. As recommended in IPA analysis (Smith et al., 2011), superordinate themes were developed to bring together related themes. Themes that represented similar issues in the carer transcripts were highlighted, and codes were reviewed and merged as illustrated on the following two pages for overlapping codes. Titles of the themes were refined to reflect the participants' words.

| Super-ordinate Themes | Related Themes | Themes Reviewed | Themes Merged | New Theme Created |
|-----------------------------------|---|-----------------------------------|--|--|
| Emotional impact of caring | Control: <i>you can't ever plan for tomorrow</i> | Loss of independence | Merged into Social isolation | |
| | Social isolation: <i>I've got nobody out here</i> | | | |
| | Coping with the challenges of caring: <i>I don't know how much more I can take</i> | | | |
| | Unpredictability | | | |
| | Facing the future: <i>live every day like it's your last</i> | Unpredictability | Merged into Control | |
| | Loving relationships | | | |
| | Congruence | | | |
| | Rewarding aspects of caring: <i>it's really a pleasure</i> | | | |
| | Loving relationships | Loving relationships | Merged into Rewarding aspects of caring | |
| | Congruence | Congruence | | |
| Living as a carer | Physical effects of caring | Taking care of finances | | Practicalities of caring: <i>just felt useless that I couldn't do anything for him (incorporates Organising equipment, Accessing services, Taking care of finances, Managing medications)</i> |
| | Managing medication | Physical effects of caring | | |
| | Financial implications | Managing medication | | |
| | Accessing services | Financial implications | | |
| | Organising equipment | Accessing services | | |
| | | Organising equipment | | |
| | Differing relationships | Differing relationships | | Resilience of the carer and patient: <i>he would still look after himself; he is just that type of man</i> |
| | Resilience | Resilience | | |

Newly gained knowledge

Newly gained knowledge

Merged into Coping with competing demands: 1,001 things to do

Coping with competing demands: 1,001 things to do

**Caring as a job
Coordinating care**

| | | |
|----------------------|--|--|
| Carer support | <p>How support was organised: <i>I did all the running</i></p> <p>Information needs of carers: <i>nobody offers anything freely</i></p> <p>Significance of support networks: <i>I wouldn't have got through without the neighbours</i></p> <p>HFN role</p> <p>Improving the caring experience: <i>you need reassurance that people are going to take responsibility</i></p> | <p>Targeted support of the HFN: <i>heart nurse has been brilliant</i></p> |
|----------------------|--|--|

Refinement of emerging themes

Whilst the steps identified were utilised, the core principle of the analysis was to maintain an innovative and iterative stance that evolved when I was fully engaged and emerged within the carers' experiences as expressed within the transcripts.

6.5 Ethical issues

Prior to conducting the data collection, NHS and University of Sheffield ethical approval was obtained. A meeting was held with the Head of Research Management and Governance responsible for the HFN services in

Nottinghamshire to discuss the research proposal; the notes of the meeting are outlined in Appendix Ten.

In addition to the ethical approval, it was recognised that there were specific matters to address when conducting the research with this carer population.

Key issues that were considered are highlighted below:

- approaching carers in a sensitive manner in recognition that this was an emotionally vulnerable study population
- there may have been a reluctance to complete the questionnaire if carers perceived it to be too time consuming
- practicalities of conducting interviews in the carer's home; due to fluctuating symptoms of the patient, carers may not have been willing to be interviewed on a given date if the patient had become unwell
- potential high levels of attrition due to changing condition of the patient that the carer was supporting
- as a prospective study when considering the disease trajectory of HF, there may have been carer bereavement issues to address, and I needed to respond appropriately if and when this occurred

Fitzsimons and Strachan (2012) identify strategies for overcoming challenges of conducting research with HF patients. Whilst these strategies relate to research with patients, they were useful to consider in relation to the potential challenges of this study. Fitzsimons and Strachan recommend researchers are prepared to adjust the completion date of written documents such as questionnaires and to reschedule interview dates according to the participant's needs. They advocate that interviews ideally are conducted in the participant's home with time included for breaks and time-outs as necessary. Sensitive and effective communication skills are essential when considering the issues of potential bereavement during the course of the study; ideally researchers should be trained in advanced communication skills to manage sensitive situations. It is also important that researchers take time to establish relationships with clinical teams and service users in the development of the research project.

The following actions were taken to address anticipated challenges:

- a meeting was held with an HF carers' group to discuss the research proposal (Appendix Seven)
- HFN services were engaged from the development of the research project and liaised with the team on a monthly basis to keep them up to date of the research progress
- participants were offered regular breaks during the interview, particularly if they were finding some aspects of the discussion distressing. If participants became distressed during the interview, appropriate support was offered, and the participant was provided with information regarding support services as necessary
- the interview schedule was developed so the interview would last between 30 and 60 minutes. This was to ensure that the interview was not too lengthy, which could have made it difficult for the participants to cope with
- as an experienced HFN, I was accustomed to communicating in a sensitive manner during complex clinical situations.

6.6 Potential challenges to the research

In regard to the recruitment to phase one of the study, it was necessary to review the distribution of the questionnaires due to the slow return rate, with an average of five questionnaires being received each month. It transpired that the distribution rate was extremely variable; one HFN had distributed 20 questionnaires whereas three HFNs had not distributed any questionnaires. In total, at the end of the quantitative phase of the present study, of the total 160 questionnaires given to the HFNs in Nottinghamshire, 68 questionnaires had been distributed to carers.

Reflecting on this methodological dilemma, in order not to compromise the sequential design of the present study, it was agreed to set an end date for the quantitative phase whilst acknowledging that this incurred the risk of low responses for phase one. Identifying an end date enabled the quantitative analysis to begin prior to commencing phase two of the study, and this could be

done in a timely manner. This amendment was a necessary step in order not to lose carers who had expressed an interest in being interviewed for phase two. The intention was for questionnaires returned after the end date to be included in the descriptive statistics but not in the statistical analysis. Initial interviews were commenced prior to the end date, but these interviews were viewed as pilots of the interview schedule. This proved to be a beneficial action as the pilot interviews affirmed the interview schedule.

6.7 Reflexivity/positionality

In developing the research questions it was necessary explore the relationship between my position as a researcher and my particular interests in relation to the research topic (Denzin and Lincoln, 2008).

My personal aim when undertaking the research was driven by my clinical experiences working as a community based HFN. As a nurse I visited patients with advanced HF in their own homes to optimise the management of their condition with the aim of improving their quality of life. Many patients were living with family members or had friends and neighbours who were providing supportive care on a daily basis. I was mindful that the main focus of demonstrating the effectiveness of the HFN service was a reduction in unplanned patient admissions to secondary care. However during the time I spent working as a HFN I had an increasing awareness that the role additionally offered support to carers that was not captured. I was interested to note some carers appeared to be able to deal with their circumstances with positivity and enduring resilience, rather than viewing their situation as a negative experience.

Many carers I encountered during my time spent working as a HFN had great responsibility for the day to day care and used opportunities during home visits to gain reassurance and information in order to effectively and safely support the patient. I felt compelled to raise the profile of this carer population as an important and worthy topic of investigation.

Thus I did not embark on my research journey with a paradigm influential as to how I would conduct the research, rather I was motivated by what I wanted to find out. I felt it was important to look at how caring affected QOL both in a

positive and negative way and the perceptions of carers about caring for a patient with advanced HF. My experience of the HF carer population was that many were older people with their own health issues which they often neglected. I was concerned that if carers were vulnerable in relation to their own QOL then this could negatively impact on their ability to continue to care. I also wanted to explore why some carers coped whereas others struggled; my aim was to consider if we could identify those more vulnerable carers and offer proactive interventions to help them. In my role as a HFN I offered a plethora of information to carers, both relating to HF but also to many other issues that carers needed help with. This was done in an ad-hoc manner and I wondered if a more structured approach could be adopted.

Thus I came to the research with clear ideas as to areas where I wanted to deepen my understanding, driven by my clinical experience. Whilst this helped shaped the research methodology namely pragmatism as presented in section 6.1, it also required consideration to reflexivity.

To incorporate reflexivity in research, consideration should be given to two specific characteristics: careful interpretation and reflection (Alvesson and Sköldberg, 2000). The researcher must look inwards to their individual characteristics and experiences, the research participants the research context and the influences of the wider society. By doing so, there is an exploration of how these attributes may influence the interpretations of the study findings. Additionally, reflection can facilitate an 'insider perspective' when the nurse researcher explores their own area of clinical practice (Pringle et al., 2011b). The ability to maintain objectivity when studying a field of practice that the researcher has prior experience and/or knowledge in is open to debate. The value of an insider perspective as proposed by Pringle et al. (2011b) can be viewed as a positive asset. This knowledge, however, may also be considered as a liability if assumptions are made by the researcher leading to information being overlooked (Kanuha, 2000).

Hennick et al (2011) considers that there are two aspects of reflexivity: personal and interpersonal. Personal reflexivity refers to researchers reflecting on how their own backgrounds and assumptions that may influence the research process and data created. Interpersonal reflexivity refers to the interview

settings and the dynamic between interviewer and interviewee and how this can influence the dialogue and data created.

Considering my personal reflexivity as a nurse with over thirty years' experience I was confident and comfortable with listening to peoples' experiences and acting to try to resolve problems they share. However, I was mindful of my position in the present study as a researcher which necessitated stepping back from my nursing and indeed my personal preconceptions. Thus whilst I had a contextual awareness and an established rapport with the HFN service and was accustomed to working with HF patients and carers in their own homes I needed to consider how this could influence the findings via the recruitment, interview process and data analysis.

It was important that the recruitment was conducted through the HFN service rather than directly approaching carers myself; in this manner the HFN acted as a gatekeeper to the participants and as such I did not influence the types of carers recruited into the study based on my previous knowledge and experience. Additionally for robustness in the process of analysis, verification of the analysis and interpretation from a sample of the transcripts was undertaken by the supervisory team.

As regards interpersonal reflexivity from the outset of the study, I was mindful of how my nursing background and clinical experience may lead me to make assumptions about what I have understood rather than a pure interpretation of the participants' narrative accounts. Additionally, I needed a strategy of how to conduct the interviews that reconciled the roles as an experienced HFN and as a researcher. I contemplated how I should introduce myself when conducting the interviews and how this could lead participants to respond in a particular manner. If they were aware that I was a nurse and had previous experience as HFN they may divulge information that was not related to the research topic, and this could have resulted in the need to give advice and dealing with the concerns from a nursing perspective. Conversely I also perceived that my nursing experience could enhance my rapport with participants and thus facilitate a rich dialogue during the interview. A strategy I planned for how I would respond if participants' raised clinical concerns was to make a mental note of the issue and when the interview had been concluded I would address

the concerns and refer onto the relevant health care professional accordingly. A reflexive diary was an instrument that I used to record my thoughts following each interview and during the process of analysis. Writing my thoughts down and revisiting the diary assisted in helping me to stand back from my understanding and views to see how interpretations had been developed throughout the research process (Clancy, 2013). By being mindful of my positionality, I propose that the interpretation and analysis of the findings was a rigorous and transparent process.

6.8 Chapter summary

This chapter has presented the rationale for the sequential MM study design, the theoretical concepts relating to MM methodology and the underpinning theory relating to IPA research. The sampling and data collection strategies have been discussed. Associated challenges encountered with recruitment were critiqued with reflections on addressing these challenges. Analysis for phase one and phase two were presented with supporting literature to demonstrate rigour and transparency. Ethical implications of the conducting the research was outlined and the chapter concludes with consideration to researcher reflexivity. The next chapter presents the quantitative findings from phase one of the study.

Chapter Seven: Phase one quantitative findings

This chapter describes the results of the quantitative data analysis.

The quantitative research questions were:

What are the levels of physical, psychological, social and spiritual wellbeing for carers of patients with advanced heart failure?

How do levels of wellbeing vary by types of carer?

The objectives of the survey was to measure carer positive and negative aspects of caring (physical, social, psychological and spiritual) QOL carer using the structured FAMQOL survey. The FAMQOL tool selected for the study is a brief, easy-to-administer instrument that has evidence of reliability and validity in HF family carers as described in section 4.7. Physical, psychological, social and spiritual wellbeing was measured with four-item subscales. Participants were asked to complete questions about the impact of being a carer, and responses would range from 'strongly agree' to 'strongly disagree'.

Basic demographic data was collected including age, sex, marital status, living arrangements and working status (Table 2). Additionally, information was collected relating to time spent caring, how often the participant was involved in caring, how long they had been caring for the person and if they had their own health issues.

The questionnaire data was entered into the study database by the researcher. The following statistical tests were conducted using the statistical package SPSS 22: descriptive (demographic and baseline) statistics and correlations.

7.1 Scoring and reliability of the FAMQOL instrument

FAMQOL questions that were negatively worded were reversed (FQ8-FQ16) before the reliability of the FAMQOL was assessed. The subscales of physical health, psychological health, social and spiritual wellbeing were checked separately. Cronbach's alpha for all variables (16 items) was 0.877 suggesting good internal consistency reliability for the scale with this study sample (values of above 0.8 are preferable).

For the overall FAMQOL score, all items were summed. There is a possible range of scores of between 16 and 80, with a score of 80 representing higher carer quality of life.

For each of the wellbeing subscales, there was a possible range of 4-20, with 20 representing higher carer physical, psychological, social and spiritual wellbeing.

7.2 Results

7.2.1 Response rate

A total of 160 FAMQOL questionnaires were distributed to the HFN services in Nottingham and Nottinghamshire. However of these 160 a total of 68 questionnaires were given to carers. 57 completed questionnaires were returned. Therefore the response rate for phase one of the study was 84%.

Non-response bias in the present study links to types of carers who may not have responded (older, frail, or those with their own health issues, or HFNs selecting which types of carers to recruit). Additionally 92 questionnaires were not distributed. There were differences in the distribution rates between the eight HFNs which could be related to differing workload demands leading lack of prioritisation for the research study. Furthermore as regards differing patient caseloads, the HFN may not have high numbers of patients who they deemed to have advanced HF resulting in low numbers of questionnaire distribution for these particular HFNs.

However it was evident that despite the difficulties of recruitment the response rate was high for a self-completed questionnaire (84%) and the carer demographics (table 2) are representative of gender, age and relationships.

The original target number of respondents at the outset of the study was 100 carers. This total number of respondents would have allowed for sufficient statistical power and any incomplete data. A larger sample additionally would have enabled multiple regression analysis to be conducted to examine joint effect of different factors on quality of life.

The total response rate of 57 completed questionnaires led to consideration of the valid statistical analyses that could be undertaken. Whilst the sample did not

enable regression analysis, descriptive and correlation statistical analyses were conducted and provided important findings. Mean values for the overall FAMQOL scores and the physical, psychological, social and spiritual wellbeing subscales were analysed using analysis of variance (ANOVA), and in the cases of two categories the data was analysed using a t-test. Due to the small sample size and the exploratory nature of the analysis, a p-value of less than 0.1 was considered a finding of interest rather than conventional p-value of 0.05. The findings that demonstrated statistical significance are presented in this chapter.

7.2.2 Respondents characteristics

The majority of the participants were female (49), with 8 male carers completing the questionnaire.

A high proportion of the study participants (56) were providing care on a daily basis. Many carers had been supporting the patient for several years; 20 (35%) of the study population had been caring for the person for more than 10 years, and 24 (42%) had been caring for the person for between 5 and 10 years. The mean age of the participants was 67.2 (SD 12.9) with the youngest carer being 37 years old and the oldest carer being 88 years old (Table 2).

Table 2 Description of all participants' demographics

| Characteristics | Participants |
|---|--------------|
| Gender | |
| Male | 8 (14%) |
| Female | 49 (86%) |
| Mean age (Standard Deviation SD) | 67 (12.99) |
| Ethnicity | |
| White | 57 (100%) |
| Marital status | |
| Married | 48 (84.2%) |
| Civil partnership | 3 (5.3%) |
| Widowed | 1 (1.8%) |
| Divorced | 2 (3.5%) |
| Single | 3 (5.3%) |
| Relationship to the patient | |
| Husband | 10 (17.5%) |
| Wife | 30 (52.6%) |
| Daughter | 10 (17.5%) |
| Daughter-in-law | 2 (3.5%) |
| Niece | 1 (1.8%) |
| Best friend | 2 (3.5%) |
| Granddaughter | 2 (3.5%) |
| Living arrangements | |
| Lives with the person they are caring for | 43 (75.4%) |
| Does not live with the person | 14 (24.6) |
| Working status | |
| Working | 18 (31.6%) |
| Retired | 31 (54.4%) |
| Never worked | 5 (8.8%) |
| Missing data | 3 |

The mean FAMQOL scores for all participants in phase one of the study are shown in table 3

Table 3 Mean Family Quality of life (FAMQOL) scores

| | |
|--|-------------|
| Mean FAMQOL score (SD) | 3.13 (0.71) |
| Mean physical wellbeing subscale score(SD) | 3.43 (0.83) |
| Mean social wellbeing subscale score (SD) | 3.35 (0.92) |
| Mean psychological wellbeing subscale score (SD) | 2.51 (1.02) |
| Mean spiritual wellbeing (SD) | 3.31 (0.90) |

1 is a low score, 5 a high score

The distribution of the FAMQOL scores in the 4 domains are shown in table 4.

Table 4 distribution of responses in FAMQOL domains

| Items | Strongly disagree | Disagree | Neither agree or disagree | Agree | Strongly agree | Missing data |
|--|-------------------|------------|---------------------------|------------|----------------|--------------|
| <i>As a caregiver;</i> | | | | | | |
| I seem to get sick more often | 13 (22.8%) | 20 (35.1%) | 14 (24.6%) | 5 (8.8%) | 1 (1.8%) | 4 |
| I am overwhelmed | 8 (14.0%) | 5 (8.8%) | 18 (31.6%) | 14 (24.6%) | 8 (14.0%) | 4 |
| I feel selfish considering my own needs | 8 (14.0%) | 3 (5.3%) | 9 (15.8%) | 20 (35.1%) | 11(19.3%) | 6 |
| <i>Because of caregiving;</i> | | | | | | |
| I am tired | 4 (7.0%) | 3 (5.3%) | 11 (19.3%) | 23 (40.4%) | 13 (22.8%) | 3 |
| My physical health has suffered | 10 (17.5%) | 10 (17.5%) | 18 (31.6%) | 13 (22.8%) | 4 (7.0%) | 2 |
| I am strained emotionally | 5 (8.8%) | 5 (8.8%) | 9 (15.8%) | 26 (45.6%) | 10 (17.5%) | 2 |
| I am socially isolated | 13 (22.8%) | 13 (22.8%) | 8 (14.0%) | 17 (29.8%) | 5 (8.8%) | 1 |

Table 4 distribution of responses in FAMQOL domains

| Items | Strongly disagree | Disagree | Neither agree or disagree | Agree | Strongly agree | Missing data |
|--|-------------------|------------|---------------------------|------------|----------------|--------------|
| Caregiving, | | | | | | |
| Adds to my purpose or mission in life | 4(7.0%) | 5 (8.8%) | 17 (29.8%) | 23(40.4%) | 5 (8.8%) | 3 |
| Adds to my feelings of inner strength | 2 (3.5%) | 9 (15.8%) | 15 (26.3%) | 25 (43.9%) | 3 (5.3%) | 3 |
| Gives me a sense of inner peace | 3 (5.3%) | 11 (19.3%) | 16 (28.1%) | 21 (36.8%) | 3 (5.3%) | 3 |
| Gives meaning to my life | 3 (5.3%) | 10 (17.5%) | 16 (28.1%) | 21 (36.8%) | 5 (8.8%) | 2 |

7.2.3 Physical wellbeing

The measurement of the impact of caring on physical wellbeing using the FAQMOL showed that 28 (49%) participants reported experiencing their own health issues at the time of caring.

Interestingly, however, since becoming a carer only 5 (8.8%) of the participants responded that they agreed that they got sick more often. Additionally, 33 (57.9%) responded that they agreed that they could readily get to their own health checks. Conversely, 23 (40.4%) of the participants agreed and 13 (22.8%) strongly agreed that they were tired, with 13 (22.8%) of participants agreeing and 4 (7%) strongly agreeing that their physical health had suffered since becoming a carer.

There was variability in the physical wellbeing in the types of carer in the study population. The working status of the carer had an impact on the physical wellbeing of carers. Carers who had worked expressed higher physical wellbeing scores than those who had never worked (mean score 2.40), where 1 is a low score and 5 a high score.

A one way ANOVA was conducted to compare the impact of working/not working on physical wellbeing measured by the FAMQOL questionnaire. Subjects were divided into three groups: working, retired, never worked. The means are presented in table 5. There was a statistical significant effect between the groups (2, 50) =5.78, p=0.006

Table 5 Working status and mean physical wellbeing score

| Working status | N | Mean | Standard deviation |
|-----------------------|----------|-------------|---------------------------|
| Working | 18 | 3.29 | 0.57 |
| Retired | 31 | 3.61 | 0.80 |
| Never worked | 5 | 2.40 | 1.00 |

Post hoc comparisons using Bonferroni corrections indicated the mean difference for group 1 (working M= 3.29) was significantly different from group 3 (never worked, M= 2.40), $p= 0.005$. No other differences were significant.

7.3.4 Psychological wellbeing

Feelings of being overwhelmed are commonly reported in the research literature relating to the carer population as presented in chapter three. Levels of poor psychological wellbeing were evident in the present study; 14 (24.6%) of participants agreed they were overwhelmed, and 8 (14%) strongly agreed they were overwhelmed.

A high proportion of the participants reported feeling emotionally strained; 26 (45.6%) agreed and 10(17.5%) strongly agreed that they were emotionally strained. Many carers reported feeling selfish when considering their own needs; 20 (35.1%) agreed and 11 (19.3%) strongly agreed with this statement.

7.3.5 Social wellbeing

Additionally, it was evident in the present study that social isolation was a key issue, with 17 (29.8%) of carers agreeing and 5 (8.8%) strongly agreeing that they felt socially isolated. There was variability in levels of social wellbeing; carers with no health issues expressed higher social wellbeing scores mean score 3.61) than carers with existing health issues (mean score 3.08), where 1 is a low score, 5 is a high score.

Table 6 health status and mean social wellbeing score

| Health issues | N | Mean social wellbeing score | Standard deviation |
|----------------------|----------|------------------------------------|---------------------------|
| Yes | 28 | 3.08 | 0.92 |
| No | 27 | 3.61 | 0.87 |

An independent samples t-test was conducted to compare the social wellbeing scores for carers with health issues and carers with no health issues. There was a statistically significant difference in scores between carers with health issues (M=3.08, SD= 0.92) and carers with no health issues (M=3.61 SD= 0.87), $p=0.03$.

The working status of carers showed differences in the impact of caring on social wellbeing. A one way ANOVA was conducted to explore the impact of working/not working on social wellbeing as measured by the FAMQOL questionnaire. Subjects were divided into three groups: working, retired, never worked. Carers who were working reported higher levels of social wellbeing (mean 3.37) as compared to carers who had never worked (mean 2.38). There was statistically significant difference in the social wellbeing FAMQOL scores for the 3 groups, $F(2, 51) = 3.02, p = 0.057$.

Table 7 Working status and mean social wellbeing score

| Working status | N | Mean | Standard deviation |
|-----------------------|----------|-------------|---------------------------|
| Working | 18 | 3.37 | 0.73 |
| Retired | 31 | 3.41 | 0.96 |
| Never worked | 5 | 2.38 | 0.83 |

Post hoc comparisons using Bonferroni corrections indicated the mean score in social wellbeing for group 1 (working $M = 3.37$) was significantly different from group 3 (never worked, $M = 2.38$), $p = 0.092$. No other differences were significant.

Variability in social wellbeing was related to relationship to the patient being cared for. Spousal carers expressed lower social wellbeing (mean score 3.20) than non-spousal carers (mean score 3.70), where 1 is a low score and 5 is a high score. An independent samples t-test was conducted to compare the social wellbeing FAMQOL scores for spouse and non-spouse. There was a significant difference in scores for spouse ($M = 3.20$ $SD = 0.93$) and non-spouse ($M = 3.70$ $SD = 0.83$). $p = 0.06$

Table 8 Spouse/non-spouse and social wellbeing score

| Spouse | N | Mean | Standard deviation |
|---------------|----------|-------------|---------------------------|
| Yes | 40 | 3.20 | 0.93 |
| No | 17 | 3.70 | 0.83 |

7.3.6 Spiritual wellbeing: positive outcomes of caring

Objectives 1 and 3 of the research aimed to explore positive influences of caring; findings showed that many of the study participants reported positive aspects of being a carer as shown in Table 9.

Table 9 Positive aspects of caring

| Positive aspects of caring | Participant responses |
|------------------------------------|-----------------------|
| Adds to purpose or mission in life | 23 40.0% |
| Adds to my feelings of inner peace | 21 36.8% |
| Gives meaning to my life | 21 36.8% |

Male carers however expressed lower spiritual wellbeing (mean score 2.78) than female carers (mean score 3.40), where 1 is a low score and 5 is a high score.

An independent samples t-test was conducted to compare the spiritual wellbeing FAMQOL scores for male and female carers. There was a significant difference in scores for male (M=2.78 SD=1.04) and female (M=3.40 SD 0.85), $p=0.07$.

Table 10 Gender and mean spiritual wellbeing score

| Gender | N | Mean | Standard deviation |
|--------|----|------|--------------------|
| Male | 8 | 2.78 | 1.04 |
| Female | 47 | 3.40 | 0.85 |

7.4 Correlations.

Correlational analysis was used to examine the relationship between the variables: living arrangements, time spent caring, how long the carer has known the person, how long they have been supporting the person and scores for the four domains.

Whilst $p < 0.1$ is not normally considered significant, as this is an exploratory study with a small sample, results of $p < .10$ are of potential interest and were further explored in the qualitative phase of the study.

Table 11 Correlations between variables and four domains

| Scale | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-------------------------------|---------|---------|---------|--------|--------|--------|--------|-------|---|
| 1.Overall FAMQOL | — | | | | | | | | |
| 2. Physical wellbeing | 0.727** | — | | | | | | | |
| 3. Psychological wellbeing | 0.701** | 0.626** | — | | | | | | |
| 4.Social wellbeing | 0.643** | 0.564** | 0.434** | — | | | | | |
| 5. Spiritual wellbeing | 0.348** | 0.170 | 0.165* | 0.103 | — | | | | |
| 6.Living arrangements | 0.051 | 0.034 | -0.028 | 0.098 | 0.055 | — | | | |
| 7.Time spent caring | 0.030 | 0.011 | 0.061 | 0.042 | -0.061 | 0.234 | — | | |
| 8.How long known the patient | 0.071 | 0.013 | 0.067 | 0.055 | 0.086 | -0.134 | -0.031 | — | |
| 9.How long supporting patient | 0.005 | -0.009 | 0.034 | -0.032 | -0.083 | 0.057 | 0.034 | 0.040 | — |

**p<.01 (two tailed) *p<.10

The FAMQOL scores are highly related to each other. There are correlations between living arrangements, time spent caring and how long the carer has known the patient. This indicates that carers who have known the patient for longer are more likely to have been caring for longer.

There are no correlations above 0.10 between any of the FAMQOL scores and any of the covariates, demonstrating that there is no indication of any associations between these covariates and carer QOL.

7.5 Discussion of the quantitative findings

The quantitative survey aimed to measure levels of physical, psychological, social and spiritual wellbeing for carers of patients with advanced HF and examine how these levels vary by types of carer. Due to the sample size, there were limited statistical tests appropriate to use for analysis of the data. The challenges relating to recruitment to phase one of the study are presented in section 6.7.

Overall the study population were older carers, often with their own health issues, and this may be a contributing factor to the majority of the participants reporting that they had been physically tired since taking on the caring role. The psychological wellbeing subscale, whilst not demonstrating findings of statistical significance, did indicate that carers in the study reported feeling overwhelmed and emotionally strained. Additionally, the majority of carers in the study reported feeling selfish when considering their own needs.

Predominantly, carers in the study were the spouse of the person they were caring for; spousal carers had statistically significant lower social wellbeing scores than non-spousal carers.

Living arrangements and how long the person had been caring demonstrated statistically significant findings on overall QOL, physical wellbeing and psychological wellbeing. This is an important consideration since 75% of the carers in the study were living with the person they were caring for all of the time and 42% of the study population had been caring for the person for between 5 and 10 years.

Additionally, there was a correlation between how long the carer had known the person, living arrangements and how long they had been caring; this indicates that carers who have known the patient for longer are more likely to have been caring for longer. As 95% of the study population had known the person they were caring for for more than 25 years, the indication is that these carers will have been offering support for an extensive period of time, with 98% of carers in the sample providing support on a daily basis.

Difference by working status was of statistical significance, with carers who had previously worked reporting better overall quality of life and better physical health than those carers who had previously not worked. Additionally, carers who had worked reported better social wellbeing than those carers who had not worked.

In the study population, it was clear that the FAMQOL instrument captured positive aspects of caring; 40% of carers reported that the role added purpose to their lives and 36.8% that it gave meaning to their lives.

7.6 Chapter summary

This chapter has presented the quantitative results from phase one of the present study. Despite the limitations of the statistical analysis due to the small sample size in phase one of the study, there are important findings of interest which, in keeping with the sequential study design, were explored during the interviews in the qualitative phase of the study. Additionally, the quantitative findings were influential in guiding the topics in the semi-structured interview schedule for the qualitative phase of the study. The next chapter provides an overview of the participants' demographics and biographies for phase two of the study. This is followed by the in-depth qualitative findings presented in chapters nine, ten and eleven.

Chapter Eight: Qualitative phase two: overview of the study participants

This chapter presents details of the response rate for phase two of the study, a table of participants' demographics and a brief biography of each of the carers who participated in the interviews. The relationship to the person being cared for and social setting of the patient-carer dyad is presented to add context to the interview dialogue.

A total of twenty one respondents agreed to participate in an interview. Four of these respondents withdrew from the study prior to the interview. Reasons for withdrawal included the patient being admitted to an acute care setting, the patient's condition deteriorating or the patient had died. A further three respondents were unable to be contacted by telephone despite several attempts. Therefore the final number of participants in phase two of the study was fourteen. The participants' demographics are detailed in Table 12.

Table 12 Demographic data of interview participants in phase two of the study¹

| Participant's name | Gender | Age in years | Relationship to the person cared for | How long they had been caring for the person |
|---------------------------|---------------|---------------------|---|---|
| Sue | Female | 37 | Wife | 5 to 10 years |
| Dave | Male | 75 | Husband | Less than a year |
| John | Male | 88 | Husband | 5 to 10 years |
| Clare | Female | 72 | Neighbour | More than 10 years |
| Kate | Female | 72 | Wife | Less than a year |
| Stella | Female | 71 | Wife | 2 years |
| Maureen | Female | 77 | Wife | Less than a year |
| Marie | Female | 69 | Wife | More than 10 years |
| Sarah | Female | 57 | Daughter | More than 10 years |
| Brian | Male | 67 | Husband | Less than a year |
| Simon | Male | 43 | Husband | 18 months |
| Patricia | Female | 81 | Wife | 5 to 10 years |
| Belinda | Female | 47 | Daughter | 5 to 10 years |
| Helen | Female | 40 | Granddaughter | 5 to 10 years |

¹ Pseudonyms were used

8.1 Participants' biographies

Sue:

Sue, aged 37, was a full-time carer for her 40-year-old husband Mark. Mark was diagnosed with NYHA 3 HF following a sudden onset viral infection. Mark had experienced several decompensations of his HF over the previous year resulting in unplanned admissions to the local hospital. Mark also had episodes of acute anxiety and regular panic attacks.

The couple were living in rented social housing on a large estate in the city with their two boys aged 10 and 14. At the time of the interview, Sue had been caring for Mark for over a year. Due to her caring responsibilities, both for the children and her husband, Sue had recently resigned from her part-time job as a receptionist at the local GP practice. As a result, the couple had experienced recent financial difficulties. Whilst Sue and Mark had family living nearby, they had limited contact with their family, and therefore Sue was supporting Mark and her children independently. They were receiving weekly visits from the HFN at the time the interview was conducted.

Dave:

Dave, aged 75, was the full-time carer for his wife, Elaine, who had NYHA 3 HF. Prior to his wife becoming unwell, they had regularly spent several months abroad each year; it was during their last visit abroad that Elaine had become unwell. Elaine spent a significant period in hospital before she was well enough to travel back to the UK. Dave had retired early from the navy, and consequently he adopted a very practical but regimented approach to the caring role. Dave lived with Elaine in their own home on a small housing estate in the county and had lived there for the last 40 years. He had a close-knit family living nearby, and his niece, who worked for a care agency, lived next door. The niece called in every day and had been instrumental in organising the assistance Dave and his wife needed. As Elaine, the patient, was a retired nurse she was well informed about her own condition. The HFN was visiting monthly at the time of the interview.

John:

John, aged 88, was the full-time carer for his wife, Dot, who had NYHA 4 HF. They lived in their own bungalow in a small village in the county and had lived in the village for the whole of their married life. John was a retired long-distance lorry driver, and the couple had two adult children who both lived abroad. John and Dot were a very close couple, and with no family living close by, they were a couple who were accustomed to being together and relying on one another. John did not have any of his own health issues, and whilst Dot was symptomatic, she had not had recent hospital admissions, and the couple were not receiving the support of social services. The HFN was visiting weekly at the time of the interview.

Clare:

Clare, aged 72, was the main carer for her neighbour, Doris, who was 90 years old. Clare had been supporting her neighbour for a number of years but was offering increasing support due to Doris' failing condition; Doris had NYHA 3 HF. Doris lived in social housing that had not been modernised, and therefore the house she was living in did not have central heating; additionally, Doris did not have a washing machine. Clare and her husband offered Doris regular meals in their own home and helped her with her washing when she would allow this. Whilst Doris had a son, he lived a couple of hours' drive away, and Clare was therefore the person who had taken on the responsibility of liaising with health and social care services. At the time of the interview, the HFN was visiting Doris once a fortnight, and Clare would contact the HFN in between visits as necessary.

Kate:

Kate, aged 72, was a full-time carer for her husband, Ken, who had NYHA 3 HF. Kate and Ken had taken early retirement and moved abroad but had returned to the UK in the last year when Ken became unwell. They had bought their own home in a small town in the county. The couple had two adult sons who offered good family support and a close network of friends. Despite his symptoms, Kate's husband tried to be as independent as possible. Kate previously had received treatment for breast cancer but was now fully recovered

and did not have any of her own health issues. At the time of the interview, the HFN was visiting monthly to monitor Ken, and the couple were not receiving any additional services.

Stella:

Stella, aged 71, was a full-time carer for her husband, Don, who had NYHA 4 HF. Don was symptomatic and experienced regular decompensations. Stella and Don lived in private rented accommodation in a deprived area in the county. The accommodation they inhabited did not meet the requirements for Don; he was unable to manage to get downstairs due to his breathlessness, and he was unable to leave the bedroom. They did have a son and daughter living locally, but they were unable to offer support as they had their own dependent children, one of whom Stella looked after in addition to her husband. Stella had previously worked and had enjoyed her job, which she missed since retiring due to ill health, namely fibromyalgia. At the time of the interview, Stella was pleased to have been informed that they were able to move to a warden-aided bungalow which was nearer to her daughter. The HFN visited one to two times a week due to Don's unstable condition, and Stella had recently been referred to the community Mental Health team.

Maureen:

Maureen, aged 77, was the full-time carer for her husband, Bill. At the time of the interview, Maureen was recovering herself from a serious illness but had recently taken on the responsibility of supporting her husband. Consequently the couple were both physically frail but were managing with assistance from their supportive family. The couple lived in an ex-mining town in the county and had lived in their home for over 50 years. They had two sons who lived on the same housing estate who visited weekly and assistance from their longstanding next-door neighbours. Despite having been acutely unwell, since coming home Bill's condition had been stable, NYHA 2/3 HF, and the HFN was visiting monthly unless Maureen contacted the nurse for advice or requested a visit.

Marie:

Marie, aged 69, was the full-time carer for her husband, Jim, and her elderly neighbour, Edna. Marie had previously worked as a nurse in the army; her husband had been a prison officer but had been unwell for many years with complex long-term conditions including unstable diabetes that led to him requiring a below-knee amputation. In relation to his HF, his condition was NYHA 3 HF. The couple had moved to a bungalow due to Jim's mobility issues; in order to find suitable accommodation, they had moved away from the village they had lived in for most of their married life. The move had been unsettling for Marie as she had many close networks in the village where they had lived previously. The couple had two adult children, but they did not live locally and therefore Marie was supporting her husband on her own. They were receiving the services of the District Nursing team to manage a diabetic foot ulcer, and the HFN visited fortnightly to manage Jim's HF.

Sarah:

Sarah, aged 57, was the full-time carer for her mother, who had NYHA 3 HF. Sarah was a nurse but had taken early retirement due to chronic back pain. Since her mother had become unwell, Sarah had to manage the sale of her mother's house in order for her to buy a house which was closer to her. Sarah visited her mother every day, at least once a day. Sarah did have a brother that also visited, but Sarah took on the main caring responsibilities. Sarah's mother was receiving the support of the HFN and had recently begun to attend the local hospice once a week. Sarah was married with adult children.

Brian:

Brian, aged 67, had been a full-time carer for a short time. His wife was diagnosed with HF following an admission to hospital, and during this admission the couple were told that her condition was NYHA 4 HF. Brian's wife was discharged home but had died in the weeks prior to the interview. Brian was retired as an engineer; he had lived with his wife in their own bungalow in a small village where they had lived for the last 30 years. They had an adult

daughter but she did not live close by and had her own health issues. During the time of his wife's illness, Brian had limited contact with his friends, and consequently Brian supported his wife up to the end of her life without the help of family. He did have the assistance of the District Nursing team, and the HFN visited twice weekly up until his wife's sudden death.

Simon:

Simon, aged 43, was the full-time carer for his wife, Karen, who developed NYHA 3 HF during her second pregnancy. Simon was working part time and was the main carer for both his wife and his two young children. At the time of the interview, the family had recently moved to a bungalow to accommodate Karen's deteriorating condition. As a result, Simon had to undertake extensive work to prepare the house for his family. During this time, he had continued to work and deal with the children. Whilst Simon and Karen had family living locally, they did not have any support from them, and Simon managed the caring responsibilities on his own. Simon found the understanding of his employer essential to enable him to balance work, child care responsibilities and supporting his wife. Due to the complexities the family were dealing with, the HFN was visiting weekly.

Patricia:

Patricia, aged 81, was the full-time carer for her husband, who had NYHA 2/3 HF. The couple lived in their own home with their adult son. Patricia was a very independent lady who had no health issues of her own; she was physically active and regularly volunteered at the local hospice. Her husband had several health conditions in addition to his HF, but the couple were very positive about their lives. At the time of the interview, they were looking forward to going on holiday. The HFN was visiting monthly and they were not receiving any additional support.

Belinda:

Belinda, aged 47, was the full-time carer for her mother, who had HF NYHA 3 HF. Belinda was working full time, and in addition to supporting her mother was also the named carer for her adult sister, who had longstanding mental health issues and was living in supported housing. Belinda's mother lived close by in warden-aided accommodation; she was receiving daily support from social service carers, alongside weekly visits from the HFN. Belinda had three brothers who also lived locally, but they offered her limited assistance and she described herself as both her mother's and sister's main carer. Belinda lived on her own and did not have a partner or family. She enjoyed watching football and up until recent months had been a season ticket holder. Recently, however, she had not been able to go with friends to watch football due to her caring commitments.

Helen:

Helen, aged 40, supported her grandmother, who had NYHA 4 HF, up until she died at home. Her grandmother had lived in warden-aided accommodation and received the services of social service carers. Towards the end of her life, Helen's grandmother received daily visits from the district nursing services and daily care from social services carers. Additionally, the HFN visited up to twice weekly. Helen did not work as she was the full-time carer for her nine-year-old autistic daughter and had one other son. Helen had cared for her mother, who had died from breast cancer in the previous year.

8.2 Qualitative themes

A number of themes emerged from the interviews with study participants: the emotional impact of caring, living as a carer and carers' experience of support. The following three chapters will describe each theme in detail, with supporting verbatim quotes from the interviews.

Chapter Nine: Emotional impact of caring

The carers interviewed were asked if there was anything that they found particularly difficult about caring or aspects of caring that they found rewarding. From the analysis it was clear that participants experienced challenges, many of which had caused emotional distress. However, alongside these challenges carers also described a sense of achievement that helped them sustain their caring role. Several subthemes emerged from the analysis relating to the emotional impact of caring such as control, unpredictability social isolation, loss of independence, coping with the challenges of caring, facing the future and rewarding aspects of caring, and these subthemes are presented in detail below.

9.1 Control: “you can’t ever plan tomorrow”

When embarking on the journey of caring, some participants described feeling out of control of what was happening to both them and the person they were caring for. Words that were used in the interviews included *juggling, chasing, frustrating, life changing, trial and error, run with it*.

Feeling out of control was a great source of anxiety to some of the participants. This was commonly associated with the person being sent home from hospital and the carer taking on the responsibility for the care.

Brian’s wife was discharged home from hospital with limited notice. He recounted the fear of not knowing what to expect or what he needed to do. The terror he described about coming home from hospital was associated with a lack of communication from the hospital about the support he needed. He used the phrase *‘you’ve got to run with it’* implying he had to take control and see how the situation unfolded.

“We were terrified to start with, because it all looked like she was going to be in hospital for a while longer, and then all of a sudden I got the phone call in the morning saying she can come home this afternoon. I thought bloody hell, you know, now what do we do? Because there was nothing in place, and I suddenly thought, you know, all of a sudden you’ve got to run with it.” Brian

In the context of trying to sustain control, some carers used language that described navigating their way through a complex health care system to get to grips with the situation. Belinda was working full time when she took on the care for her mother; she was also responsible for her adult sister, who had mental health problems and lived in residential care. She described a daily struggle to concentrate at work due to the distractions of her caring responsibility; she was unable to control or plan her day.

“...it was like okay then, you know, and you’re there at work and you’re trying, you think you’ve just come away from your desk and you’re trying to think while she’s telling you. Yeah sometimes when you’re talking to people, when you’re talking to people and, you know, you can get frustrated ... sometimes you’re not sure if you’re harassing them.” Belinda

Helen was a younger carer who was supporting her elderly grandmother. She had extensive carer experience as she cared for her mother at home until she died from cancer; she also had a severely autistic daughter who had support from a range of social services. Yet despite this knowledge and experience, she also felt frustrated and out of control of managing the needs of her grandmother.

“Just trying to sort everything out, I think. Just trying to find out what was going off and getting in, just sorting things out. The amount of phone calls and hours on the phone trying to sort this direct payment thing out and social care adding more hours on and it was just a nightmare.” Helen

Stella, a 71-year-old lady, lived with her husband, who had NYHA 4 HF and was physically frail. She described frustrations at being left alone with the responsibility of organising everything with similar experiences to that of Helen in that she could not find the help she needed.

“It’s took us seven, nearly eight, weeks to get any care in place at home. It was a matter of asking questions, ringing, chasing, everything ... I was spending hours on the phone finding, ringing numbers and no sorry no, and they give you another number, no, no, no, oh its really, really frustrating yes.” Stella

In contrast to Stella and Belinda, Sue a younger spousal carer, felt that she needed to be in charge of everything as being in control helped her cope with the situation. When Sue was interviewed, she was planning a holiday with her two young children. Her husband had saved to pay for her to take the children away on her own as he was too ill to travel. Yet despite the fact that her husband was encouraging her to go on the holiday, Sue was anxious about not being in control of her husband’s care. She viewed herself as the expert in his care and described how this expertise had developed over the months she has been caring. She repeatedly used the word ‘control’ in this extract.

“... it’s like I’m not going to be in control when I’m away. I’m in control when I’m here. Yeah, because in the beginning I didn’t know anything. But yeah, in the beginning because obviously I wasn’t in control because I didn’t know anything, I didn’t know anything about his medication, I didn’t know about what we need to do in a crisis, I didn’t know anything. It was like trial and error, learn as you go along, that was it. Obviously because I’m in control of things I’ll be able to control it.” Sue

For many of the carers interviewed, it was the unpredictability of HF that caused increased feelings of being out of control. Simon was caring for his wife since she developed HF during her second pregnancy. He had continued to work part time and, in addition to caring for his wife, Simon was the main carer for his two

children. When his wife was first diagnosed, they were told that her symptoms would improve along with a better prognosis following the implantation of a cardiac device. In this quote, he talked about his feelings when receiving the prognosis.

“Well, my wife got diagnosed when she was 32 weeks pregnant. So that came as quite a shock, we sort of realised how serious it was as it was going along then, and then we’ve realised now that it’s lifelong ... It was life changing for us. Everything we ever did and do is not the same anymore.”
Simon

Simon recognised that their lives would not be the same by using the term lifelong, but in the early months following the diagnosis, they were hopeful that things would improve following the insertion of the cardiac device. During this time Simon was dealing with the complexity of a new baby and his wife’s condition in parallel, dealing with major life transitions in a very short space of time. Unfortunately, following the insertion of the device Simon’s wife’s symptoms did not improve. The disappointment associated with this was palpable.

“But we pinned all our hopes on it thinking this is it, you know, things are going to change now, and then it didn’t, and we’re still sort of in the same boat as we was right at the beginning, and that’s sort of 16 months in now.” Simon

Simon perceived that nothing had improved and their situation was unfolding in a way they did not want or expect.

Brian also felt this uncertainty of what to expect when describing how he felt when his wife first came home.

“Yeah, and scary. Because I was looking at what is the likely outcome of all this.” Brian

Brian used the word *'likely'* about his circumstances; he could not predict how the situation he is facing would evolve.

Evidence from the literature presented in chapter two indicates that HF has an unpredictable trajectory, and the analysis demonstrates that carers struggled to cope with this; they did not know what to expect and lived with a person whose condition could change rapidly. When Belinda referred to her situation, she used the following imagery to illustrate it:

"but it's such a minefield ..." Belinda

The metaphor of a minefield used by Belinda emphasised the unpredictability of the condition; she was facing unseen challenges which may 'explode' at any time.

HF differs from other conditions in respect of this unpredictability; Helen highlighted this when she compared caring for her mother, who had cancer, and her grandmother.

"I think it was different because my mum had been diagnosed as terminal; you know, she'd got care in place at home, they'd set up a plan, everything was sorted. The end-of-life drugs were there at the house, they'd already set that up, she'd got a bed at home, occupational therapist number was there if we needed anything else. Do you know what I mean? It all, she got a definite problem so therefore it all went a bit smoother. Whereas my grandma, she'd got heart failure, she was old, nobody really knew how long she was going to go. But I was telling people she'd not got long left, but they were disagreeing." Helen

Helen articulated that it was a much clearer process when caring for someone dying with cancer than someone dying from HF; the issues were associated with the unpredictability of the symptoms and challenges of prognostication. Helen felt she was the expert in her grandmother's care but was ignored.

Towards the end of her grandmother's life, Helen was coping with expecting bad news every day.

"I was expecting a phone call every morning to be honest with the carers going for the last month of my grandma's life, because I was so sure at some point the carers were going to be ringing me saying we found her dead." Helen

This manner of living 'day to day' was replicated in the interviews with Stella, Marie and Sue. Stella had been caring for her husband for several years, during which his condition had deteriorated slowly. She described struggling to face each day and was increasingly finding it difficult to deal with her husband's needs both physically and emotionally.

"Some days, it's fine. He's bubbly, he's bright, he's talking, and then another day he's so lethargic, so tired, so exhausted, you never know what the day's going to face until he gets himself roused and up. This is what you can't plan, everything changes." Stella

The effect of this on her emotionally was emphasised when she outlined why she found it difficult to sleep.

"Over the last month, he's had a real problem of sleeping ... he's not slept; he's not had a good sleep. So when I'm hearing noises, bear in mind he's got a lung problems, I'm waking up to go and see if he's all right, because I'm frightened since he's had his heart condition." Stella

Likewise, Marie found it frustrating that there was a lack of understanding of this unpredictability.

"But you see the problem is a lot of people don't realise when you're a carer no two days are the same. At the moment Jim is

what I call on a plateau. Now next week he could either dip or he could go a bit higher up.” Marie

For Sarah, a nurse who had retired from work because of ill health, the unpredictable nature of her mother’s condition had an impact on her own health. She described omitting her prescribed painkillers at night in case she needed to drive to her mother’s if her condition deteriorated.

“...yes, and that’s the thing you see. There’s some things sometimes at night; I’ve got nortriptyline and stuff and I don’t take it because I think I can’t drive my car once I’ve had certain medications. But I don’t take it in case I need to go to my mum’s in the night.” Sarah

By following an ethos of ‘living day to day’, Stella, Marie and Sarah described an existence in which they make no plans. Thus the unpredictability had implications for maintaining social contacts. For Sue, a younger carer, this lack of ability to plan applied not only at a social level but also to protect herself from anticipating what she might be facing over the next months or years.

“When you’re living day to day, obviously we live day to day, you can’t ever plan tomorrow ever, not when there’s this HF, you can’t plan for tomorrow. So if people say to me do you want to come out next month, I can’t plan that far ahead. And my friends, my true friends, now know I cannot plan that far ahead so they won’t ask. But if I sit and think about what’s going to happen in the future, then it sets me right back to the beginning, because I can’t cope with ... I’d rather live day to day and cope with the here and now, because if you start thinking ahead it just messes up all the rest of your plans in your head.” Sue

The experiences of Stella, Marie, Sarah and Sue vividly illuminate how the clinical complexities of HF create a caring culture in which carers survive by restricting their resources to cope one day at a time to sustain their emotional

resilience. Trying to predict the days, weeks or months ahead appeared to be too overwhelming; therefore they took each day in turn.

9.2 Social isolation: “I’ve got nobody at all, nobody bothers”

Evolving from living with the unpredictability of HF, the carers interviewed faced circumstances in which they became increasingly socially isolated. This was as a result of reduced access to social activities that the carers could not commit to, lack of respite from their caring responsibilities or limited social networks.

Findings emerged from the data relating to the ability to engage in social activities, and carers commonly indicated that they did not consider this as a priority.

*“We had quite a routine with some friends. We used to meet up regularly sort of monthly, but that’s all gone by the by now.”
Belinda*

“I have lost, I wouldn’t say lost a lot of friends through it, but when I’m letting them down all the time because I’ve planned to go out and then Mark turns sick.” Sue

“No. I’ve lost the things I used to do. A Tuesday club meeting up with my friends, an hour shopping, you know, seeing my daughter. I’ve not actually been out.” Stella

One of the issues associated with accessing social activities was lack of respite for the carer. Brian described his isolation when he was caring for his wife; he was facing the end of her life but with no one that he felt he could share his concerns with. Brian’s daughter was not living locally, and he was reluctant to ask for her help as she had her own long-term condition which required her own care. Here, however, he acknowledged that he would have benefited from her support at times.

“Could have done with her to talk to now and again, but with it being 24/7 looking after her then somebody else to look after her as well. My friends popped in now and again, but it was largely the two of us.” Brian

Additionally, Brian felt that he could have benefited from short-term relief from the ‘24/7’ of caring.

*“... but in hindsight, yes, it would have been nice if somebody had come in just for a few hours and said you know, just clear off and have a chill for a bit, just to give us a bit of a break.”
Brian*

In contrast, Marie appeared frustrated with the respite services she had been offered. She was given the opportunity to attend a workshop run by a voluntary organisation for carers providing advice on how to create time for herself and how to cope with stress. She described the challenges attending the course would have posed for her.

“... it’s all very well people saying have ‘me’ time, but you’ve got to work round. You see, everybody thinks that when you’re a carer you’ve got, your daughter lives four doors down, your son lives the next village. It doesn’t work like that in this day and age. Yeah, but you see the problem is it’s leaving him all day. I don’t mind leaving him for half a day, but going out at eight in the morning and not coming back until half-past seven at night, I just find that’s just too long, do you know what I mean?” Marie

Marie was knowledgeable about how to access local support groups but was unable to commit to events. The absence of family living nearby made it additionally difficult to access support. Importantly the support services in this context were not appropriate for her, demonstrating a lack of insight from service providers. A key aspect for Marie was the issue of leaving her husband for the whole day.

“He’s always on my mind. Yes, 24 hours a day. Well, you’re anxious all the time. You can’t think straight because you’ve got somebody on your mind” Marie

This constant caring and use of the term ‘24/7’ was evident in both Marie and Brian’s experiences; a sense of always being in the role even when not physically present, the relentlessness leaving them unable to relax.

From the analysis, it was evident that for some carers the isolation was exacerbated by changes made to their lives to adjust to the needs of the patient. Marie had moved home to find accommodation that would be accessible for the physical needs of her husband. This major transition created additional difficulties for her in relation to her isolation.

Marie talked at length about the difficulties she experienced when she and her husband moved home from the house they had lived in for over 36 years. They had to move away from the area they had been living to find a bungalow that was appropriate for their needs.

“I didn’t want to live here; I wanted to live in [name of the village] because all my mates are there. But we couldn’t find anything suitable. And I by this time was exhausted. I couldn’t care less what the house looked like as long as we could get him in it. But all with everything else I still had to pack up everything, 36 years of living in a house, get rid of a lot of stuff, find a new house, well, new bungalow. There was no support. I mean I’m stressed out even now after 18 months. This is all on my own; I’ve got no children here.” Marie

She had to ‘*pack up her life*’ as it was and restart again with no networks or family support nearby. She seemed distressed that she had to move; she had sacrificed her friends and hobbies. She made it clear that her home now was not a place for her but had been chosen based on its suitability for caring for her husband. Marie was ambivalent about her home, which resonated when she said she ‘*couldn’t care less*’ about the house.

Before they moved, Marie was active in the local community and coordinated a ramblers group. She highlighted here the stark social isolation she was experiencing; this was a complete contrast to her life before caring.

“... so I’m sitting here most nights on my own. Well, it’s very lonely here. I get bored out my mind. I hand crochet blankets, what you’ve got behind you. But I used to, before he got taken ill I was socialising all the time. I used to do 30 miles a week walking. I had a fantastic crowd, didn’t I, still have. But the problem is I just couldn’t get up the hill. I was just exhausted. But you see I prefer to be out with all my mates. But the trouble is now I’m too tired and too exhausted to do it.” Marie

When Marie reflected on how she felt since they moved home, she concluded that it had made the situation easier to manage physically, but emotionally it had taken its toll. She described a distressing event that arose when they first moved.

“... but he fell in the front garden; I had to lift him out of there as well. See, none of the neighbours gave us a hand. Well, I felt abandoned. But it’s just I feel like I’m abandoned out here, do you know what I mean? I don’t really know many people here.” Marie

It is sad reflection that she felt no one offered to help her; perhaps the neighbours did not offer to help her because they did not know her. As she is new to the area, she did not know anyone to ask to come and help her. There was a sense that she felt she had been abandoned by friends, services and perhaps by her children.

Simon echoed the experiences of Marie following his family’s move to a new home.

“She’s quite isolated and it’s down to me and it’s, I do everything I can to sort of encourage her to do things, but yeah it’s hard work sometimes ... It’s pretty sort of lonely for me. I go up the school on my own, you know, drop him off in the morning on my break time, so it’s one big mad rush for me, and

then pick him up from school at the end, and I sometimes think do the other parents think that I've split up with her, and that side is for me, it's quite lonely for me sometimes." Simon

He was the only social contact for his wife due to her physical limitations; they had no established networks due to their recent move. This appeared to lead to instability in the supportive social infrastructure they could look to and deepened their isolation.

However, in contrast, for Stella, she was anticipating moving home as a means of improving her social situation as she described here.

"And I think getting away from this terrible area we live. It's dreadful. It's absolutely dreadful. I feel isolated here. We're shut in, we've been burgled; it's been horrendous living here for the last eight years." Stella

Stella and her frail elderly husband were living in rented accommodation in a deprived mining village with high rates of unemployment and crime. During her interview, Stella disclosed that they were living next door to known drug dealers who were subject to regular raids by the police. She was fearful of asking for help from any neighbours because of this.

"...not at all, not at all, and I haven't got anybody here, around here that I could knock on the door and say ooh dear can you come round, I've got nobody at all, nobody bothers. They keep their doors shut and they don't bother at all. Nobody, nobody's asked how he is or anything, and I just think that's the – that bothers me as well that I couldn't knock." Stella

At the time of the interview, Stella had been informed that they were being rehoused to a warden-aided bungalow which was nearer to her daughter and grandson. She viewed the bungalow as a positive means of re-engaging in social activities and having access to safe and reliable social networks.

“Yes, we’ve confirmed that we’re taking that on Tuesday, which will, oh massive, massive help. It’s seven miles away. It’s nearer my daughter, so absolutely, it’s fantastic. I think it’s going to be far, far better for with a living space and everything like that. Access to the shops and different things like that. The daughter’s five minutes away, I could walk.

I went up to see that bungalow, just to see if we were interested in taking, and I came back and I slept, that first time, and I told my husband that’s first time I’ve slept for months. I had a good night’s sleep because I think it’s lifted a lot of the pressure. I’m now thinking it’s got to be better, it’s going to be better, it’s going to be much better.” Stella

These quotations highlight the enormity of how the environment in which Stella was living was impacting on her emotional wellbeing. She drew on the tangible benefits of the new bungalow and was linking how this was making her feel emotionally more relaxed and thus she was able to sleep well.

There is the analogy of bricks and mortar, something tangible and solid, that would make her feel safer, which links to feeling in control of what is happening in a situation which to all intents and purposes she could not control.

Marie’s, Simon’s and Stella’s dialogues demonstrated how the absence of social networks can worsen carer emotional wellbeing. Indeed, carers with strong social networks acknowledged how these social interactions and personal relationships sustain them.

Maureen had a very supportive family living nearby and felt this helped her continue to care.

“... we’ve had extremely good neighbours, that was another thing. I wouldn’t have got through without my family, without the neighbours; they were both so good. People that’s got no one, I don’t know how they cope. And my daughter-in-law, especially the one that’s got the hairdressing shop, she couldn’t have been any better if she’d have been my own daughter. She was absolutely brilliant, weren’t she? She still is. Yes, they are, yes. I wouldn’t, if we hadn’t have got good neighbours and good family, I don’t know how people cope.” Maureen

These networks can be inclusive of formal service providers including general practitioners, health and social care staff and local pharmacies.

“The GP’s always on hand as well. We’ve got a chemist across the road who knows ... very well, and if I have any problems or anything and there’s nobody around, they’re open until midnight; I’ll nip over and they can advise me. So we have got a big care support team, which is good.” Sue

“They’ve got brilliant staff, lots of lovely nurses. I’ve been going there 40-odd years, but not the same doctors, and stuff, but you know, the practice, we’ve always known it.” Patricia

An important element of these networks was that they were accessible and that the carer had an established relationship and familiarity with the service providers to generate a trustworthy rapport.

A common experience amongst the participants was a feeling of loss in relation to their own independence. As previously discussed, this could be related to the lack of social support or respite care available to the carer. Additionally, for some carers interviewed, this loss related to their feelings of guilt when pursuing their own lives.

“...so whenever we’re going out it’s mainly me. She only gets out mainly because of me ... I do it and then you feel guilty because she’s stuck in the house all the time, but what can you do? Yeah, every day. Yeah, yeah, it’s very, it’s only a rare occasion that I don’t go, but it causes such rigmarole, you just end up feeling guilty.” Belinda

Belinda used the word ‘guilty’ twice in this extract to describe why she felt she needed to see her mother every day. She implied that when she opted not to visit her mother, the ‘*rigmarole*’ or complexities of making the decision not to visit weighed heavily on her conscience, resulting in feelings of guilt.

Sue also explained feeling uncomfortable when she left her husband, but interestingly this was not in relation to social activities but rather day-to-day tasks she needed to undertake.

“... even when I nip to the shops, if I’m longer than I say I’m going to be, he’ll be ringing me, where are you, what are you doing? He doesn’t feel comfortable on his own. How long are you going to be? So I know then he’s starting to panic because he’s been on his own too long.” Sue

She could not leave her husband for long as he was frightened on his own; there also seems to be the suggestion of questioning of what she was doing when he asked ‘*where are you?*’ Her husband’s panic reduced her ability to take time away from him.

John was an elderly gentleman who lived with his wife in a rural location. Here John recounted how he limited the time he left his wife by not engaging in social activities with friends but rather focusing on the essential tasks he needed to complete.

“I’ll take the mobile. Are you going to be all right for 10 minutes, she says yes, so I go. I don’t hang about talking or having pints at the local; I get back and she’s all right.” John

Stella talked about her sadness about the loss of her independence and related this in particular to the fact that she had worked all her life so was accustomed to having her own time and networks.

“Having worked and gone out and done my own thing for all these years, then to be here the side of him all the time, all the time. I just like think I’m independent woman and I like to do things. I’ve always had my own friends and I’ve always done my own things. I’ve gone away on holiday with friends right from us being married. I’ve always done that. I’ve always had my own space; I haven’t now.” Stella

Now Stella was a full-time carer, she did not have any time for herself; she desired time to have space from caring and to have social contact with her friends.

Access to activities, friends, work and wider networks is lessened by the real need to be physically in attendance with the person being cared for, but also the loss is driven by a fundamental emotional guilt associated with being absent.

9.3 Coping with the challenges of caring: “I don’t know how much more I can take”

Carers drew on a range of resources to cope with the challenges they encountered; the interviewees recounted particular aspects of caring that they found difficult to cope with. For some carers, there was an attitude of ‘*getting on with it*’; others described accumulative circumstances which led to a crisis in coping.

When embarking on the caring journey, a recurrent issue that increased emotional distress was access to help and, in particular, timely help. Helen was extremely frustrated by the difficulties she encountered when asked about organising help:

“And how easy was that to do?” Interviewer

“It wasn’t, none of it. It was an absolute nightmare, all of it. I would never do it again. By the time social care had gone there, and I’d met social care at my grandma’s house to do the assessment, I said we’re desperate, we need it now, not six months’ time when you’ve done, sorted something out; she needs it now. It was just a nightmare, absolute nightmare.”

Helen

Helen repeated the word ‘*nightmare*’ three times in this short extract, which emphasised how her experience was like a ‘bad dream’ causing despair and anxiety, something she would not want to go through again. A key issue was that she needed the help when she asked, not in the future.

Simon recalled a similar situation following his wife's diagnosis. They were caring for a new baby and had just received the devastating diagnosis of HF. At this point, no health care professional made contact, but weeks later they were contacted to ask how they were getting on and if they needed help.

"... you get like the health visitor ringing up saying do you need anything? But not now, no, but we did at the time and we seem to have missed the point, you know, we missed it. When we were trying to say, you know, she's struggling, I'm struggling, there was nobody there. Because we struggled before and it's like no I don't need you now, can you just leave us alone, and it's like trying to justify why they're ringing and they don't need to, do you know. We are managing."

"So you sort of go around in circles with it all. And there's just no support whatsoever for anybody, and I do think a lot of that as well is because of her age, because she's only like 35."

Simon

They had needed help at a specific point in time, proactive support, but this was not their experience; support was offered too late. Simon stated the services *'missed the point'*; thus it seems he felt that no one believed that they needed help when they did. Now they were coping, it appeared they felt harassed by the services; a sense of too little too late. Simon seemed angry that when he needed help, it was not there, but when he had managed to get on top of things, he kept being contacted to be asked how he was coping, and he wanted to be left alone to get on with things. The problematic situation may be related to the fact that both he and his wife were young; there could have been an assumption at the point of diagnosis that they would be able to cope better because they were young, but younger carers face particular challenges of continuing to work and support their children.

Sue's experience as a younger carer was similar to that of Simon, and as a result of the conflicting demands on her, she decided to give her job as a receptionist for a general practitioner in order to be a full-time carer.

“But he kept ringing me at work saying he wasn’t well, so I was having to leave work all the time, and at the end of the day I managed about four months working and caring for him.

... family that used to watch the kids while I went in, or his mum used to go in with him if he was taken ill at night, and I’d stay at home with the kids because he wanted one of us to be here for the kids and he did get upset. And then it was just the fact of juggling the kids with school.” Sue

Sue used the word *‘juggling’* to describe trying to keep up all the different roles she was expected to fulfil: mother, wife, wage earner and carer. There was a sense that she was keeping the ‘balls’ in the air but recognised that one may drop at any point.

A lack of understanding and empathy by professionals and family members reduced resilience in some carers. For Belinda, this related to not being considered as vulnerable.

“I’m always, I’m always, I’m always wary of saying too much because of the responsibility I’ve got and if you become, if you become vulnerable then you can’t, I just feel you can’t protect them the same, you know, and that’s my worry. It can be a battle there and you just think if anybody thought that you were, that you were vulnerable they could use it against you and you can’t get her the same help whereas if you’re strong. But if you start indicating that you’re vulnerable yourself, then I just think they’re not going to listen to you the same.” Belinda

She did not want to seem weak and helpless as this could impact on her credibility to cope. She had to be seen as robust physically and emotionally in order to be listened to. This desire to be heard was also evident in Stella’s interview; she described how she felt when she and her husband were first given the diagnosis of HF.

“Angry and upset and thinking yeah feeling he’s been left on his own, nobody cares, that’s all I heard every day, nobody cares! And that’s how both of us felt, because we’d been given that statement, well your heart’s knackered, nowt they can do for

us, do we just chuck us on scrapheap and that's it then. When the hospital, I think it was just a dismissive attitude, well what do you expect, he's got a bad heart and lungs, what do you expect?" Stella

Stella appeared to have been deserted and understandably she was angry; they were told that her husband's heart was *'knackered'*. She repeated the phrase *'nobody cares'* and used the analogy of been thrown on a scrap heap implying that they had been treated like rubbish and discarded. Stella perceived that the health professionals had dismissed her husband from their care as nothing more could be done for his condition. This attitude created a sense of worthlessness for Stella, which she described here.

"... I just felt useless that I couldn't do anything for him, and whatever I was doing didn't seem to help him at all. So I just felt inadequate. Yeah I wanted some support, some professional help as what to do with him." Stella

She outlined her weariness associated with caring for her husband on her own; she was the *'linchpin'* in meeting his care needs, but she still described feeling *'useless'* and *'inadequate'*.

Incongruence in the patient-carer dyad intensified the difficulties in coping. The interview with Stella was particularly demanding due to her emotional stress and anger. A source of her anger related to the quality of their relationship. When asked about the effect of caring for her husband on her social activities, she described the dynamic that was always present in their marriage.

"It used to be because, how long you going to be, when you're going to come back, and if I hadn't caught the bus for some reason, we're talking 20 minutes, where are you? Oh really anxious yeah. And he didn't get himself anything to eat; he'd wait until I come home to do that. Caused a few problems. I felt like, well I couldn't do anything unless he said I could ..."

"Well, I'll be honest, he's a man that's – he's the man, I'm the woman. When I went to work, yes you go with my permission but the house doesn't miss out, you look after the house, you

know, make sure that my daughter's all right, but that's it, you make sure that's right. So he's been a man that, yeah I have done, I've done everything old-fashioned." Stella

This gender demarcation had been established over many years of marriage, but the additional pressures Stella was feeling since caring for her husband seemed to be uncovering deep-seated dissatisfactions. She felt that he did not recognise what she was doing for him and importantly that as she was getting older she was finding his expectations increasingly difficult to cope with.

"Yeah, I've looked after my husband. If he can just see that I've got to that age, yeah I want a little bit of thought and I want him to say thank you, yeah, because he just expects me to just do everything just the same, and I can't. I can't keep it up." Stella

There was disparity between what her husband expected and what she could actually do; she was physically and emotionally exhausted. She viewed caring as something she had to do rather than something she wanted to do.

"I'll not say demanding, but his expectations are [click fingers]. But I want, I want, I want that. Yeah, it's very hard. I don't like it, no, but I've got to, I've got to do it ..." Stella

Simon's struggles to cope with lack of understanding were twofold; from his family's perspective, his wife looked healthy, which led to the misconception that she was not ill. Additionally, he strove for appreciation from his wife as regards the impact of caring on his wellbeing.

"And it's the understanding, because people don't, even people in my own family don't get it, because they look at her and think she looks all right. And, you know, sometimes I've been absolutely drained myself, you know, I'm having to do all the garden and everything else on top of everything else, and then it's like, I'm sort of drained. And then when she's tired and I just think well I am too. And this is what I tried to say to her the

other day, you don't realise like how much it affects me sometimes, because it does, you know." Simon

This again this seemed to be related to the fact that his wife was young and because of the physical presentation of HF. She was perceived not to be ill, which is in contrast to other illnesses where physical deterioration is clearly evident, for example cancer. Simon's tone appeared angry, a desperation for the impact on his own wellbeing to be acknowledged and understanding and empathy to be offered.

From Simon's account, it seemed that the combination of initial lack of support and lack of understanding of his situation created a crescendo in his coping crisis. Importantly this was not linked to his physical capability but his emotional ability to '*keep going*'.

"I thought I knew what I was dealing with, you know, but it has definitely been emotionally straining mentally. Sometimes I just think, god, I don't know how much more I can take." Simon

He used a very emotive statement '*how much more I can take*' indicating he had reached his limit. As a younger carer, he was evidently fitter than many of the older carers interviewed, several of whom had their own health issues, yet he recognised that the emotional strain was almost intolerable.

Evidently, for some carers interviewed there were intricacies in their lives that intensified the difficulties in their resilience to cope; this related both to external and intrinsic factors including poorly timed support, incongruence in relationships and lack of understanding. For other carers there was an attitude of '*getting on with it*'. Notably the ability to take such an approach was linked to the same factors that were lacking for those carers who described struggles with coping.

Congruence, namely agreement, harmony and compatibility in the patient-carer dyad engendered acceptance and stoicism. Brian described a conversation he had with a friend about their caring responsibilities.

“No, you just cope. You just have it to do. Because a friend of ours was saying well I’ve got to bloody do everything for her and all that, I said well, you’re a husband, you know, it’s what you sign up to.” Brian

Brian viewed his marriage like a contract, something you ‘sign up to’ and that as part of that you take things for ‘better or worse’. He went on to say

*“you sort of, you’re just in among it and you’re carrying on.”
Brian*

This implied that expectations and day-to-day demands become a part of normal existence. This ‘normalisation’ is mirrored in the experiences of Sue and John. Sue, a younger carer, talked about how she responded when people asked her how she coped.

*“...but it’s like people are saying to me how do you cope, but this is life for us, this is normal to us. Oh yeah, this is my life now. I’ve adjusted to how it is, and I’ve had to try and adjust.”
Sue*

Sue had shifted her expectations to normalise the adversity she was facing. Similarly to Sue, John, who was in his late eighties, described his attitude to caring for his elderly wife.

*“Well, it’s worrying, isn’t it? But I’m not a panicking person, you know, take things very gently... I’m not a panicky person ... I can cope. You see, I can cope. But I’ve never been one to ask for any help from anybody, so I’m, I don’t like to overload anybody, you see, to try and do it ourselves. Well, it’s not hard.”
John*

John repeatedly used the word ‘cope’; perhaps as a carer who is in his late eighties he felt he had to keep stating he could cope because he did not want to

be seen as a frail older carer. John wanted to be considered as independent and did not want to ask for help. For Sue and John, this fortitude was embedded in the enduring solidarity they described in their relationships.

“Me and Mark have been together for 24 hours for seven years, and we don’t argue, we don’t. We niggle at each other because he does get on my nerves, and I get on his, but to say that we’re together 24/7 we just get stronger and stronger anyway. So it does help to be still in love with the person that’s ill, because I think if we weren’t I think things would have broke down a long time ago.” Sue

Sue considered that her husband’s illness had brought them closer together and believed it had made their relationship stronger; it was important to have been in a loving relationship at the beginning of the illness in order to manage the emotional challenges.

John recounted his relationship in a manner similar to Sue.

“And yeah, and we’re a very fortunate pair because I’m thinking all the time of her, wherever I am, whatever I’m doing, I’m thinking is she all right, so. I can concentrate in our little community.” John

John and his wife had a loving reciprocal, partnership; ‘*our little community*’ refers to them as a couple. They had always done things together so did not find that they had lost friendships or social networks since the illness; it had always been just the two of them together.

As John indicated, an important aspect of sustaining the harmony in the patient-carer dyad was the reciprocal nature in the relationship. Maureen talked about how she and her husband had tackled both their illnesses together as a ‘*team*’.

“... we did dinner between us, me and Bill, you know. I didn’t feel like it but we did it, you have to do. But I’m very determined you have to do what you can, you don’t have to let things get on top of you and you’ve got to do it ... But we do get through

between us, what we do now. So we did it between us. But we do nearly everything together.” Maureen

Kate had lived overseas with her husband before he became unwell, but following his illness Kate and her husband had to come back to the UK, where she was now his full-time carer.

“You just carry on. It’s no good kind of falling apart. And we still kind of look after each other a little bit, because that’s how, you know. I mean we’ve always, unless he’s really bad, we always wash up together and do jobs together. He’s done the potatoes ready this morning. You know, we do things between us. Yeah, and it works well. Because if I had to wait on him hand and foot, I’d go under. So if we do it this way, you know, we can both take it a bit easier other ways. But we always have actually, it’s our marriage.” Kate

This closeness helped them cope together, adopting team work to sharing the household tasks. This was necessary for her to keep physically and emotionally well.

These extracts from the carer interviews demonstrate the importance of the established roles and gender expectations in the relationship. When a person has to take on a caring role, the attributes of the interpersonal relationship become intensified, and indeed a level of resentment can build as Kate discussed here.

“It’s helped, yeah, an awful lot. Because it’s helped us just kind of carry on with life as we had it. Does that sound silly? Resentment is the wrong word but I’ve heard some people when their husband is ill say, oh we can’t do that and we can’t, you know, and you just have to forget that. You’ve done things in the past, what you can’t do now, hard luck. I mean we had nine good years in Spain, you know, a lot of people have never done that, and we’ve enjoyed a life as much as a lot.” Kate

She seemed to be referring to other people who show resentment when they have to care for their husbands, but she looked back at the life they have had and these memories sustained her. As Kate had been in her marriage for over 50 years, the ability to look back over the years offered a positive reflection.

It could be proposed that this may be challenging for carers who have difficult relationships or past lives and that younger carers may not have the capacity to do this due to the limited years with their partner. However, two younger carers reflected on the transition that had occurred in their lives and how they had adapted to this. Simon talked about conversations with his wife about their circumstances. He thought it was important that they had a close and loving relationship before his wife became unwell as this had helped them to be open and honest with each other. They had a good way of talking things out, and they continued to do this in order to not let things build up between them.

“...even Karen said this is not what you signed up for, is it? I try and turn it into a joke and say yeah, for better or worse, I think I’ve got the worse, and I try and make it a joke, but it ain’t funny, do you know what I mean? It’s bad. It’s not something in a million years you would ever thought was going to happen to us. But I just think as long as we talk to each other.” Simon

Simon believed that there was a gender difference in the way that people would handle his situation; he indicated he felt a lot of men may have left their wives, but he viewed it as his duty as her husband; what else would he do? He thought that this was related to him as a person and the strong loving relationship that he had with his wife and children.

“...you know, there is times where I’ve felt like running a mile and not coming back – but that’s not the answer neither! How could you do that? We’ve got two kids, not well do you know, not that type of person. There’s been people who have even said to me, I’m surprised you stuck by her, and it’s like that’s my wife, what do you mean? You know, especially blokes, blokes are different to women. Blokes are like I don’t know how you’ve managed it? Well, you have no choice, that’s the situation, you know.” Simon

This acceptance of the transition and moving into a new phase in the relationship was also evident in Sue's dialogue.

"Yeah, we've always been close anyway, always. I mean, I met him on the Friday night, moved in on the Saturday and 16 years later we're still here. So we were meant to be from the beginning, but we've been through that many testing things it's just, like I said I've left my old life behind." Sue

Congruence was integral in sustaining resilience and nurturing acceptance for carers. It acted as a solid foundation on which new structures evolved to address challenging and complex circumstances carers and their families faced. These structures offered emotional props or tangible support, but without firm foundations in the relationship on which to build these props, cracks could appear, leading to emotional crisis in coping.

9.4 Facing the future: "live every day as if it's your last"

When the participants were asked about the manner in which they dealt with the uncertainty and poor prognosis associated with HF, they described that they were preparing themselves for the likely deterioration in the patient's condition but sustained their resilience by living day by day.

Belinda talked about her feelings in terms of the future for her mother.

*"...yeah, it's just going to carry on, isn't it? With my mum this'll just carry on until that day comes, won't it? Some days I look at her and I think she doesn't look well at all and, you know, is this nearly it and then she's just totally different. So you sort of, you always feel as if you're trying sort of preparing yourself."
Belinda*

She was insightful about the poor prognosis and, whilst she alluded to the unpredictability of what occurred day to day, she recognised that her mother would die from the condition.

"It's going to be the inevitable ..." Belinda

This insight into the poor prognosis and a need to prepare for dying was also demonstrated by Helen when she talked about her grandmother.

"She wanted to be at home. I was trying to make it as comfortable as possible for her to stay at home." Helen

As a granddaughter she wanted to fulfil her grandmother's wish to die at home and acted as the expert to facilitate this process.

"I said to the HFN I think it's going downhill and HFN was coming more often and seeing the deterioration and she said, you know, she gave me a phone call and said I think we're getting to the point where she's nearing the end of her life. And I agreed and said yeah you know I can see it." Helen

Helen recognised that her grandmother's condition was deteriorating; the closeness in their relationship allowed her to see that her grandmother was dying.

Stella indicated her awareness into the poor prognosis and her acceptance that inevitably her husband would die from HF; whilst upsetting, she seemed to be able to deal with this but described how she found the unpredictability of when this would happen intolerable.

"I've come to terms with it. It's not if, it's just when, and that's it. And I think I'd feel better if there was a bit of light thinking he were improving a little bit, but that's what I want, then I'll feel better. Otherwise, yeah, it's just every day, every day thinking,

god, I hope nothing happens today. You're on, I'm on edge ..."
Stella

She was seeking something positive to give her some hope but contradicts this by saying *'it's not if, it's when'* in relation to her husband dying. She was trying to take each day as it came but was always worried that something was going to happen. In living with this uncertainty, she described herself as literally *'living on the edge.'*

Despite carers being prepared, albeit by information provided by clinicians or their own tacit knowledge, they still articulated the worry they endured daily. Maureen demonstrated this when she described her fears about her husband's heart condition.

"don't really find it difficult, you do worry, you wouldn't be human if you didn't worry. Well, if ever his heart's going to happen again, if it's going to stop again, but it's like everything else. You don't know, so it's no good worrying over something you don't know, to me." Maureen

She starkly referred to her worry that her husband's heart could stop again but as Stella also said, that as she did not know when this may occur, she did not dwell on this.

"But the only thing is I try and look at it that we have got a bit longer, I know I get upset because we've both been that poorly, that we have got more time, and let's make the best of what we've got. And I always think there's somebody a lot, lot worse than us." Maureen

Maureen tried to have a positive attitude to their future and treasured the time that they have together. As both she and her husband had been seriously unwell, she now wanted to make the most of the time they have left together, and thus Maureen demonstrated her resilience to carry on.

*“But no, I think what’s happened. We’ve come through it, and you’ve got to get on with it. You haven’t got to dwell on it.”
Maureen*

She retained a positive attitude to the future and did not want to focus on how unwell her husband had been but wanted to keep moving forward. It seems she had a survivor instinct following her own illness and that they had worked together as a team to come through the difficult times.

Sustaining a positive attitude was evident in Sarah’s dialogue when she describes her worries about her mother dying.

“... I can look at it two ways. I can think, oh no, I don’t want my mum to go, or I can look at it well she’s had a good life. And she has. And people don’t live forever. But it’s like I’m one that copes better if I know what’s coming.” Sarah

Sarah showed an awareness of the poor prognosis and could accept that at some point her mother would die as she was 84 but again what she seemed to struggle with most was the unpredictability of the condition and when she could expect this decline to occur.

The reality of the physical aspects of dying was a source of fear for some of the carers interviewed. For example, Marie recounted how her mother had found her father dead in the bedroom; this past experience was a real fear for her in that history would repeat itself and she would find her own husband dead.

“I know it’s horrible to say but my one thing which has been in the back of my mind since he’s been ill. With him having congestive HF it’s going in there one morning and finding him dead. Yes, it plays on my mind, because that’s how my mother found my dad.

I mean I’m all right at the moment because I know he’s fine. But I mean it’s just, that’s how my mum found my dad. She went up with a cup of tea one afternoon and he was dead in bed. He’d gone up to have a lie-down, and he was only 70 when he died.” Marie

Marie was fearful of the sudden death of her husband and, as in the dialogues of Stella and Sarah, linked this to feeling out of control and not knowing what may happen next. In the context of HF this is a key concern as the condition is associated with sudden death in 50% of patients (Penrod et al., 2011).

For younger carers the enormity of the diagnosis and how it altered their futures was bleak. Simon discussed his fears for the future.

“Is this how I’ve got to live forever? And it is, it’s soul destroying. I mean I’m worried, you know, it’s going to get worse anyway. I don’t understand fully myself, you know, if she’s got something that’s going to progressively get worse and then she’s going to have to have a transplant anyway or, you know, where are we going to be in another 10 years’ time. You know, we often read things where say some people don’t live longer than five years after diagnosis and that sort of thing. It’s soul destroying knowing that this could be the way things are forever.” Simon

Simon used the term ‘soul destroying’ twice in this extract, which implied his despair, a sense that his spirit was broken at the thought of living in a situation that will never improve. He showed an awareness of the poor prognosis but again he faced the difficulty with this prognosis because of the uncertain disease trajectory and that he could not predict what will happen over the next few years.

Sue, in contrast to Simon, faced her future with a different mindset.

“I always worry about it because I know realistically we won’t grow old together. He’s given me the opportunities over the years to get out and go and find a life that I can live, a long life with somebody else. But he’s my soul mate so I’m prepared for everything, but it does scare me. And it scares me to think of how the kids are going to deal with it, just having me, because the kids are his life and the kids feel the same way about him. When he goes in hospital and he goes in in the night, I tell them he’s gone fishing and then they find out, and then they’re mad

with me. So we've started to tell the kids the truth about things."

Sue

There was a close bond between the couple which enabled them to discuss the implications of the condition, and this helped Sue to feel prepared whilst she recognised that she was not able to be in control of what comes next. Sue talked openly about her husband having a shortened life span and that she was scared of living her life without her 'soul mate', but they were dealing with the situation and their future by being truthful with each other and their young children. Due to the disease trajectory, the children had grown up since their father became unwell and so their expectations of what they needed to be told had changed. Sue recognised that she needed to address this as her husband's condition had progressively deteriorated and the children were aware of this. Here, Sue offered her advice for carers facing a similar future.

"...yeah, because you can't plan tomorrow; nobody knows what's going to happen tomorrow, even with a healthy person. So the best way to live with someone with HF is just live day to day and don't worry about tomorrow because you don't know if he's going to be here. But no, I just say live every day as if it's your last." Sue

This fatalistic acceptance may seem out of place for a younger person, but caring for a person with HF means facing a life-limiting existence. In this manner, Sue's attitude mirrored those expressed by the older carers interviewed who, as they were in their late seventies and eighties, viewed their situation as something you would expect to face at their stage of life.

"I think when you get to our age you've got to start preparing yourself because, I mean I could go first for that matter but it's one of them things." John

"No, we manage quite well. It's easy really. Life's pretty fairly ordinary, you know, it's nothing. Not worries, no. No, I've got no, everything is on an even keel really; there's nothing to worry about." Patricia

“And you just carry on. It’s no good kind of falling apart. I mean I’ve kind of got the boys, I must say, but it’s no good falling apart, is it? We’re just ticking over nice.” Kate

To comprehend the future they face, it was clear from the interviews that carers used a range of emotional reserves to sustain them. Consistently, insight was shown into the poor prognosis, but what was difficult to comprehend was unpredictability, and a recurrent tactic to deal with this was to live day to day.

9.5 Rewarding aspects of caring: “it really is a pleasure”

In spite of the emotional demands placed upon them, carers who were interviewed talked about the positive and rewarding aspects they gained from providing the support, as shown in the following extracts.

“It’s keeping her safe, isn’t it? Well, actually keeping her safe, you know, you’re doing the right thing.” Belinda

“Yeah. I would do it again, don’t get me wrong. She’s my grandma, I loved her you know, I didn’t feel like it was a massive burden and I really didn’t not want to do it, because she looked after us when we were younger.” Helen

“But it gives me a lot of satisfaction that I can still do things without somebody having to do them for me.” Maureen

For these carers there was a sense of reciprocity, giving back to someone who has supported them. Sarah elaborated on this in her interview.

“Well yeah, that she’s my mum. I wouldn’t like to just, I want it to be that if there’s anything I can do to make her quality of life any better I’d do it, so that she’s, at least I can think, well, we did all we could do. And anything you need I’ll do it for you, it’s a pleasure. And it really is a pleasure.” Sarah

These carers were offering support to a close member of their family, namely mothers and grandmother. It could be proposed that they were driven by family expectations; however, Clare described similar rewards when she spoke about caring for her elderly neighbour.

“It’s just something I do automatically. You know, it’s as though she is a relative and I just make sure, you know, no, it doesn’t cause us any concern, you know what I mean. No, it just makes me feel good and ... It makes me feel positive, yeah, that I can help somebody. I do, I do, yes. I do enjoy learning different things, yeah. So yeah, so, and then I had a mum that she was, she’d had a stroke so I was taking care of her as well. It seems as though that’s what I’ve brought onto this earth for, to be honest. Yeah, I would do anyway. It just comes natural to me.”
Clare

Clare gained satisfaction in the care she was giving, enjoying the fact that she was helping somebody and embraced the new knowledge she had gained. She associated caring as something inherent in her personality when she said *‘it just comes natural to me’*, and considered it her role in life despite never having worked in the caring profession.

As previously identified, carers felt valued when they were listened to and were viewed as an expert in the person’s care. Stella discussed how such involvement facilitated a more rewarding experience for the carer.

“Yeah, I think you’ve got to be involved. You’ve got to be involved. That’s what it’s all about, ain’t it? I think you’ve got to involve the carer.” Stella

It was important to her that she was able to be involved with discussions about the patient’s care which was central to the caring role.

Fundamental to carers acknowledging rewarding aspects of the role was the relationship they had with the person they were caring for. For those carers with strong emotional bonds with their partner, they did not see what they were

doing on a daily basis as an additional expectation, rather a deep-rooted reciprocal part of their relationship. Sue described her feelings about her husband and how these feelings helped sustain her.

“Still loving him the same way that I did when I met him, because he’ll say to me sometimes how can you live with me when I’m like this? Because he’s still the same person. He might be physically different, might be physically different inside but he’s still my Mark. He’s still the bloke that I met; he’s still the bloke that I married. And that’s the main important thing to me is still loving the person like you did in the beginning no matter what you go through. It makes you stronger anyway, and I think the amount of battles we’ve been through over the years I think if we weren’t meant to be we’d have found out by now. But we just get stronger anyway, so.” Sue

The challenges they faced, rather than drive them apart, made them closer, but Sue was aware that for many in her situation the emotional enormity would be too much to contend with.

“Yeah, it’s just how we are. But I can imagine a lot of people having to go through what we have to go through, a lot of marriages would break down because it is hard, it is hard to do. So you have truly got to in the beginning know, not your options but know what you’re in for. But obviously I’ve grown with it now, this is my life, I’ve left my old life behind, this is us, and apart from Mark being ill I wouldn’t change a thing at all.” Sue

John talked about how he considered what he did for his wife as an expression of his love for her. They had a close, loving relationship and had been married for 63 years.

“Because it’s Dot I enjoy it. Well, I wouldn’t want to be caring for anybody that I wasn’t close to, you know, although I have a bit of a caring instinct. But no, Dot is my life, and I enjoy it. I always say do you want me to do that, Dot. Anything you want doing, don’t I? What do you want doing for, you know, the dustbin or anyway daft? It perhaps sounds over the top, but I’ll say is there anything you want doing while I’m doing this. But I can see how people get left behind if they weren’t so independent

as us two. And we've got one another. If they're on their own, it must be awful. It just comes natural to me, that's it." John

The positive quality of the relationship enabled John to feel rewarded by the support he offered, and he enjoyed making things better for Dot. He recognised the importance of having a supportive partner and the longevity in the relationship made being a carer a natural progression in the dyad. This natural progression due to the longevity in the relationship was in contrast to Sue's, who as a younger carer, had only been with her partner for a few years. However, what does appear to be key for both these couples was the depth of the emotional love and respect they had for one another, and this was integral in enabling them to appreciate the rewards caring offered them.

9.6 Chapter summary

This theme explored carers' perceptions of the emotional impact of caring. Carers expressed a need to feel in control of their situation, but a challenge associated with the concept of control is the unpredictability of the HF disease trajectory. Thus participants reported reduced social contacts and social isolation as a consequence of living day to day. Social isolation was further exacerbated if there was a change in social circumstances such as moving home to meet the needs of the person they were caring for. Carers described needing to be visibly present with the patient and thus felt guilty when pursuing their own interests. The quality of the carer/patient dyad influenced carer resilience and positivity; where congruence was evident in the dyad, carers reported that caring gave them meaning and purpose.

Chapter Ten: Living as a carer

Contemplating how caring impacted on their day-to-day the lives, carers demonstrated variability in their experiences but also commonality in the challenges they had encountered. The variability related to the level of practical tasks required of them as carers, the support they had available to them and the physical condition of the person being cared for and indeed the carer themselves.

In addition to these practical tasks, the data from the interviews demonstrated the importance of the individual carer characteristics and how this influenced how they tackled each day.

10.1 Practicalities of caring: “I just felt useless that I couldn’t do anything for him”

Carers engaged in a wide range of practical activities to fulfil the requirements of the person they care for. These incorporated undertaking ‘hands on’ physical tasks, organising equipment, accessing services to initiate support, and managing finances and medications. These are discussed in detail below.

Brian’s wife was discharged from hospital with limited notice and with no supportive care package in place. Brian talked about how he addressed the situation in a pragmatic way and used the internet to try to find the type of equipment he may need to help him.

“Well, I bought a, what do they call them, rollator, I think, but we actually found, because the bathroom door’s fairly narrow, so I actually found one narrow enough to go through there, so she was able to trundle backwards and forwards with that.” Brian

Brian additionally had to find a solution to the peripheral oedema that his wife was struggling with. He proactively developed a way to deal with her weeping legs in the absence of the support services.

"...because we had to keep sorting the bandages out and everything got wet, so then it was sort of removed a bit of the bandage to try and let the fluid go a little bit, just trying to make life comfy for her. But once or twice we did, because we cut a polythene bag and put it round her legs and sellotaped that in place." Brian

After a week at home, the district nurses began to visit Brian and his wife; despite his wife's condition, the services were initially only visiting once a week.

"Eventually they came daily. It took a while, it was sort of, well, once a week and then there was that much fluid coming out and all the bandages were soaking wet through, I rang the, is it one, contact thing or something like that." Brian

His use of the word 'eventually' implies he perceived it took a long time for the nurses to visit and assist in managing his wife's physical needs. Brian's experience indicates how he adopted an innovative and improvising attitude to managing his wife's care by using plastic bags to absorb the fluid leaking from her legs.

The ease of carrying out practical activities varied from carer to carer irrespective of carer age. Stella talked about the total, constant responsibility she felt she had in providing physical care for her husband.

"I'm here all day every day, every night to look after him with his needs, which is exhausting, very exhausting. Can't get out and about, and we've had a setback now that he can't walk about now. Once he comes down, very difficult for him to get back up then really. Frightening at times actually. It's a lot for me going up and down stairs." Stella

Due to a deterioration in her husband's condition, Stella referred to the difficulties of her husband going up and down the stairs, which were extremely steep as they lived in a terrace house. In feeling 'frightened' she implied it was

her duty to ensure her husband did not fall down the stairs; thus there were physical implications for her when she moved her husband as she was a frail elderly lady herself. The fear may have been associated with her concern she would not be able to get her husband back up the stairs and not knowing what to do if this occurred. The dialogue indicates that Stella was obliged to carry out all the practical duties on behalf of her husband and that the obligation was a 24-hour, seven-day-a-week occurrence. When asked how she assisted her husband, Stella responded:

“... helping him dress, obviously cooking, feeding him – he could manage. He could manage, but he’s got to have help. I’d got to be there, I’d got to be there. And he just couldn’t do anything” Stella

There is an implication here that her husband could manage but she had to be there; however, the language in the extract is contradictory. Whilst Stella described how her husband could ‘manage’ she went on to say ‘he just couldn’t do anything’; perhaps this was because he could not do it or conversely he would not do it because of the established roles in the patient-carer dyad.

“Because I tried to do my best, I mean they were lots of issues with him not eating, not sleeping. Trying to feed him, trying to get him settled to go to sleep, and I just felt useless that I couldn’t do anything for him, and whatever I was doing didn’t seem to help him at all. Plus in the night time, listening for him and not, I weren’t sleeping, not sleeping now ... it’s like listening for a baby, yeah that’s, you know.” Stella

Stella’s words reflected her overwhelming isolation in caring for her husband; she endeavoured to meet his physical needs, but despite this she implied that what she did was not enough by saying ‘I just felt useless’. She used the analogy of her husband needing caring for as a person would care for a baby; this analogy could also be applied to this extract:

“I’m helping him well bath, bath, wash his self. The thing is he can’t stand a long time. Dressing him, just make sure he’s comfortable and seeing to his meals and his drinks and, yeah, just generally making sure that he’s comfortable, you know.”
Stella

She repeated that she wanted to make him comfortable, with the focus being completely on her husband’s needs and comfort despite her own health issues.

“I’m all right with the housework and that, but it’s when this, my polymyalgia starts. Yeah, I mean I fetched some Fortisips for him. I shan’t do that again, carrying from chemist up the hill.”
Stella

Yet despite the demands on her as a carer, it was important to Stella that she maintained her household to her own high standards.

“Well, it’s just me generally housekeeping, just, you know. I just like to keep a standard up and yeah just do it.” Stella

For Stella the practical tasks were made increasingly difficult as her husband’s condition was deteriorating, and the house in which they lived was unsuitable to meet their physical needs. Added to this were the entrenched beliefs in the dyad regarding the ‘division of labour’ resulting in Stella being overwhelmed by the physical duties she had to endure.

An assumption could be made that the younger carers interviewed would cope better with the physical demands, but importantly two of the younger carers described a contrasting experience.

Simon and his family had moved home due to his wife’s deteriorating condition, and whilst this was necessary, it created practical pressures for Simon which impacted on his own physical health.

"I had to paint it and I was literally, I was painting at night until midnight, getting up at like five in the morning for work, so I was having no rest whatsoever, and then doing a full-time job at work and then coming home, then you start again with the kids and then the garden was like a jungle, I hacked it to pieces and I've done all that, and then I think that's why I lost so much weight because I took that much on. And I don't think I realised until we was in it, how much we took on." Simon

Simon was caring for his wife but additionally was responsible for supporting a young family and working in a full-time job. He described a typical week in his life.

"Yeah, generally dinners, things like that. Yeah, all them type of things. Like the bedding and things ... can't do things like that, she's just too out of breath. So just the things that you would normally take for granted, and especially on the days where she has bad days and, not only can you say the good days, but she has better days, and them bad days, she says, she describe it like, she's got no energy, she can't physically move. And, you know, sometimes I've been absolutely drained myself, you know, I'm having to do all the garden and everything else on top of everything else, and then it's like, I'm sort of drained." Simon

Following the diagnosis, the family's life had to change to cope with the practicalities of living with the condition, and the consequence for Simon was that his life and expectations of their future were entirely disrupted. He seemed overwhelmed with the enormity of the situation and desired acknowledgement of how it was affecting him. As Simon's wife developed HF during her second pregnancy, what they were planning and looking forward to was a new baby, but now they were faced with a life-limiting condition. Because of the physical condition of his wife, Simon was required to care for the baby as well as his wife.

"She couldn't get upstairs every time the baby needs a vest or something, they're upstairs, so she had to keep sitting down all

the time, and that was the situation we was in at the last place. Basically we had a newborn baby to deal with as well, so I was off work for a long time, you know, because ... was unable to cope at the time.” Simon

Simon was fulfilling multiple roles, and the data indicates that these roles differ from those expected of an older carer.

For Sue, her husband’s age was linked to how much help he would accept. Here she talked about her husband not wanting to use a wheelchair due to his embarrassment. This was associated with her husband being a young man in his thirties and not wanting to seem physically dependent.

“He had a wheelchair. He refused to go in it because he said it’s like embarrassing.” Sue

This embarrassment was also a factor in Simon’s interview when he described his wife’s experience.

*“... she’s really self-conscious of everything, people looking at her. If anyone gets to find out what’s wrong with her and asks her, she’s dead embarrassed because she don’t want people to pity her neither. She wants to sort of try and carry on as normal, but she don’t like all that attention, so she’s not one for that.”
Simon*

For both Simon and Sue, the day-to-day practicalities of caring were intensified by the consequences of supporting a younger person with a condition commonly associated with older people. Additionally, they faced conflicting demands of being a parent, working and caring, which ultimately had changed their life course.

In contrast, Patricia, an 81-year-old carer, described the help she provided for her husband.

“It’s not difficult. It’s just very slow, it’s just very slow. He’s had horrendous leg ulcers as well, and he’s got water on his leg. So these are just ongoing things that sort of, you know, you’ve got loads of things wrong, but it’s nothing. I don’t know, they’ve told him with his cancer that he’s got probably another 10 years. I said okay crikey, that’ll make him 94, do you mind? The only thing I do really for him is shower him, because we’ve only got a shower over the bath, so I don’t let him go in the shower while I’m not here. So I shower him.” Patricia

Patricia and her husband had moved to a bungalow to adapt to his physical needs, and she felt that she could cope quite well. It is interesting to note that she described her husband having a range of health issues including HF and cancer but then stated *‘it’s nothing’* and *‘the only thing I really do’*. There was a sense that she was understating how much she was dealing with and did not view the practical tasks as particularly arduous as she described here.

“I care for my husband. What do I do? I don’t, you know, being a carer is not hard because with his heart problem he takes his medication. He does it all himself; I don’t have to do anything for him in that respect. I just watch his breathing.” Patricia

Kate demonstrated a similar attitude to the practical care she provided for her husband. When asked about the care she undertook on a daily basis, she responded:

*“...it’s really not caring for him, but watching him all the while.”
Kate*

As with Patricia, Kate was dismissive of the tasks she provided and did not associate them with the concept of caring. She went on to say.

“I mean, if he’s not well, then I will kind of do things, but on a general week if he’s all right he would still look after himself, yeah, because he’s just that type of man. It really is watching

him ... I mean from that point of view I haven't had to look after him as I said to you earlier ..." Kate

Both Patricia and Kate described how they were 'watching' but did not see this as a task; they seemed to associate caring with doing something physical rather than observing. John also described how he was always observing his wife when she was undertaking daily activities.

"Well, I make sure she's safe in the bathroom, and never lock the door or anything like that, always on hand. And I'm very aware, I listen for any sort of a tap. I always say tap on the floor, it's the easy way of communicating, and I go up there and meet her." John

He used the phrase 'always on hand' to indicate he was readily available to assist; he seemed to have a tacit knowledge of knowing that his wife was safe, an instinctive manner in how they communicated demonstrating the closeness in their relationship.

"I do all the washing up. I get the stuff ready for ... she can stand and iron all right. And washing out and washing in and that I get done. Yeah, I do most of the shopping. Well, not hard..." John

They worked together as a team to tackle the day-to-day tasks. He viewed the support he was offering as something that had to be done but did not consider it to be difficult. As the couple were in their late eighties, this level of acceptance could be associated with an expectation of caring for each other in older age.

A similar attitude to day-to-day tasks was evident in the interviews with Dave and Maureen. Dave embraced the new duties he had each day and considered his role as a carer as being stimulus for learning.

“I mean, when she was in hospital I knew that I was washing different things; I mean, men don’t do it normally, but it’s made me look and do it, learn how to do it. I know in the future it might happen a lot more, so I’ve got to start learning different things.” Dave

Despite an established view of gender expectations, he was embracing the challenges and viewed the tasks he was undertaking as a learning opportunity. Importantly Dave appeared to be preparing for future years when he may need to increase the level of physical support he was providing; by learning new skills Dave felt this would help him when his wife needed more assistance. This resonates with the ‘*positive aspects*’ of caring in the theme one.

“I mean, obviously I’ve had to learn how to use a washing machine and that type of thing, but she does it herself now. It certainly made me start doing things. It does make you start thinking I might end up being more of a carer than what I am at the moment, if you understand what I mean?” Dave

Maureen’s dialogue further demonstrated the importance of congruence in relation to the carer’s resilience to take on and carry on with the daily practical tasks. Both Maureen and her husband had been seriously ill in the last year, and in dealing with this they had embarked on this testing time as a team and delegated day-to-day activities between them.

“Well, it’s easy enough because I just held his hand to steady him just, I said to him just do what you can, and what you can’t, I will do. So we did it between us. I just made it as easy as I could for him. Well, he usually washes up for me, I will say that. I cook and he washes up.” Maureen

Maureen did not consider her contribution of great significance, but it was evident that she provided fundamental functions which were emphasised by her holding his hand; this acts as metaphor for a visible, steadying presence to keep her husband upright both physically and emotionally.

When Clare considered what she did to help her 90-year-old neighbour, she described having a 'chat.'

"We have a chat. I have a chat to her and sometimes I stop and have a cup of tea or we invite her round here for a cup of tea, and things like this. Yeah, she's up and dressed. Yeah, she don't, she can do, very slow mind you, but she said she can do it herself, so we let her do it. As much as she can do herself, we'll let her do." Clare

Despite the age of her neighbour, Clare encouraged her to maintain her independence. Initially in the interview, Clare was unspecific about what she actually did to support her neighbour on a day-to-day basis but explained:

"She's a very independent person really, but it's just that she, we like to just make sure she's okay." Clare

The focus of the support was evidently on the social contact rather than physical support as described in other interviews. This contradicts an expectation that, as an older person, the neighbour would need more physical support than a younger person. This is a positive example of supportive care without limiting the person's autonomy and demonstrated the importance of social care rather than care that purely focuses on health.

10.2 Sorting out equipment: “... made it up as we went along”

Lack of organisation in support services including the provision of equipment led to additional stress for the carers in the study. In the interview with Belinda, the things that helped her in the day-to-day tasks of caring were not complex; she required practical help, but the lack of organisation had meant she had to ‘*make it up*’. She listed the practical things that helped her in the day-to-day caring role, and to emphasise this she used the word ‘*marvellous*’ to show how important they were. Significantly her dialogue indicated that she needed them from ‘*day one*’, but again fragmentation led to the support not being readily available. These pieces of equipment were key to helping Belinda in undertaking the physical care that her mother requires, namely washing, toileting and dressing.

“...tend to, made it up as we went along. But yeah, it’d have been an awful lot easier if they’d had the OT out, this is what you’re likely to need. It was like the sort of, the seat to sit in the shower, and like little wafer things sort of about three deep that provide a step into the shower, because about that much step up into it. And the raised toilet seat and they were marvellous pieces of equipment. But if we’d had them from day one, it would have been an awful lot easier.” Belinda

As in Belinda’s experience, other carers referred to an ad hoc approach in how they managed to organise equipment to help them undertake the practical care. In Stella’s case she had to strive to get help from her GP; it wasn’t until a practice nurse visited to carry out a routine blood test that concerns about their situation were raised. Despite the intervention of the nurse regarding how to access equipment, it was still left to Stella, a frail elderly carer, to arrange the equipment she needed; thus the onus of responsibility was on her.

“Yes, and insisted somebody comes out and gives him some help. He was on weekly testing for warfarin. And actually the young lady that came out to do that was helpful as well, she

give me a few tips on what to do and where to go. But yeah it were all down to me to try and get it all sorted out.” Stella

For some participants, as they faced such difficulty in coping with the physical aspects of the day-to-day duties, they sought out and funded equipment themselves. The level of this varied for each person; for some it was specific pieces of equipment, but for others it was major adaptations.

“We’d bought a wheelchair beginning of June because my mum just, it was impossible even walking or anything.” Belinda

Belinda had to fund the purchase of the wheelchair herself, but without it her mother would be housebound due to her immobility. Thus there were evident financial implications for Belinda.

The financial implications of making adaptations were substantial for Sarah as well. As a retired nurse she had insight into the types of adaptations that would be beneficial to support her mother to stay at home. Early in the interview, Sarah talked about the wishes of her mother to be cared for in her own home.

“...they gave us an option to go into a nursing home for six weeks, community hospital for six weeks or home with carers. And I knew my mum. She made the decision but I agreed with her that, and she kept saying but I don’t want to go in a nursing home ...” Sarah

The situation Sarah was faced with was complicated; for example, in order to meet the physical needs and preferences of her mother, she was required to undertake major adaptations to her mother’s home. This added to the physical and emotional pressure for Sarah, and there was a sense that she was driven by her mother’s decisions rather than her own when she says ‘*she made the decision*’. When she described the alterations involved in ensuring her mother could be cared for at home, Sarah outlined the structural conversions required.

“I had a new bathroom put in. It was then I realised that she weren’t having baths. Why aren’t you having baths, Mum? Oh, because I can’t get out, I had a bit of a do when. I don’t know why she did it, but when my mum went in the bath she tried to turn onto her knees, to then stand to get out the bath. So I put grab rails in, etc. I knew she weren’t going to do that. So then I took the bath out, put a walk-in shower, and got a seat and everything that she needed really.” Sarah

Sarah had progressively made changes to the mother’s home as her condition had deteriorated and her physical needs had increased. Throughout the dialogue Sarah used ‘I’ indicating she addressed the situation in a singular manner. Using her knowledge as a nurse, she proactively managed the deteriorating situation single-handed without the support of health services in order to meet her mother’s desire to stay in her own home.

10.3 Accessing services: “I feel like I’m abandoned out here”

As with the organisation of equipment, participants recounted trials and challenges in accessing a range of services, aspects of which were related to physical limitations of the person being cared for, others related to knowledge and information. Belinda recalled her first encounter with social services, who conducted a home visit to assess her mother.

“And it was like, you know, and then she came to do the assessment and I said to her, you know what the first thing that’s wrong is. She was like – I said, well, the steps. No, she says the ambulance will carry her, the ambulance crew will just carry her upstairs. It’s like well there’s no way she’s just going to be stuck in that house, you know. So I managed to get this one-bedroom bungalow for her.” Belinda

The steps presented a physical barrier to her mother getting access to the outside world; the use of the word ‘stuck’ implies being trapped; Belinda was strongly opposed to her mother being left in such circumstances, ‘there is no

way ...'. For this patient-carer dyad, there was a sense that the consequences of staying in the home would result in isolation from the community and thus reduced capacity to access assistance. Even when the home environment was improved by moving her mother to a warden-aided bungalow, Belinda had to confront difficulties in getting her mother to the GP surgery for consultations.

"... you know, I've been around and I've taken her. But it is quite a rigmarole to do the process because there's no easy way of parking up around the surgery and then you've got to get her out, you've got to wheel her in and you know and the rest of it so" Belinda

Sarah described comparable efforts in taking her mother to the general practitioner's practice; she reflected on occasions when she had not taken her mother to appointments as she could not face the burden associated with the activity.

"It's an absolute nightmare, because it's not just getting her in the car, getting to the car park ... her breathing's so poor, to get her from the car park to walk round the front and then in, sit waiting, and then to take her in. And I think, god it's like anywhere else, she's in this state now, she's going to pick up god knows what while we're sat in here waiting. So it's something I've been putting off, I suppose for the right reasons but the wrong reasons." Sarah

It was clear how challenging it was to physically get to the doctor's appointments, and Sarah therefore made a decision to postpone visits, but she was contradictory in her rationale for this, '*right reasons but the wrong reasons*'. The right reasons may have been associated with protecting her mother from an exhausting encounter and exposure to illness whilst at the surgery; conversely the wrong reasons may have related to Sarah's own fatigue both physically and emotionally at the prospect of undertaking the endeavour. Additionally, she illustrated how the unpredictability of HF made preparing for appointments almost impossible.

“When I took her to opticians, three attempts we had to get her to opticians for the same thing. And it’s like this weakness that comes over her and then she starts, ‘I feel sick; I’m really sorry’. So now I’ve got carrier bags and kitchen wipes and towel and baby wipes with me if I’ve got to take my mum out, which makes me feel do I really want to take her out? How’s she going to be when we get there?” Sarah

The level of dependency compromised the patient’s access to essential health care services despite the support of an able and informed carer.

A further issue with accessing services was associated with timeliness. A common thread throughout the interviews was services not being readily available when the patient-carer dyad needed them. Helen spoke about a meeting with her social services team to discuss the support she needed to care for her grandmother.

“By the time social care had gone there, and I’d met social care at my grandma’s house to do the assessment, I said we’re desperate, we need it now, not six months’ time when you’ve done, sorted something out; she needs it now.” Helen

In using the word ‘*desperate*’, Helen gave the impression of someone who was exasperated and in urgent need for someone to offer an immediate solution to help her. The sense of frustration was palpable in her words and is reinforced by the repetition of ‘*we need it now ... she needs it now*’.

Stella described similar frustrations in accessing help and additionally concerns regarding how she accessed services in her local area.

“Yes, and insisted somebody comes out and gives him some help ... but it’s back of my mind if I go and leave him, we’ve got no access to any emergency care that ... Wouldn’t even be able to deal with. Yeah. Transport, I don’t drive. There’s a car there, and yeah, I can get on a bus. I’ve got a bus pass, but I’m miles away from anywhere.” Stella

Not being able to drive isolated Stella, and due to poor transport access she was fearful of what may occur in an emergency; she had limited information about who would help in a crisis.

Lack of information about how to access services also caused anger and frustration for Marie. She needed to move home to accommodation more suitable for her husband's physical needs, and she discussed this with the hospital prior to her husband's discharge. Marie described her experience.

"I said to them, well, I can cope with him but we need a bungalow. So, oh, you need to get in touch with social services. So I tried that. Bang. I tried the local council. Bang. You're not homeless, you haven't come in from abroad, no, we can't give you a bungalow. We filled out pages after pages after pages."
Marie

The word 'bang' was repeated twice in this quote; it created the analogy of the door repeatedly being slammed shut when she asked for help. This led to Marie describing how she felt 'abandoned'.

"But it's just I feel like I'm abandoned out here, do you know what I mean?"

For one of the younger carers interviewed, an issue that related to accessing services was a lack of understanding on the part of service providers. Simon relayed the difficulties he encountered when trying to obtain a badge for his car that would entitle his family to use disabled parking spaces.

"That goes against you, you know, even, we applied for a blue badge for the car. We were not even going to apply for a blue badge, but we was struggling and it never even entered my head we'd be entitled to it at first, until the heart nurse suggested we applied for it, so we applied for it, and then she got turned down. Now I still think that's because on the photo she looks like a picture of health, but you know. It's as if like they don't believe us." Simon

The carer perceived his application for disabled parking was not successful due to a lack of understanding of his wife's condition associated with her age and the fact that she did not look physically unwell. This caused exasperation for Simon; he felt that no one believed that they needed help.

Lack of understanding by service providers of the supportive needs of patients was additionally encountered by Clare when she was trying to organise respite care for her 90-year-old neighbour.

“... because we was all a bit concerned about her, and I said that my concern is when we're away, we're going away for six weeks. And I did get a call from them last week, but they'd got it all mixed up. They thought we wanted her to go into a respite and I said oh no, she won't leave that house. So she says well okay, it's just somebody to pop in, I said yes, that's just basically somebody to pop in, have a cup of tea with her, perhaps a little chat, and, you know, that's all.” Clare

Interestingly, despite the age of the patient, the respite support that the carer required focused on the social needs rather than health care needs; she described it as a 'pop in', but currently there is lack of clarity as to which services would offer such an intervention.

10.4 Taking care of the finances: “a big struggle”

Several carers in the study faced significant financial concerns due to the changing circumstances and additional responsibilities. Helen was accustomed to negotiating the health care benefits system as she had a disabled daughter; despite this she found the process of managing the financial support for her grandmother complex to navigate.

“So they would set up a prepayment card, put so much onto a, it's like a credit card, they would put so much onto that each

month and then I would physically pay the carer that they'd set up. The carer would, they'd bill me and I would pay the carer. But they needed to do an assessment of how much my grandma had got coming in." Helen

When Helen recognised that the home carers needed to provide more intensive support, she had to make financial negotiations to achieve this.

"... I had to go back to Social Care and say, look, she needs this care, she cannot afford to pay £60 a week towards these carers so something needs to be done. So we had backwards and forwards and toing and froing. They didn't pay her enough in the first place; there was a deficit between what they said they were paying and what my grandma had said they got to pay. So I had to try and explain that that there were some missing, who was going to pay that." Helen

Helen had to negotiate on behalf of her grandmother to ensure that her physical care needs were met despite a shortfall in the funding provided by social services. In the case of Helen and her grandmother, they were fortunate to have compassionate home carers who went above and beyond what was charged for.

"They were there longer than they billed. Do you know what I mean? They cleaned up. They, yeah, sorted her out when she was in a right mess. Do you know what I mean?" Helen

Helen wanted to care for her grandmother in her own home at the end of her life, but even this wish was marred by financial difficulties.

"... limited budget from social care of what they were going to pay and how many visits we could have, I couldn't really, my grandma couldn't afford to pay for any more. I could have really done with somebody going and a few more visits from somebody else or somebody going and being with her overnight." Helen

Helen described how she was offered the following advice.

“...you need to get the carers, if you’ve got extra money or a bit of spare money try and get the carers to go and physically put her into bed and so that she stays in bed overnight.” Helen

By using the words ‘you’ and ‘you’ve’, the onus was on Helen to provide the additional funding to ensure her grandmother was put to bed safely; Helen was already providing care for her disabled daughter and due to this was unable to work. Her position was compromised; she wanted to fulfil her grandmother’s wishes to die at home but did not have the financial means to do so. This was a situation that could potentially lead to the carer blaming themselves when the reality was in fact due to shortcomings in service provision.

Similarly to Helen, Sue as a younger carer faced financial difficulties following her husband’s diagnosis. As well as caring for her husband at the beginning of his illness, Sue was working part time and had two children under the age of 18. When asked at the interview if she was working, Sue responded:

“A big struggle, because we were waiting for, because obviously he was full-time work, I was part-time work, so for waiting for his benefits to be sorted out and for the right benefits took a while. And obviously I worked as long as I could, but then obviously everything snowballs on top of you because he needed me at home, we needed money as well, so it was like ...” Sue

As in Helen’s situation, Sue’s choices were compromised by financial pressure; whilst she had to give up work to care for her husband, this had negative financial implications for her and her family. Sue uses the metaphor ‘snowball’ to emphasise how she felt the situation she was facing was escalating out of her control. Sue went on to explain how she tried to manage the finances.

“So financial support as well, if there’s people out there that could advise us financially because what we had to do back then is doorstep loans that come offering us money. We didn’t have any because it was all being sorted, so we took all them out, as many as we could to keep us going, and obviously now we’re still paying them back bit by bit.” Sue

Due to lack of information about the financial benefits they were entitled to, Sue took on several pay day loans at higher than usual interest rates. Sue was aware of the high rates of interest, but the convenience of taking the loan on at the ‘*doorstep*’ seemed like a quick fix for her at a time of financial crisis.

Kate was more fortunate in that she was able to afford to arrange for someone to help them with physical tasks that her husband was no longer able to undertake.

“... we’ve had to start paying for people to do the jobs really that we would have done, he would have done and I can’t do anyway.” Kate

However, their circumstances were in stark contrast to those of Helen and Sue. Kate and her husband were a retired couple with no additional dependants and described themselves as financially secure. This security enabled them to make choices about the services they needed to ensure they could stay in their own home.

10.5 Managing medications: “over to you, here’s a bag full of medicines, off you go”

Numerous interviewees carried the responsibility of managing the patient’s medication on a daily basis. Brian felt that he had to take on this responsibility when his wife was sent home from hospital and he was presented with multiple medications.

“... they seemed to send her out all of a sudden. And it was sort of over to you, here’s a bag full of medicines, off you go from there.” Brian

The HFN assisted Brian in dealing with the medications, but interestingly he used the word ‘we’ when describing this so clearly felt he had accountability for managing the medications.

“... HFN came and we were sort of juggling with the meds to try and get a balance. Because, I’m trying to think, there was a whole heap of them. And I think what ... HFN wanted to do was put some more beta blocker in to slow her heart rate down, because that was about 90. But her blood pressure kept dropping way, way down, so we were sort of juggling that for a while ...” Brian

Brian showed awareness of the effects of the medication and used the word ‘*juggling*’ to illustrate how the medications were titrated according to his wife’s symptoms.

Brian provided a list-like answer when asked the types of medications he had to coordinate and demonstrated his insight by using the drug categories. Notably he, as a carer, had taken on the medication management due to his wife’s cognitive impairment, a common symptom in end-stage HF.

“I had to do all that because she was getting confused anyway. And you know, it was, I forget the routine now, but there was sort of an anti-sick one to start with, and then give that half an hour, then the furosemide, then furosemide again, and then beta blockers later.” Brian

The role of prompting to take medications was evident in several carers’ dialogue.

“Sometimes I’ll remind her like six o’clock time, I know she’s got, I sometimes text her from work to make sure she hasn’t

forgot, you know, things like that. Because with her having this depression she is quite forgetful as well.” Simon

“Because I have to keep my eye on ... tablets all the time, but we have one of those things you fill for the week. Yes, yeah, just put it on there with water, warm water.” John

“He had loads of tablets; I had to give him his medication all the while to make sure.” Maureen

Additionally, some carers interviewed organised the provision of medications to ensure adequate supplies. For Marie this caused dissatisfaction with the communication between services.

“I have to go to reception and say ... on such and such a drug, he’s been put on it by let’s say the heart specialist at ... We know nothing about it, but we’ll go on the computer and have a look. Oh yes, he is on it now but he’ll have to go through to the doctor to get a prescription for it. Can you come back tomorrow and pick up the prescription? Then you go to the dispensary, oh it’s going to take three days before you can have the drug. Well, quite often when I’m running around trying to do all these different things, I run out. I might only have two tablets left. Oh no, you can’t have any more. But they don’t realise somebody who’s caring has got so many different balls they’re playing with they haven’t got time sometimes to realise they’re down to, when you’ve got these metal foil things that you’re down to the last two tablets, do you?” Marie

The sense of frustration at the systems in play resonates in this quotation; there was annoyance with health services that show lack of understanding of her situation. She alluded to the many demands on her time and how overseeing the medication was only one aspect of the care she provided. Consequently, on occasions she had to request medication urgently but the services do not acknowledge this. Marie used the analogy of ‘*different balls*’ to highlight the multiple roles she manages on a daily basis, as did Brian in his interview.

For Clare, ensuring an adequate supply of medication for her neighbour was facilitated by a positive relationship with the local pharmacy. Clare monitored the medication stock, and if new medications had been prescribed, she made sure the prescriptions were dispensed in a timely manner. This close relationship with the pharmacy allowed for an understanding of the patient's situation and a person-centred approach to managing medications which reduced the burden on the carer.

“Well, I just check that they've gone, you know, and if there are any problems with her pills, I sort it out for her at the chemist, or if when the nurse comes and they feel that she needs a prescription from the doctors, you know, so.” Clare

A person-centred approach as defined in chapter two, as illustrated in Clare's situation, can prevent inappropriate prescribing and in particular the issues associated with repeat prescriptions. Helen encountered problems with medication being dispensed on repeated prescriptions and in inappropriate packaging for her grandmother due to her visual impairment.

“I'd sort prescriptions out. She [grandmother] was sorting her own tablets out. They were sending like the packets. She was ordering a repeat prescription, they were sending the packets and then she was trying to sort out what she was supposed to take, but she was almost blind. She was blind in one eye and it got to the point where she wasn't taking any because she couldn't figure out what was what and what she was supposed to be taking ...” Helen

Without the intervention of Helen, in this scenario, her grandmother would have experienced physical deterioration in relation to her HF due to missed or incorrect medications. Thus Helen carried the critical duty of coordinating the supply and administration of medications additional to the plethora of caring duties both for her grandmother and her own disabled daughter.

Whilst managing medications is a common requirement for people caring for a person with a long-term condition, HF carries additional complexities as the medications are commonly prescribed according to symptoms. Informal carers are therefore required to ensure that there are adequate medications in stock and may indeed be responsible for increasing or decreasing specific medications accordingly. Sarah recalled her actions when she realised her mother's condition was deteriorating.

"...we reduced her tablets down to one bumetanide a couple of weeks' ago, and within three days I could see the difference in mum's breathing and everything. So I rang him (GP) on the week, so just a week at one tablet, and I said I'm sorry for, I don't want you to think I'm being a bother but Mum's struggling now again just in this week, can I increase my mum's bumetanide? And he said, yeah, that's fine; do that and I'll come out and see her next week." Sarah

Sarah saw herself as part of the team with the doctor, which is illustrated by the use of the word 'we'; there appeared to be a mutual respect between Sarah and the doctor regarding skills and knowledge in managing the mother's HF. There did, however, seem to be a level of concern when contacting the doctor as she used the word 'bother' as though she may have felt that asking for help may be troublesome. This could be due to reticence regarding professional boundaries, but there was a positive response to her request, which importantly acknowledged the expertise of the carer. The fact that Sarah was a retired nurse facilitated this expertise, and her clinical insight was demonstrated in the following excerpt.

"If she is breathless and she's struggling with things, then I'll spend more time with her on that day. I'm checking, I think you do it instinctively anyway, you don't even realise half the time that you're doing. But if I think she's getting a bit dehydrated, Mum, I'm leaving you this water, I'm going to call back in a bit, don't forget to have a drink." Sarah

Whilst Sarah had awareness of HF and symptom management from her

experience as a nurse, John, who had no previous medical experience, also demonstrated insight when discussing his wife's medication.

“And I have asked various things, like can she take this sort of a tablet while she's taking all this, these others. Because I have to keep my eye on ... tablets all the time, but we have one of those things you fill for the week. Yes, yeah, just put it on there with water, warm water” John

John liaised with the HFN to manage the medication and ensure that there was an adequate supply; he viewed it as his responsibility to oversee and be informed about the medication including filling up the dosette box with the correct tablets. He had acquired the necessary knowledge, with the support of the HFN, regarding the dose and effect of the prescribed medications to meet the requirements of medication management.

The manner in which the participants in this study embarked on the practical caring tasks in their day-to-day lives was influenced by complex components. These components could be tangible including the level of hands-on care provided, accessibility of support, financial circumstances and dealing with multiple medications. Furthermore, the characteristics of the carer were integral in how they coped with living as a carer. These characteristics incorporated the skills and knowledge of the individual, alongside the ability to cope with competing demands and responsibilities. Additionally, the personality traits of the person cared for should be acknowledged as influential to how the carer copes. These components are discussed in detail below.

10.6 Resilience of the carer and the patient: “he would still look after himself...he's just that type of man”

Two of the participants in this study felt the resilience of the person they were caring for helped ease their burden. Helen talked about her frail, elderly neighbour.

“She’s 91 this week, yeah, so.” Clare

“And she’s still in her own home?” Interviewer

“Oh yeah, she’s still there. She refuses any meals-on-wheels services. You know, because she’s very, she gets, her hands and fingers go blue with it and she’s got no central heating, see, so she just tries to keep warm the best way she can. She’s a very independent person really, but it’s just that she, we like to just make sure she’s okay.” Clare

Despite the age of the patient and the fact that she was living in social housing that had not undergone modernisation including a lack of heating, she was able to maintain her independence with help from Clare.

Kate considered the personality of her husband as integral to how much help she had to provide, implying he was determined to be as independent as possible; *‘not that type’* indicated she believed there is a type of person that is better at coping with chronic illness and that her husband fitted in this category.

“... suppose I don’t do an awful lot because he won’t let you. I mean, if he’s not well then I will kind of do things, but on a general week if he’s all right he would still look after himself, yeah, because he’s just that type of man.” Kate

Reflecting on her caring experience over the last year led Maureen to contemplate her own resolve and how this sustained her to carry on. She was seriously ill before her husband’s illness and was still recovering when he had become acutely unwell. She referred to using *‘mind over matter’* indicating her psychological strength helped her to endure the difficulties she faced in spite of her own compromised physical condition. In using the phrase *‘I don’t like things to beat me’* there was a war-like analogy; she was embarking on a battle to be won and by being strong minded she would survive

“The only thing I found difficult was when I was really poorly, when I came out of hospital. It was a nightmare, because I didn’t feel at all well, and of course when you’re not well, you can’t cope ... But it’s mind over matter and I did it, and I’m just

very determined. I don't like things to beat me, I don't really. But that's the bit I find frustrating. I live with it, but it's just sometimes when I'm feeling tired or I think oh, come on ... you know, that's what I find difficult. But it's just when I've got an off day or. But I'm so, if I've got something to do, even if I can't do it, I'll give it a damn good go." Maureen

Maureen articulated her desire to be seen as independent and capable as a carer, and it was these qualities that provided the fulfilment to continue caring.

"But I am, as I say, I just don't like asking people to do anything. I'm a bit independent, bit too much perhaps, according to some. But it gives me a lot of satisfaction that I can still do things without somebody having to do them for me." Maureen

Positive personality traits were also illustrated in Dave's, Patricia's and John's dialogues. When asked in the interview if they found anything about being a carer particularly difficult, they responded as follows.

"It just comes so natural, didn't seem to concern me at all. I'm quite content, me." Dave

"I care for my husband. What do I do? I don't, you know, being a carer is not hard ..." Patricia

"Well, not hard. A bit that has to be done again, that's what, it carries on and on and on, doesn't it?" John

10.7 Coping with competing demands: “1,001 things to do”

During the interview, carers were asked about their own family situation. In response, several carers openly discussed complex circumstances which added to their caring responsibilities. Belinda, a single woman living on her own and working full time, described how she had been caring for members of her family for several years.

“There’s actually five of us, but there’s two brothers that do help when I need it. One I’ve not seen of them for what happened in April. I’ve not seen him for 15 years although I’ve seen him a couple of times since this year. And then the other person I care for is my sister. She’s got mental illness and I’m her named carer and go to all the meetings and everything.”
Belinda

Within the family, Belinda currently had responsibility of supporting her sister and her mother. In prior years she was also caring for her father.

“So it is wearing, it’s very wearing and, you know, it’s strange because I mean up to 2014 I was actually caring for three of them because I was caring for my dad as well. I used to literally leave my job of an evening, go to my dad’s, have an hour with my dad and then go to my mum and then go home. So, but now it’s all my mum and then obviously my sister rings and creates over the phone and wants reassurance over something and, you know, I go and visit her at least once a week to take her money and everything.” Belinda

The support she offered her sister was not readily received and her sister was often aggressive during her visits; this made enduring the situation hard to sustain and reduced her own resilience.

“I go there and I get the odd good visit and she’s pleased to see me and she’s all smiles. The rest of the time she just, she hates

me and I'm just there to take her money and be shouted at and told off." Belinda

She alluded in the interview that her brothers would help her if she asked them, but it seemed that she continued to carry the obligation for care. It could be proposed that it has been assumed by the siblings that Belinda would take on the care of her mother as she had previous experience of caring. However, she was obviously finding the ongoing demands difficult both physically and emotionally. Consideration should similarly be given to the associated gender expectations; it seemed that Belinda was the only female in the family capable of taking on the supportive role, and perhaps this is why the assumption was made that she would readily accept this. Or indeed it may relate to an instinctive desire to care; although she was finding her situation 'wearing' perhaps the rewards outweighed the challenges to fulfil this instinctive need.

Marie similarly demonstrated a caring instinct which goes beyond supporting her husband's needs. Despite finding the demands on her difficult, she continued to offer help and support to an elderly neighbour.

"Anyway, I had to go and pick my neighbour up. She collapsed on the Monday. She's 94. She had a urine infection. I caught the bus up to see her, and while I was out Jim had diarrhoea everywhere. So I came home to that. I had to clear all the mess up. I had to shower him on my own. But it was the stress of having Edna in one corner, Jim in the other corner." Marie

By providing assistance to her neighbour, she highlighted how this added to her workload and ultimately her stress levels that day. Both Marie and Belinda faced balancing demands between differing caring duties, and both had insight that these additional roles made caring for their spouse and mother progressively problematic.

Two carers described dealing with the stresses of their own health conditions. Stella had significant health conditions that she recognised impacted on how well she coped with caring for her husband.

“Yeah, I’ve got polymyalgia; I’ve got osteoarthritis and diabetes. It’s the osteoarthritis and polymyalgia which, if I get a bad do with that, I’m incapacitated because I can’t do anything.” Stella

Sarah had retired from nursing due to her back pain. Whilst she was limited by her own health issues, she still allowed her own health condition to come secondary to her mother’s needs.

“Because I retired with ill health because of a back condition, so I know my limitations.” Sarah

It was interesting to note that, in the cases of Stella and Marie, in spite of finding the situation with their husbands arduous, they appeared to embrace the opportunity to care for others. Here Stella talks about her young grandson; she viewed it as diversion or distraction from the ongoing care she provided for her husband.

“My escape, as I call it, my escape, I help out with my little grandson. I’m, yeah, perfect for grandchild, I’m doing child care. Yeah, I’m playing, you know, like you’re playing one and that yeah, I’m playing all sorts of roles now.” Stella

Stella used the concept of playing roles to illustrate the different expectations required of her; the role of nurse for her husband and grandmother to her grandson. In this manner, Stella may have felt that there was the expectation that she was able to perform these ‘parts’ in the same way in which Belinda and Marie performed as protectors/carers in their own communities. This leads to consideration as to why these individuals continue to offer this help: from obligation, duty or an inherent caring instinct?

Younger carers faced many additional demands including dealing with work commitments and their own families. For Helen, caring for her grandmother was particularly hard as she was a full-time carer for her disabled daughter. She was

already dealing with her daughter's complex health issues when she became responsible for grandmother's needs.

"... it took up a lot of time and obviously I didn't have a lot of time because I've got a disabled daughter that I look after. Just carrying on. It just carries on, yeah, just from one appointment to the next kind of thing. It kind of carries on. I have problems with Georgina all the time. She has medication problems, she's on and off things, she's yeah, it just kind of carries on." Helen

It is evident that Helen had multiple demands on her time and differing caring roles. She repeated the phrase 'carries on' several times in this quotation; this implied her situation was persistent and relentless, a sense that the demands of both caring roles 'carries on'.

Sue echoed this feeling when she described the opposing pressures she contended with.

"And when he's really sick or when I've got 1,001 things to do and he needs me as well, that's when it gets harder; I just want to scream and shout. But I just do what I need to do and then when everybody's in bed I have my time." Sue

Sue was aware when she was feeling frustrated and overwhelmed by the multiple roles, '1,001 things' she had to fulfil, but was unable to express these feelings as she prioritised her family's needs before her own. There was a similar attitude to Helen's in that the needs of the family are relentless but she sustained her resilience by ensuring she has some time, at some point to herself each day.

For Simon, the demands he faced were substantial and involved caring for a newborn baby, a toddler, his wife and working full time; additionally, Simon's family had moved house.

"... and it was such a massive feeling ... getting diagnosed, having a baby and then moving house and then having to renovate it, and it was like everything all at once, and I think

that's what, I think realistically no one in their right mind would have done what we did." Simon

Simon recognised that they faced major life transitions in a short space of time and goes on to describe how this affected him.

"... then things sort of hit me as well. It was like I just ran into a brick wall or something." Simon

It seems, as with Helen and Sue, it is the relentless requirements and multitude of roles that led to Simon abruptly metaphorically *'hitting the wall'* with an overwhelming fatigue and emotional exhaustion. What differed for Simon was the lack of capacity to have time for himself.

"So there's part of, a chunk of my day gone, and then I don't have break times. Well, I have to come home to take the little boy to school because Karen is unable to walk that far to school." Simon

"And I said, do you know it's all down to me to do things all the time with the kids and she's missing out. I get worn out. I'm not able to just sit down and go to asleep or anything." Simon

Simon repeated *'all'* to emphasise the total obligation he felt in dealing with the everyday demands on his time. As he had to finish work in order to collect his son from school, Simon worked through his lunch break, but when he finished work he did not have any time to rest before embarking on the remaining activities of the day.

Dialogue from interviews with Belinda and Sarah as daughters and Helen as a granddaughter illustrated differing demands and expectations. Belinda, Helen and Sarah did not live with the person they were caring for; here Belinda and Helen described their feelings of responsibility in making regular contact to reduce the isolation of the patient.

“So whenever we’re going out it’s mainly me. She only gets out mainly because of me. But, you know, whether it be that I do all the shopping or take her shopping or anything we do, it’s either she comes with me or I do it and then you feel guilty because she’s stuck in the house all the time, but what can you do?”

Belinda

“... because she was struggling to get out and about I used to pick her up and take her shopping.” Helen

As regards ‘hands-on care’, it is interesting to note commonality in these three carers’ experiences. They had all been frustrated by their mothers’ and grandmother’s attitudes to aspects of personal care.

Belinda recounted her frustrations with the conflicting information her mother gave to her and the social service carers.

“The carers will put in the notes Mum is fine, you know, and everything’s all fine and she’s okay today and all well and leave and everything. And then I’ll go of an evening and it’s like you know and she’s struggling, and it’s like, Mum, explain to me what’s the difference here? Where are we going? And I even showed her the notes a few weeks ago so she could read them, and I’m saying to her where are we going here? How come they’re saying you’re fine and then I’m coming and you can’t walk and you can’t manage to get to the toilet and you can’t do this and you need me to help you pull your pants up; what’s the difference?” Belinda

Belinda wanted to understand why her mother would say she was ‘okay’ to the home carers, but then when Belinda visited, she had to assist her with personal care. This could be linked to the intimacy that the personal care entails, for example taking her to the toilet and that her mother would prefer this care from her daughter rather than from a stranger. Helen’s grandmother showed similar reluctance to have assistance with personal care.

“...we were telling right just stay in your pyjamas, there’s only you, you’re not going anywhere. Just stay in your pyjamas, don’t bother getting dressed. So it’d got to that point where she wasn’t getting dressed anymore; she was just constantly getting up and going to bed in the same pyjamas.” Helen

Helen was evidently distressed that her grandmother had to stay in her nightwear, and events deteriorated which definitively denied both carer and patient dignity.

“She was soiling herself. She’d have been, if grandma was aware she’d have been absolutely disgusted with herself. She was sat in it. Do you know what I mean? She was sat wetting herself.” Helen

For the carer, there may be concerns that this reflected on them as the daughter or granddaughter, that they would be judged as uncaring and not fulfilling expectations. Sarah talked about this in the following extract.

“... I love you all the world, I just want you to just make sure you look nice and you’ll feel nice then. And what if anybody come and saw you looking like that, would you be embarrassed? I would be. I’d feel that people would be thinking, oh, what’s the matter with her daughter. And then he’ll phone me (her brother) and he’ll say I’m just letting you know my mum’s not brushed her hair today and blah, blah.” Sarah

Sarah showed the importance of physical appearances to her as a daughter and how this reflected on her, the concept of ‘keeping up appearances’. It could be proposed that this relates to gender expectations and leads to consideration as to whether this would be a different dynamic in a mother-and-son relationship. As Sarah described, when her brother contacted her, she felt it was her responsibility to go and attend to her mother’s physical care needs rather than asking her brother to do it.

She used the word ‘*struggling*’ to illustrate balancing her own demanding life with the additional responsibility of caring; there was a sense of frustration due

to her mother forgetting to tell her that she needed shopping. This forgetfulness could be linked to the physical effects of HF and was repeatedly alluded to in the interview: not brushing her hair, forgetting about shopping and here washing and cleaning. This led to increased frustration and stress for the daughter. She felt she was unable to meet her caring responsibilities adequately because she considered caring as a 'chore' rather than something she was doing out of love; it was not a pleasure anymore, rather laborious tasks to be completed.

"...frustrated, because I want to do more, and I want to be able to do it as it was always a pleasure. You've got to get, work with me, we're a team. Now it's becoming a chore. But my mum's always been one that nobody can tell her what to do; it's got to be her decision on everything. And I respect that, because she's my mum. But at the same time, it's just like roles have reversed now in a sense, and I don't think either of us like that." Sarah

Sarah acknowledged the difficulties with the changing dynamics in their relationship. Her mother had previously asserted her own wishes, and they had worked as a team to get things done. Sarah now sensed that her mother was saying what she thought her daughter wanted to hear and, similar to Stella's experience, the person being cared for acted like the child and Sarah had become the parent.

HF is a complicated condition to manage, and for the participants, this required that they develop new knowledge and in particular the ability to recognise the signs and symptoms indicating any deterioration. Participants described how they tackled coordinating care in the same manner they would a job; this involved the acquisition of skills and knowledge which was a combination of drawing on previous experiences and from new sources of information to become expert carers.

Both Marie and Sarah, as retired nurses, actively utilised their clinical understanding of the condition to observe for changes in the person.

Marie illustrated this when she talked about how she provided wound care for her husband. She followed a structured routine each time the wound needed

redressing, and this structure resonated in the following dialogue.

“Yes, I love to keep his foot right, don’t I? I shower him on a Saturday morning. We have to go to the garage to get the shower chair because it’s so big. I’m looking to see if there are any abrasions on him. I’m looking to see if there’s any bruising on him, any change in his skin colour or anything like that. And I’m looking at the colour of it to see if it’s gone a bit red or it’s purple or if there’s any circulation problems or anything like that. But I do check him from head to foot.” Marie

Throughout the description that Marie provided of the wound care, she highlighted the rationale for her actions and in this manner was using a nursing process to the wound care in that she assessed, planned, implemented and evaluated the required care. She repeatedly used the word ‘*looking*’ as she observed for any changes in the wound and the skin of her husband. Marie’s nursing experience enabled her to be knowledgeable as to what to observe for and importantly to recognise signs of deterioration. Again, Marie appeared to find this aspect of the caring role rewarding, which she articulated when she said ‘*I love to keep his foot right*’ as she felt in control of the situation she was managing.

From the terminology Sarah used during the interview, it was evident that she was knowledgeable about which warning signs of a physical deterioration to observe for. In this way, she was tackling the management of the condition as she would in her job as a nurse, ‘*instinctively*’. Interestingly, Sarah talked about how the knowledge she gained from checking the blood pressure, pulse and peripheral oedema helped to ‘*pacify myself*’. Thus this knowledge enabled her to feel in control of the situation, and she was able to do this because of her nursing background and implicit instinct.

“Yeah, I regularly check her blood pressure and her pulse. And if she’s gone on a down, as I would term it, then I’d do it daily. If she seems to be stable then probably a couple of times a week, just for my own information really, just to pacify myself. But every day I’ll check her feet and her ankles, just watch her with

her breathing, when she's speaking or she gets up to put the kettle on." Sarah

Conversely, carers with no previous knowledge or health care experience demonstrated considerable ability to acquire and develop the required knowledge to become competent in proactively managing care. Helen found the information that the HFN provided enabled her to be aware when her grandmother's condition was deteriorating.

"I think you just, I got to know ... the heart nurses had come and said, yeah, the breathing is to do with water around the lungs and various other places, I knew what I was looking for then, I could keep an eye on how bad she was getting." Helen

Clare liaised with the HFN to ensure that her neighbour's condition was closely monitored; she recognised the links between the medication and symptoms and instigated action to deal with this.

"Decrease (medication) you see like a few week ago, she was very, very dizzy, and one of the things I was concerned about was the fact that she was on blood pressure pills, and her blood pressure was really, really low. You know, because I go around there when the nurse comes, and so I know what her blood pressure was. And I just mentioned to nurse one day, and I said to the nurse I cannot understand why she's on blood pressure pills when her blood pressure's as low as it is. So we got that all sorted ..." Clare

This dialogue describing the management of the medication demonstrated the new knowledge acquired. It was Clare that initiated concerns about the neighbour's blood pressure and the dosage of medication she was prescribed; by using the word 'we', Clare implied that she viewed herself and the nurse as working as a team to titrate the medication according to the symptoms. Clare received positive validation of her contribution when the nurse acknowledged the improvement in her neighbour's condition.

“But the nurse came, I think, two week ago and she said her blood pressure was the best it’s been for a while, so something, you know?” Clare

When asked about where her she had obtained her knowledge about HF, Clare described past involvement with a family member’s cardiac conditions and the need to have an understanding of the treatments.

“ Well, I’ve got a family, well, on my husband’s side, his heart problems, so in fact we was with, one of his uncles had to have a heart transplant and we actually was with him in Papworth. So the nurse says I had to learn all his medication and everything. I find it very interesting actually. You know, it’s something that when I was working I took first aid course and things like this, so I do ...” Clare

It was Clare’s desire to be informed that was influential in her attainment of the knowledge of the condition, both in the case of her family and her neighbour. She acknowledged that she found health issues of particular interest and this motivated her to acquire the information required to be a knowledgeable and conversant carer.

It appears that there was an inherent assumption from some health services that carers could rise to the expectations required of them as regards their level of knowledge. For carers such as Marie and Sarah, this was facilitated by their previous nursing experience; Clare actively sought out information as she found the acquisition of the new knowledge satisfying. For two carers, however, it seemed they were compelled to become knowledgeable experts because this had been presumed of them. Kate indicated her uncertainty when she talked about the home monitoring equipment she had to use.

“And you had to send your weight every morning because obviously because the fluid on. And then once a week you had to send, now you’ve sent in your weight, your blood pressure and – I thought I’d done it all right.” Kate

Whilst Kate was aware of why the observations were being recorded, she required confirmation that she was conducting the activity correctly; her confidence wavered when she said *'I thought I'd done it all right'*. Maureen was also issued with home monitoring equipment when her husband was sent home from hospital.

"We've got a monitor in the other room, a little machine from the hospital that's for pacing. So that we won't have to keep going to hospital. But when we agreed to this, they didn't say to me, they just said you just plug it into your phone socket and leave it, that's what they said. But when we read the instructions, you're really supposed to have it in the bedroom through the night. Well, there's no sockets in the bedroom."
Maureen

As in Kate's experience, Maureen understood the purpose of the equipment but was not provided with adequate details about where the machine should be sited. Maureen had to seek out the practical information herself; the onus was on her to procure procedural facts to ensure she was using the equipment safely and appropriately.

Sue recognised that she had to become an expert in her husband's condition in order to be an informed and intuitive carer. She had been caring for her husband for over three years, during which he had several acute episodes of sudden decompensation of his HF. As Sue had gained insight from these past experiences and her confidence had grown, she recognised the signs and symptoms.

"I've had to be the expert because when there's people at night-time that aren't on hand to help me I have to sort it out myself. Like if he goes on his heart monitor or his blood pressure's high or it's low or his heart rate's too high, then I know what to look for and I know that I need to contact somebody. Or if he's panicking, I know how to calm him down to say, right, well, let's just give it half an hour; we'll check in another half an hour and see if it's any different. And nine times out of 10, it's gone back down, because if I'd have panicked

and phoned straightaway like I used to back in the day, but now I've learned when he needs to he needs to.” Sue

In the same manner that Marie and Sarah used their tacit nursing knowledge, Sue developed her own tacit knowledge in managing her husband's anxiety. She was proactively managing his condition by learning from her past experiences of when he had been unwell. Additionally, she had begun to use language that reflected nursing terminology as indicated when she referred to 'a plan'.

*“So if you can, in the beginning obviously you don't know anything about HF at all. So as you're getting to learn how things are if you can write out a plan of, well, what if this happens and I can't do this, then this needs to be on hand.”
Sue*

The tacit carer expertise was also evident when Stella described how she had an awareness of when her husband was becoming unwell.

“Well, I can pick up when he's picking a chest infection up. I can pick up when he gets a very bad sore throat and when he's really getting, he gets exhausted so quick, and I can see it coming and I know what's coming.” Stella

There was a desire to be in control evident in Stella's account of how she organised hospital appointments.

“Appointments, the calendars, oh, my calendar's full, and he couldn't cope with phone calls and discussing what and where and when. He just can't cope with that at all. I've had bad nights with ... I had a bad night with him the other, and I'm thinking, and I've got to look at my calendar and I've got all these things arranged ...” Stella

Stella, similarly to other participants interviewed, was, in effect, her husband's 'care coordinator'; she liaised with the nurses and dealt with his hospital appointments. The implication was that her husband would not be able to manage to do this due to his poor physical condition: *'He just can't cope with that at all.'* Stella's husband was extremely short of breath on minimal exertion, and consequently it would have been difficult for him to engage in discussions both face-to-face and over the telephone. Thus Stella felt she was accountable for coordinating her husband's care despite finding this difficult when she was physically exhausted herself, which she alluded to when she referred to having a *'bad night'* when her husband was unwell.

Brian similarly explained how he coordinated his wife's care using his skills as an engineer; when he talked about a typical day in his life as a carer, he explained how he dealt with it as he would an engineering project.

"just drew a chart up with the, normal engineer's way of doing things, yeah." Brian

He used the chart to document upcoming hospital appointments, home visits from nursing services, and timing and administration of medications. Evidently Brian drew on his past working expertise to prioritise and plan his days; in doing so he, in the same way as Stella, was able to feel in control of an unpredictable situation.

One carer, Maureen, had never worked but she talked about her experiences of running her household and how this helped her manage the varying demands on her time.

"Well, I've always done, I know it sounds as if I'm praising myself, but I've always run the house. He went to work and he's one of these, well, he was a miner, and he thought that the wife stopped at home, brought the children up, which I did, and did everything in the house. And he just sort of relies on me. So I do all the banking." Maureen

Maureen had a sense of pride when she talked about her organisational skills; she seemed to embrace the fact that her husband *'relies'* on her and the

opportunity of putting her skills towards the effective coordination of her husband's care.

Evidently, for a minority of carers the ability to effectively coordinate care and demonstrate the requisite skills and knowledge was a presumption made by health care providers; this belief caused anxiety as carers worried about their own shortcomings.

10.8 Chapter summary

This theme explored the participants' experiences of day-to-day life as a carer. Carers articulated how they used pragmatism to deal with array of physical and practical tasks they had to manage on a daily basis and illustrated substantial resilience in meeting the needs of the person they were caring for. However, despite their resilience, the day-to-day demands took their toll on the physical wellbeing of some participants, who discussed their physical exhaustion from the multiple demands placed on them; interestingly it was the younger carers in the study who commonly reported this. Furthermore, differing expectations were illustrated by the interviews with daughters and granddaughters. A predominant issue for the participants was timely access to information, support and services; for younger carers there was a lack of services that were fitting for their needs. Consequently, participants expressed how they had acquired the skills and knowledge to enable them to meet the requisites of the role. This was less arduous when the patient-carer dyad showed congruence in their relationship and they worked well as a team and had good support from family and community networks. Additionally, participants drew on the skills from life experiences including their working lives, and several participants talked about gaining new skills and knowledge as a positive experience.

Chapter Eleven: Carers' experience of formal and informal support

Dealing with the needs of the person they were caring for was clearly challenging and at times placed great burden on carers in this study. This burden was alleviated by support from both formal and informal sources including statutory and non-statutory services, family members, friends and neighbours. However, the way carers experienced the support available was varied, and it was evident that access to support and timeliness of support interventions could be improved to reduce carer burden.

The themes that emerged from the interviews were how support was organised, the information needs of the carers, support networks for carers (including the role of the HFN) and carers' thoughts on what support would be helpful to them. These are explored in detail below.

11.1 How support was organised: "I did all the running"

All of the carers in the study were known to statutory health services including district nursing services, general practitioners and hospital services. Despite this, there was fragmentation as to how they came into contact with these formal support services, especially when they needed increased access to services. In the case of Belinda, who was caring for her elderly mother, it was not a health care professional that instigated additional support; rather it was the warden from the social housing where her mother was living that recognised the situation was becoming intolerable.

"... one of the wardens walked in, decided they'd had enough and made the calls and social services came, Red Cross came and started to put a plan in place. Right, so what they did was eventually there was a social worker assigned to her, but I did all the running basically. I did all the running. The only thing the social worker organised was the meals-at-home service, and she said that that would probably be a good thing to have."
Belinda

Belinda described the warden's status as *'they'd had enough'* implying that she [the warden] could not continue to stand by and watch the mother deteriorate. The actions of the warden were driven by her compassion, and despite the fact the district nursing services were visiting Belinda's mother, it took the actions of a housing worker and not a health care profession to instigate support and liaise with services. It is additionally interesting that the service that came to the aid of Belinda was a voluntary sector service, namely the Red Cross. Within the context of this episode, Belinda implied by repeating the phrase *'I did all the running'* that she was being passed from one organisation to another in order to ensure that the needs of her mother were adequately met. This led to Belinda being unsure as to which organisation was meeting which aspect of care.

"So there was lots of things, you know, trying to work out who was responsible for her care in there and everything, but they were also good to her." Belinda

In spite of the difficulties she encountered getting increased help, Belinda still acknowledged that the quality of care her mother received was overall a positive experience. Importantly, she demonstrated a sensitive awareness of current pressures on care providers.

"And as much as they care, they'll be restricted by what they're allowed to do by law, by health and safety, by anything won't they, you know. So it's, I don't know. It's impossible, isn't it? I just, I think everybody that does this that does the caring, that tries to help in all the different ways they do is brilliant." Belinda

She referred to her gender, namely as a daughter, to rationalise why she had high expectations of the standards of care but acknowledged that her standards could not be met by services due to the limitations of the formal home carers.

“It’s just an impossible situation isn’t it because everybody, everybody cares and it’s how you care, isn’t it, and obviously being the daughter, being the family member, you’re obviously always going to think that the care isn’t right because it’s – they can only do so much, can’t they? Do you know what I mean?”
Belinda

Thus there was tension between what Belinda hoped for from the paid carers and what they could deliver in practice. But Belinda was not angry about this situation; rather she was conciliatory and recognised that the people looking after her mother did care but how they delivered this care was confined by regulations and rules. She uses the phrase *‘it’s just an impossible situation’* to stress how frustrating the situation felt but did not blame the carers as she knew that they were trying to help but within the constraints of their roles.

Stella employed a battle-like analogy; she expressed great frustration at how long it took for her to get any support.

“It’s took us seven nearly eight weeks to get any care in place at home. It was a matter of asking questions, ringing, chasing, everything. Well, I got really angry and made some threats and that, got onto the doctor and ... Well, after an argument ...”
Stella

There was the sense of needing to be doggedly persistent to get support organised. The language used here was very emotive; the words *‘threats’*, *‘angry’* and *‘argument’* implied Stella had to be confrontational, driven by her desperation.

11.2 Liaison between services: “nobody offers anything freely”

Belinda and Stella recounted *‘battling’* to find out how to get services in place. Both these carers had to persevere to get help; this related to uncertainty about the roles of the various health and social care services due to a lack of information. Similarly a lack of information was evident in other carers’ dialogue.

A particular concern was the transition between hospital and home, with several carers recalling a lack of information when they were discharged from hospital. Brian's wife had end-stage HF and consequently had a very poor prognosis; during the interview he explained how he did not have adequate information from the hospital.

"Yeah, there was a discharge sheet I think from ... (hospital) that sort of briefly said, you know, just a sort of one-word comment alongside." Brian

Due to the inadequacy of the 'one-word comment', Brian sought out the information he needed using the internet. Fortunately he chose reputable NHS websites, but despite this it was distressing for him to have to read about his wife's prognosis online rather than being able to have an open dialogue with the specialist team prior to her discharge home.

"So did you find that information helpful?" Interviewer

*"Yeah, and scary. Because I was looking at what is the likely outcome of all this, and it was sort of saying that with HF, I think it was stage four she was probably at then, and it's in there with medication and if you get past the first six months it's looking good. So obviously we didn't get past the first six months."
Brian*

Brian did not have opportunity to discuss the information he had accessed at this point as he had not been referred to support services. When asked if he talked it over with anyone including friends or family, Brian replied:

"No, no, I thought, you know, they might then drop it out in conversation with my wife." Brian

In order to protect his wife from the prognosis, Brian kept the information to himself as he was fearful of someone disclosing this to his wife. This situation left him to deal with the enormity of what they were facing as a couple in

isolation with only the internet as a point of referral. Similarly Helen felt isolated from the information she desired whilst caring for her grandmother. She implied that she felt that carers were required to actively seek out what they need themselves.

“So who explained to you about what to look out for then?”

Interviewer

“Nobody. I don’t because nobody tells you anything. If you want to know something, you have to contact them; nobody offers anything freely” Helen

The community nursing services was not proactive and did not communicate with the family; again this resonated with the necessity for carers to persist and persevere to get the essential care and information they need. For Helen, accessibility to information and the plan of care was hampered by her grandmother’s hearing and visual impairments, which she illustrates here.

“They (DNs) went in, . what they did while they were there was good, but they don’t keep you informed. I never knew what they were doing or when they’d been or. It’d be nice, because I think they expect, and for an 87-year-old woman who’s deaf and, you know, she wore hearing aids in both ears, almost deaf and blind, I think they just speak to them and expect them to take it all in and then explain it to the people like the family. Of which by the time I’d got there and asked them what they’d done.

Oh, I don’t know [grandmother]

What did they say?

I can’t remember [grandmother]

Are they coming again?

Yeah, I can’t remember when though [grandmother]

Do you know what I mean? They need to keep the family informed. My numbers are down on all my grandma’s stuff to contact me. I’m the next of kin, please ring me, but they never did.” Helen

There was a disparity between what she expected from the district nursing

service and what the service actually delivered. Person-centred nursing care advocates that care is planned with the person; consideration is given to the effect of what how the care delivered will affect the person as a whole (Health Foundation, 2014). In Helen's account there appeared to be a lack of sensitivity to the individual's needs; in this situation there was a supportive family who evidently wanted to be involved with the district nursing services, but this had failed to be acknowledged. There is additionally an unrealistic belief that a frail elderly person with end-stage HF will be able to retain and recall complex information. The rationale for the district nursing service not contacting Helen is unclear, but it could be proposed that as with many health and social care services it relates to time constraints and clinical pressures. Yet proactive and positive lines of communication and information sharing between families and service providers should only serve to reduce confusion about care delivery.

Stella likewise recounted a breakdown in communication between health and social care service providers. Whilst she referred to '*continuity*', it appeared she was using this term in a cynical manner as she followed on by discussing the lack of support and information when her husband was sent home from hospital.

"It's, what they call it, continuity ... all that's come into place. What we've found out is word of mouth, nobody's come. Bad experience from hospital, I think, definitely." Stella

As was evident in her previous dialogue, Stella used the phrase '*word of mouth*' to imply that they had to seek out help and support by asking whoever they came into contact with. In the same way as in Stella's experience, John and Patricia, who were caring for their spouses, demonstrated that the obligation was with them as carers to get hold of what they needed, and it was evident that the process was one in which the carer stumbled upon this rather than a process that was systematic and transparent.

"In terms of things like the equipment or practical help though for you as the carer, who would you contact about that?"
Interviewer

"I wouldn't know. Well, we haven't had any advice on that, have we? No, no. No, I wouldn't know what to do in that case." John

"Did they give a name to the condition?" Interviewer

"No, not especially, no." Patricia

"Who did you say referred you?" Interviewer

"I think the GP. Who was it who did it? Well the Social did it, didn't they?" Patricia

"The GP?" Interviewer

*"Yeah, or the nurse, somebody at the surgery, the nurse."
Patricia*

There was yet again evidence of a lack of clarity amongst the carers interviewed of which service was accountable for the differing aspects of care and a lack of information about the condition itself; additionally, for Stella, Patricia and John, fragmentation in service provision added to difficulties in accessing information.

An important finding that was apparent in several carer interviews was how the positive experience of voluntary sector services contrasted with their experiences of formal health services. For example, Belinda described the assistance from the Red Cross; as regards accessing information about how to get help, Marie's dialogue again indicated a negative experience of formal health services.

"We had no help from anybody. All they wanted to do with him was to put him into a nursing home. But nobody gave me any support." Marie

But when Marie talked about the help she received from a volunteer, her language was unequivocally positive.

“People were turning up, like we had a woman, she was absolutely lovely, Paula, from the social services, and I think she was a volunteer. She filled in forms and things.” Marie

It is interesting to note the different language used by Marie to describe the two services; there was the use of *‘they’* for health services yet she used the person’s name when she referred to the volunteer. The analogy of a faceless organisation versus a personable and individual approach to meet the carer’s needs could be drawn from this dialogue.

There appeared to be an experience of extremes; from one perspective, information and support was absent, which Marie stressed by using negative words *‘no’*, *‘nobody’*, and the only option she referred to being offered was for her husband to be cared for in full-time residential care. However, the opposite perspective, namely the input from the volunteer, was pragmatic and practical and achieved a demonstrable outcome.

A desire for such a practical stance was likewise expressed by Simon, who proposed that the lack of information was associated with the condition itself; he recounted how he felt there was great inequity when comparing the information including support available to people with HF to those living with a cancer diagnosis.

“And then it’s like the condition itself, and it’s not just her condition, I think it’s general heart conditions, I don’t think they’re recognised as a disability, and that’s the hardest thing. I wish that maybe there’s somebody that could highlight somewhere. It’s like, I know this is going off of it a bit but you watch something on the telly and someone’s got cancer. My mum’s got cancer, I understand all that, and then they’d put a helpline on at the end. Whereas something about heart comes on the telly, there’s no helpline at the end; there’s nothing. There’s never anything there to deal with it. And like I say, even the support groups, there’s none for younger people; they’re all for older people. There’s not really anyone on your wavelength.” Simon

Simon's frustrations were twofold; he was frustrated by a lack of awareness in the wider public about his wife's condition and the severity of what they were living with and the life-limiting nature of her condition; he sought acknowledgement that she had a 'disability'. But additionally he wanted public recognition that people with heart conditions need information and appropriate support. Simon used the word 'helpline', a strategy commonly used when television programmes cover difficult health or emotional issues; Simon felt that there was an absence of information about HF and this was of particular significance as it totally undermined the enormity of what patients and carers tolerate in daily life. Here Simon expressed his desperation:

"Because the awareness of it, and there's no awareness of it, and it's like, people aren't educated ... they don't understand these conditions. It's hard, so hard to explain to people what it is and what you're going through because no one understands it. So that's a big thing, I think. But I don't know how you can sort of highlight that, you know ... it's that sort of support that I think, and you don't know where to go to get it, and that's a massive thing." Simon

He sought validation and understanding of the difficulties he encountered and for understanding and empathy; as HF commonly affects older people, the information and support he was offered did not meet his needs. Sue, also a younger carer, was obliged to seek information from her peers via the internet.

"Also what I used, back in the day, CMA website, Cardiomyopathy Association, and it was like a forum and you go on and you explain that you're a carer. Because some of us are carers, and some of us have got what Mark's got, but speaking to someone who's got the same as a carer like me whose husband's going through the same thing, some of them are sicker, some of them have just got it and they're okay. And then we all start, we added each other on Facebook and any problems we had we always used to inbox each other. We've got each other's phone numbers. One lives nearby, one lives quite far away, and we're only just a phone call away from each other." Sue

What was crucial for Sue was that the people she was communicating with were in the same situation as her, namely they were a similar age and caring for someone with the same condition. Peer support was the essential element to the success of the forum and the carers' sense of ownership. This ownership was demonstrated by carers moving away from the website to using their personal internet forums to support and share with each other.

11.3 Significance of support networks: "I wouldn't have got through without my family, without the neighbours"

The availability of support networks, both formal and informal, was fundamental in facilitating carer endurance. For the majority of carers, these networks were visible, but Brian used the internet to sustain his support whilst he was caring for his wife. When asked how he kept in touch with friends whilst looking after his wife, he responded:

"When I could, yeah, just by email as much as anything." Brian

This indicated the importance of how the internet can help maintain relationships; this is particularly significant for carers who lack tangible networks or those who are unable to leave the person they are caring for.

Several participants reported positive experiences of formal support networks and in particular the quality of care provided by social services carers as illustrated by Belinda and Helen.

"... the majority of the time, because it's about the carers and the majority of the carers are the same ones, my mum really likes them all." Belinda

An essential part of her experience of the service that the formal carers provided was that it was the same people that visited her mother; this element is echoed in Helen's dialogue.

“The carers that they set up and sent were absolutely amazing. I can’t fault them at all. They were there longer than they billed. Do you know what I mean? They cleaned up. They, yeah, sorted her out when she was in a right mess. Do you know what I mean? I had their phone numbers and they rang me on a regular basis if something was going off. She had the same carers. There was a lady called Deb that used to go, do the week shifts and then another lady called, what was her name, Dawn that went on a weekend. But they were brilliant. Used to take her Sunday dinners and all sorts of things, you know extra stuff. Deb took her shopping to the supermarket on a Sunday afternoon and didn’t bill for it. Do you know what I mean? They took her all over the place.” Helen

As there was continuous care offered by the same two people, the grandmother was able to establish a rapport with them. Helen used the names of the carers, which emphasised how she considered them as people not a service. Additionally, the personal attributes of the formal carers meant that they saw her grandmother as a person rather than a job. They saw beyond the ‘bill’ and offered help and support to ensure her needs were met with dignity and in a timely manner. Helen continued to emphasise the value of this person-centred approach, focusing on the needs of the person rather than the needs of the service, as she developed the discussion relating to payment to social services.

“No, they were brilliant. They stayed for as long as they needed to be there and they did not charge for extra hours. But ... always when she sent an invoice, she always emailed me the invoices once a fortnight I think it was, and she put down charged for such and such this week because she did this, this and this on this day and she had to stay and do this, this and this. But half of the stuff that they were stopping and doing they didn’t charge for. They did a lot above and beyond to be honest that they didn’t put hours in for.” Helen

Resonating throughout this account of the grandmother’s formal carers was the fact they were not treating the interaction with the patient as a task-orientated

activity. These carers had gone *'above and beyond'*; they had exceeded what was required of them at a basic level and addressed essential social needs including continuous contact. Helen was mindful that her grandmother's experience was not reflected in the experiences of others.

"... my grandma often talked about somebody across the way that had carers that go and it was the never the same one twice." Helen

Sadly, in contrast, their experience of health services was not as positive; when Helen recalled the role of the district nurses involved in her grandmother's care, she expressed disappointing dissatisfaction.

"The carers were telling me there's no cream, and I said they'd left a note for the district nurses, of which they'd just ignored and not sent any cream. I think she'd got a blister or something that had come on her leg then and they were sorting that out as well as the one on her bum, and they turned up and my grandma had got a skirt on and a cardigan and stuff, but she'd got poo all over her. She was covered in it absolutely everywhere from what I can gather. And the district nurses had left her like it. And when the carer had got there, Grandma was covered in it and she'd asked why the district nurses had left her like that ... why had the district nurses left her in such a mess? I know it's not their job to clean her up, but could you leave someone sitting in poo absolutely covered in it, and they'd left her like it." Helen

In sharp contrast to the perception that the social service carers offered support and care that exceeded what was expected of them in their job description, Helen felt that the district nursing team did not offer such a supportive role. She says *'I know it's not their job to clean her up'*, but should not such essential care be integral to the role of a nurse in offering person-centred care to promote patient comfort and dignity?

Helen's experience of district nursing service was not reflected by the other study participants. Indeed, both Belinda and Brian described the excellent care they received from their district nurses.

“We couldn’t fault what the district nurses, we couldn’t fault what anybody did really.” Brian

“The district nurses have actually given us the okay to, if ever we’re worried about her legs breaking out we are, any, even 24 hour a day we can contact them and they will come out. They haven’t got a problem with it.” Belinda

These carers were reassured that the district nurses were able to meet their needs and in particular for Belinda that they were available 24 hours a day. As Belinda persistently referred to *‘not wanting to bother people’* throughout her interview, it is noteworthy that she perceived that it was not a *‘problem’* if she needed to contact the district nurses. This differs from Helen’s experience; Belinda found that district nurses would offer care to meet the needs of the patient irrespective of when these needs arose. Significantly Helen and Belinda lived in close proximity but social services and district nursing provision was delivered by different providers; how these providers train their teams may account for the resilience and compassion reflected in the care that their staff provide.

Several participants drew support from their informal networks, which included friends, family and neighbours. Maureen had family living close by but additionally recognised the importance of the networks in her local community that proved to be invaluable during a difficult year when both she and her husband had been unwell.

*“Yes, and we’ve had extremely good neighbours, that was another thing. I wouldn’t have got through without my family, without the neighbours; they were both so good to him when I was ill. People that’s got no one, I don’t know how they cope. And my daughter-in-law, especially the one that’s got the hairdressing shop, she couldn’t have been any better if she’d have been my own daughter. She was absolutely brilliant. She still is yes, they are, yes. I wouldn’t, if we hadn’t have got good neighbours and good family, I don’t know how people cope.”
Maureen*

There was clear recognition of how different it was for people who have no one to help cope with caring, which Maureen emphasised, repeating that she could not have coped without her neighbours and family. Maureen's husband was a retired miner and they had lived in the mining community for the last 50 years, in the same house and next to the same neighbours. These social networks were crucial to Maureen when she experienced carer crisis. Dave mirrored Maureen's experience with a close extended family offering ongoing assistance.

"Yeah, I've got plenty of support. Got my nephew and his wife next door, just straight across there." Dave

However, for other participants, such as Marie and Simon, family and social networks were disparate, leading to isolation and distress. As previously discussed, Marie and her husband had been forced to move home to a bungalow that was suitable for their needs. Consequently, Marie had lost contact with her friends and social networks. For Marie, these networks were the fundamental foundations to help her carrying on caring; without these networks and with no family locally, Marie was evidently anxious and tense.

*"There was no support. I mean, I'm stressed out even now after 18 months. This is all on my own, I've got no children here because Katie is in Portsmouth, Kev is in Chelmsford; they're both working. But he fell in the front garden; I had to lift him out of there as well. See none of the neighbours gave us a hand."
Marie*

Marie indicated she felt increasingly isolated as her son and daughter both lived a long distance away and she did not know her neighbours. Her dialogue shows the impact of having no family nearby and limited social networks.

"But it's just I feel like I'm abandoned out here, do you know what I mean? I don't really know many people here." Marie

It could be proposed that Marie's experience reflects demographic changes in society with people living longer, with smaller families, and extended family not

necessarily living close by. She appeared angry that an assumption is made that carers have families locally who will offer them support; Marie wanted recognition that this was not the situation for many carers *'in this day and age'*. She used the word *'abandoned'* implying that she felt deserted by her support networks to cope with caring on her own.

Simon's family support networks were also limited, but this was due to the family dynamics as opposed to locality.

"...because she's estranged from them anyway, so yeah. She's quite isolated and it's down to me and it's, I do everything I can to sort of encourage her to do things, but yeah, it's hard work sometimes." Simon

Due to their isolation as a couple, Simon was required to seek support and solace from other sources; in his case he found his employer to be crucial in offering help. A key factor in this support was that he had worked for his employer for a number of years and that he had a good employment history.

"My work are understanding as to let me come home, but I've been in the same job for 26 years, you know, part of the furniture, so they know my case is a genuine case. I've never really had lots of time off work, but there are people that do take the time out like that, so I know that they've been really good with me and I can't say they haven't." Simon

Imperative for Simon was recognition that he needs were *'genuine'* and the longevity with his employer assisted his ability to take the support they offered as it was not a usual occurrence for him as an employee. This is an important issue to consider as without the support of his employer Simon would have found it impossible to manage to keep going to work and meet his caring responsibilities. Clearly, not working cascades into financial difficulties and limits social contacts with work colleagues impacting on the wellbeing of the carer. Simon repeated how important his work had been to him and indicated practical interventions they offered him.

“Well, to be honest where I work have been really good and I never realised there’s a support line and they’ve said any time, you know. I’ve never rang it before I got into the situation that I ended up in, because I thought, oh no, that’s not for me. I never realised what it was but it was really good; they sort of offered me funding for the kids and things, you know, if you’re struggling. You know, if you see that, you might have bailiffs come around your house, don’t get to the point where it’s going to happen; we can help you out. They’ve been really good. I cannot fault my work at all. They have been supportive. Yeah, and they even let me go back; when I first went back to work I was doing two hours a day, and I still got paid my full pay – they was really good on that front.” Simon

He repeatedly used the word ‘good’ regarding the variety of practical help provided by his workplace. It appeared his employers were sympathetic to his individual needs and thus offered accommodating, accessible assistance which reduced the physical and emotional load on Simon.

Simon additionally acknowledged how his close relationship with his wife helped to sustain him.

“But I just think as long as we talk to each other. You know, that’s the main thing, we’ve got to talk to each other, because it is isolating. It is, it’s not a nice place to be, and like I say because people don’t understand ...” Simon

This highlights that as it is the patient-carer dyad who face day-to-day life living with a life-limiting condition and its implications, only they have a true understanding of how their partner is feeling and how to support them. This intimacy was also evident in John’s discussion of his support needs; when asked if he had any help to care for his wife, John responded:

“...it wouldn’t be in my nature, you know. It’s not in our nature, but we’d have to as we get older. Independent I am.” John
“Do you think you would do that if you felt it was getting too much?” Interviewer

“Yeah, not yet though we don’t. Another 10 years perhaps.”

John

“Another 10 years when you, how old will that be, then?”

Interviewer

“I’ll be 98 then.” John

John and Dot were also a very loving couple with a close relationship; their partnership strengthened their ability to cope.

11.4 Targeted support from specialist HF nurses: “Heart nurse has been brilliant”

All the participants in the present study had received assistance from a community-based specialist HF nurse (HFN), and the carers consistently reported the positive impact this service had on their caring experience. The nurse was seen as a pivotal point of contact for practical and psychological interventions.

When asked about how he viewed the role of the HFN, Brian described the functions she fulfilled.

“yeah, we got all the stuff from, again Jane (HFN) organised that, from Red Cross, so we got her a seat for in the shower, with Jane’s (HFN) intervention we were moving things about a bit to try and make it better. No, it was all down to HFN. Yeah, she (HFN) then got in touch with the occupational health people and they came out within days. And they assessed what we needed and then within days again, the stuff arrived. But it make life quite easier.” Brian

In this case, the HFN was proactive in recognising the equipment needs of the patient, and she took accountability for coordinating supportive services. For Brian, what was important was the help she offered helped him manage his wife’s HF symptoms and in doing so ‘*make it better*’ for his wife at the end of her life.

When Belinda spoke about the experiences of the HFN, she emphasised the importance of the emotional support the nurse offered.

“...having spoken to ... HFN this morning she is going leave her, she was leaving her number so if ever – and I say I just had a chat with her because I wasn’t sure whether to bother the doctors with what’s going off at the moment ... so it was good to have had a talk to her this morning.” Belinda

The use of the phrase ‘*had a chat*’ implied an informal conversation conducted in an easy and familiar manner; this was testimony to the communication skills of the HFN that engendered an informality enabling the carer to feel that she was readily available to address queries and concerns. The significance of communication in the HFN and carer relationship was also demonstrated in Helen’s interview.

“Jamie (HFN) was brilliant, I can’t fault, and even if it wasn’t her job, like I say I felt I could contact her and she’d perhaps know or could ask somebody for me. Apart from Jamie (HFN), it was very rare anybody let you know anything, whereas I’d got quite a good relationship with Jamie. If I couldn’t get when she was there, she would ring me when she’d got a minute later in the day to say I’ve been to your grandma today, she didn’t look too bad, I’ve done this, I’ve done that and I’ve informed such and such.” Helen

The HFN was the coordinator of the care; when the care needs were beyond the remit of the HFN role, she took responsibility for finding out what Helen as the carer required. It was vital for Helen to have a point of contact who could find out the answers, and this is how she perceived her HFN. It was important for her to feel she was in control of her grandmother’s care; this was facilitated by information sharing between her and the HFN as the nurse ensured she made regular contact. There appeared to be a mutual respect and connection between Helen and the HFN which was highlighted when she says ‘*she was brilliant*’.

Simon and his wife received support from the same HFN, and a similar connection was evident in Simon's account.

"...heart nurse has been brilliant ... you know, and she's sort of on our level because she's a similar age, well, maybe she's younger, don't tell her I said that. But no, she's, I think, and if you keep the same nurses I think that's important because you tend to build up a friendship sort of thing in a way and understanding. She understands the situation." Simon

Simon alluded to the fact that the HFN was a similar age to him and how he found this helpful as a younger carer; there was a sense that she recognised his needs as she was his peer. Simon talked in his interview about how people don't understand younger carers' needs as HF as a condition is associated with older people.

Simon considered the HFN as a continuous point of contact at an uncertain time; this continuity in care was essential as it allowed the carer to develop a rapport with one person rather than receiving services that were disjointed and disparate, which had been his experience prior to the involvement of the HFN.

John, Patricia and Sue all found the guidance and information from the HFN reassuring. These participants viewed the HFN as the first point of contact and an accessible means of help. The fact that the HFN provided home visits was seen as particularly significant for Patricia.

"HFN would always come to house if he's got a problem. She said if you ever had, because she said, I always come to the house to sort you out. You know, for six months it was horrendous, it was going somewhere two or three times a week, it was how the surgery or whatever, but we think HFN is absolutely brilliant." Patricia

"She's brilliant. Absolutely everything. She checks everything, she checks his legs, she checks everything, all his tablets, changes his tablets. He's just changed another one because it's not agreeing with his kidneys or something. So she rings us up and says do this and do that; she's absolutely brilliant. But basically I ring her up with any queries, oh yes, and she's

always at the end of a phone. I've got 100% support. I know exactly what I'm doing." Patricia

The use of the word *'horrendous'* was linked to previously having to attend HF clinics two to three times a week at the hospital; the HFN relieved this pressure as she was able to provide specialist support in the home. It was critical that the support was inclusive of the pharmacological and non-pharmacological management of the patient and, for Patricia, this reflected the importance of the specialist status of the HFN. The expertise of the HFN enabled the carer to describe having *'100% support'* which facilitated carer control and a sense they were working in partnership.

Knowing that she could always call the HFN was comforting for Patricia, and this was also evident in John's account.

"It's reassuring me greatly. Well, I know she's got her eye on ... I know that she's in good hands, I can ring HFN any day, any time, any weekend or anything." John

John's words *'in good hands'* implied he considered the HFN as offering competent, compassionate and safe care. This resonated in Sue's extract of her experience of the HFN.

"We have Haley come in, the HFN, she's fantastic. We have Medicare who does readings every day and that goes through to them. So they ring us every day regardless, just to check if he's okay. And if I don't think he's okay because obviously I've learned to know what his readings are, then I will tell them to contact HFN and she contacts me. And she either comes out or sends out the right person or tells me to contact the GP. So we have got a big care support team which is good." Sue

Sue viewed the HFN as pivotal in triaging their needs and ensuring they were referred to the appropriate person or service.

Despite Stella's many difficulties in caring for her husband, she was overwhelmingly positive in her experience of the HFN.

"So we had the heart nurse out, a young man called Abbi. Absolutely, they're fantastic, they are absolutely fantastic. Without him in the first place coming out and assessing him and talking us through what we could get, wouldn't have got anything." Stella

This was the first point in the interview that Stella described something positive in her experience; she saw the HFN as the trigger to help. She spoke as though this was the first time anybody acknowledged her needs as a carer.

*"Yes, he [HFN] talked to me last time to see as well like, you know, how it affects me and am I coping with, do I need any help. My thing is with heart nurse and that, I'm there. I'm sitting there. I let my husband do the talking, but I'm there, I want to know what's going on. Yeah, I think you've got to be involved. You've got to be involved. That's what it's all about, ain't it?"
Stella*

Stella appeared to be referring to her presence as a carer when she said '*I'm there*'; professionals may not acknowledge the importance of this presence but, in this case, the HFN saw and heard the carer.

11.5 Improving the caring experience: "you need reassurance that people are going to take responsibility"

When asked for their thoughts about what would have improved their caring experience, participants gave varied responses. Only four carers responded that they felt they would have benefited from respite care services, and a few carers expressed reservations at accessing such support. Here Brian talked about his thoughts of what he would have liked in the way of help in caring for his wife in the last few weeks of her life.

“So would there have been anything that would have helped you at those times, do you think?” Interviewer

“Yeah, probably a day off now and again. Somebody coming in to look after her and saying look, just clear off for an hour or two, yeah.” Brian

“Would you have a preference for who that would be?” Interviewer

“Well, I don’t know, because a friend of ours, her husband was dying at a similar time, and she got some support from the hospice I think it was.” Brian

“So did anyone actually ever offer you any?” Interviewer

“No, it was never mentioned at all. Yes, because again, I suppose somebody could have come in on the Sunday and I could have gone off and had a chat with my mates for a bit, if only for a couple of hours sort of thing. Say once a month would have been helpful, could have carried on that bit of sort of social life. In hindsight, yes, it would have been nice if somebody had come in just for a few hours and said you know, just clear off and have a chill for a bit, just to give us a bit of a break.” Brian

Brian implied that he needed access to respite service on an impromptu basis in that respite should be readily available when he requested it: a proactive and responsive service. For Brian, the benefits of respite would have given him the capacity to access social networks thus highlighting the importance of sustaining social networks and contact with friends.

Clare and Sue proposed that access to respite support would offer reassurance when they were away for short periods of time. At the time of the interviews, both Clare and Sue were planning holidays, and this was causing anxiety for them.

“Yes, this is how, yeah, because I feel now, as she’s getting older, we go away, I feel that we, you know, it would be helpful if somebody would go in there. It’s just for my, our peace of mind. Yeah, that would be good.” Clare

“Knowing that he’s got somebody here with him 24/7. So knowing that somebody can be here with him, I know he’s going to be fine but ...” Sue

Similar to Brian, they expressed a desire for proactive respite care on an ad hoc basis; they faced the dilemma of recognising that a break from caring was necessary but without the knowledge that the person they were caring for was being looked after, the benefits of the break would be undermined.

Clearly, respite is critical to assist carers to continue and to promote positive emotional wellbeing. However, importantly for Belinda, the quality of the respite care was crucial to her decision to access services.

“... social services have told me that any time, when we wanted this extra care because of how she is they came out and they said any time you want a break, just give us a bit of notice, you know, it’s not a problem, we’ll do it for you and all that. But it’s, I know I wouldn’t be able to rest.” Belinda

Evidently access to respite care was not an issue for Belinda, but her reluctance to use such services was associated with the service provision; there was a sense in her dialogue that she would feel uneasy about the quality of the care. Thus there would be no relief from respite; rather it would lead to disquiet as described here.

“Because you come back to more of a disaster than you went away from, don’t you? So that’s what you need reassurance on. You need reassurance that people are going to take responsibility, isn’t it?” Belinda

The use of the word ‘*disaster*’ demonstrates the strength of her feelings that the consequences of poor care could have adverse outcomes for her mother. Thus Belinda required assurance that the quality of care given to her mother would be of a high standard, which was emphasised by the repeated use of the word ‘*reassurance*’.

During the interviews, participants were asked their thoughts on a Carer Support Plan (CSP) initiative. They were informed that the CSP was a proposed instrument which outlines support services available and asks the carer to tell the HFN about support they felt they may need if they began to feel they were struggling in the caring role. This may include additional help from friends or family, respite care for the husband/wife/mother/father or increased support from services. The concept of the CSP was positively received by the participants, and what was particularly welcomed was proactive access to information.

“No, definitely. It is required (Carer Support Plan). Yes, yeah, because there isn’t, you know there isn’t really anywhere that you can get that. There’s carers’ groups, but when you’re working and everything, it’s not the same for getting the information, is it?” Belinda

“Yeah, would do that. That’d be brilliant.” Helen

The lack of information about support available and fragmentation in service provision had been persistently highlighted as a concern for carers throughout the study findings. Belinda raised the issue of the challenges facing working carers in relation to accessing information and the inappropriateness of support groups for carers in this situation. Stella reported receiving limited information when her husband was sent home from hospital, leading to lack of insight about how they could cope at home and who could help them.

“Exactly, that’s spot on, that’s what we were saying (about the CSP). Both of us thinks somebody should have talked to us properly about him coming home, what to expect when he comes home and if we needed help, where we would go. I mean, we’ve found out more through a quirky little, with changing from a house to a bungalow, with the local council that a welfare rights person came to see us, but that were just out of the blue. That would have been helpful coming out of hospital.” Stella

The use of the word *'quirky'* as regards the sources of information and support implies that this came about from unusual avenues; in Stella's case this was triggered by moving house, and it was social care rather than health care that initiated support and shared information.

"Just more information, I think, and knowing what to do and where to go and, yeah, just a bit more general – if people would have kept you informed of what was going off and what was happening I think we could have coped better. Yeah, and that's what makes it more difficult. If people communicated better, things would run a bit smoother, I think." Helen

Maureen talked about the gaps in information when coming home from hospital but raised the issue of how the information is communicated to people.

"... sometimes I think it's after you come home that you could do with someone coming and saying, to just check on you, because you don't know what you're doing really, it's just hit and miss, to explain to you what you've got to try and do ... I mean, they gave us books to read, papers, etc., but Bill ain't a reader. But I ask, if I don't know anything, I'm one of these that will ask; a lot of old people won't ask. But there isn't enough out in the community to let people know that won't ask questions." Maureen

Two aspects relating to the suggestion of a CSP were important for Maureen. As her husband did not like reading, written information alone would not have been beneficial; what they required was face-to-face contact that offered clarification on what they should expect. This clarification, as with Stella and Helen, would serve to enhance the transparency in the disease trajectory and thus reduce uncertainty. Maureen recognised that she was confident to ask for help; she acted as an advocate to initiate help, but for other carers she felt it was *'hit and miss'* rather than a structured proactive approach to ensure the information was offered in an accessible and appropriate format.

Marie, in contrast, proposed that whilst the suggestion of a CSP was a positive concept, its potential was limited due to the unpredictability of HF.

“...the problem is you don't know when that crisis is going to happen. I mean he's got, he's fine now. Now when he had the diarrhoea and one thing and another, it just came on just like that. Now if I'd rung somebody to say, can I have some help, they'd say, well, we haven't got anybody at the moment but we might be able to give you somebody in 24 hours.” Marie

Marie was unable to plan proactively the sort of services she may require as the condition of her husband fluctuated daily. She appeared irritated by the fact that the services could not operate in a rapid, reactive manner; consequently she did not bother to ask for help and just coped on her own. However, what was imperative for Marie was to have contact with someone who understood what she was experiencing, a network that was readily available whenever you required the support.

“It would be nice if they had a contact number which you could ring at any time.” Marie

Sue considered support helpful if the person understood what the carer was experiencing.

“I think it would be a good idea like I said, for people like me that's old at doing it, to speak to the newbies, just to tell them that there are people out there for us. Because in the beginning without telling me about CMA, because I used to contact and we used to talk at night obviously when everyone was asleep, how's your day been? And I'd be like, god, I feel awful, I don't want to moan but, she's like, well, we have to moan, we have to moan to each other and then you don't moan at them. And that's what we used to do, we used to be like, I've had an awful day, I've done nothing but moan today and I'm sick of it, but I don't want to feel like that. And you'd be like, yeah, but it's normal to feel like that. People need to know.” Sue

Sue wanted contact with a person facing the same situation who could verify and validate *'it's normal'* to experience frustrations and the need to complain on occasions. Sue repeated the word *'moan'* throughout this quotation, which emphasises that, in her early days of caring, support from peers enabled her to feel comfortable to share her negative feelings about the situation and how it was impacting on her as a person. By sharing and offloading to peers, Sue asserted that it helped her not complain to her husband, who she was caring for; it was a positive outlet. For Sue this outlet came via the Cardiomyopathy Association website on a carer webpage; in this manner, it was accessible and responsive. Significantly, as Sue had been caring for her husband for several years, she now viewed herself as *'old'* in the manner of being an *'old at doing it'*, namely caring and now she could share her experiences and offer guidance to new carers as she had become an expert.

In the closing minutes of Sue's interview, she wanted to raise a key issue that she felt was crucial to improve the caring experience, namely the necessity of hearing the carer's voice and seeing their presence, which resonates in her words.

"Yeah, it was all, everybody's focused on Mark. Everybody forgets the carers that are doing it. So obviously giving Mark support, all the health professionals are giving Mark support, but if somebody would have sat down with me for half an hour and said, look, this is what we can do for you, we can help you in this way, we can help you in that way, I think that would have been appreciated." Sue

11.6 Chapter summary

This theme explored carers' experience of support and illustrated a number of key issues. Several participants encountered fragmented access to information and lack of communication between themselves and service providers, with some carers describing 'battling' to get the help they needed. Communication at the transition between hospital and home was a particular concern for

participants. The quality of care provided by some health service providers was inadequate with patients being viewed as tasks rather than adopting a person-centred approach to care needs and positively acknowledging the safety, comfort and wellbeing of the individual. Conversely, social care and voluntary services were highly praised for the individualised care they provided and, in particular, continuity in the formal carers was viewed as important. In order to feel confident and comfortable in accessing respite services, carers needed assurance that the quality of care was of a high standard. Peer support was viewed as a positive means of support, but this needed to be provided by carers in similar circumstances in order to affirm the issues they were experiencing. The internet and use of social media was a pragmatic means of accessing support.

The role of the HFN was unanimously considered to be a positive and beneficial role; once the service was instigated, the HFN was critical in coordinating care and a linchpin to supporting both the patient and carer. Carers' desired access to timely, proactive information and support and the proposal of a CSP was considered as an acceptable and appropriate means of facilitating this.

Chapter Twelve: Discussion of the study findings

The chapter begins by presenting an in-depth critique of key findings from the analysis of the data with critical discussion of contributions to existing theoretical knowledge. There follows the methodological challenges encountered, and the strengths and limitations of the study are outlined. The contribution to the knowledge of carers' experiences of supporting patients with advanced HF is presented with consideration to the implications of the findings for policy and practice. Directions for future research with this carer population are outlined and the chapter concludes with reflections on the research process and thoughts relating to building on the body of knowledge from the thesis.

12.1 Key findings

The aim of this study was to use a mixed methods approach to explore factors influential to carers' perceptions of caring, appropriateness of a Carer Support Plan (CSP) initiative and measure QOL in carers supporting a patient with advanced HF.

The quantitative survey addressed the following research questions:

What are the levels of physical, psychological, social and spiritual wellbeing for carers of patients with advanced heart failure?

How do levels of wellbeing vary by types of carer?

The findings indicated variability in carer wellbeing associated with relationships, gender and time spent caring. Furthermore spiritual wellbeing, capturing positive aspects of caring was evident in this study population.

The qualitative interviews explored the following questions:

What are carers' perceptions of supporting a patient with advanced heart failure?

What are positive and negative influences on carers' QOL?

Is a Carer Support Plan an acceptable and feasible tool to provide information to this carer population?

Findings emerging from the data showed that the information needs of carers of HF patients were not adequately met; this was particularly the case in younger carers who felt they needed more tailored information and support. However, the role of the HFN was important in mitigating information needs, and findings showed many positive elements of caring including new knowledge gained and the increasing closeness the dyad experience in their daily lives. These findings are discussed in detail in the context of the literature below.

12.1.2 Contributions to theoretical knowledge of carers of patients with advanced HF

12.1.3 Dealing with uncertainty when caring for HF patients

A key finding from this study indicated that the unpredictability associated with HF enhanced the difficulties carers encountered. Murray et al. (2017) recommend services offer palliative care from point of diagnosis onwards to improve the quality of life of patients and their families through timely identification of physical, psychosocial and spiritual needs to facilitate person-centred planning of care. The authors assert that proactive planning for exacerbations should be inclusive of multidimensional needs, information and effective communication of care management plans and patient preferences regularly and routinely discussed with all health care providers. However, the findings of the present study demonstrate complexities of implementing such an ethos in the HF populations which is particularly related to the unpredictable disease trajectory, difficulties associated with prognostication and when to offer information.

Many carers in this study described dealing with the unpredictability of the patients' condition by living day to day. Whilst they demonstrated insight into the

poor prognosis, most participants talked about taking a day at a time without wanting to look too far into the future. This strategy appeared to help them to avoid predicting what the next few weeks may bring because they had previously encountered the unpredictability of acute exacerbations. One participant showed the complexity of unpredictability when speaking about a cardiac device intended to relieve symptoms; however, the device did not work and the patient's condition deteriorated. Thus it seems, in this study, participants avoided trying to predict what would unfold over the next few weeks and months but sustained their resilience by dealing with each day at a time.

This finding reflects Mishel's (1999) theory that, in the context of chronic illness, dealing with uncertainty is incorporated into everyday life. Three key components of an illness cause uncertainty: the severity of the illness, erratic typology of the symptoms and ambiguity of symptoms, which clearly apply to HF. A management model for uncertainty includes a strategy of living one day at a time and focusing on normalising life within the boundaries of a chronic illness (Mishel, 1999). The normalising of uncertainty becomes part of everyday life, which is reflected in this study by carers' comments alluding to living a day at a time.

Despite capacity to encompass unpredictability into their everyday lives, it was also evident in the findings of this study that the unpredictability of the disease trajectory was accompanied with feeling out of control leading to negative consequences for carer quality of life. Participants described dealing with the situation in a '*hit and miss manner*', navigating services as a '*minefield*' and were faced with the consequences of a life-limiting prognosis. To address unpredictability and increase control when living with chronic illness, patients and carers seek out information as a lack of information has been linked to increased uncertainty in chronic illness (Mishel, 1999).

The negative impact of unpredictability and lack of control is corroborated by the quantitative findings relating to psychological wellbeing as shown in the present study population. As outlined in chapter three, feelings of being overwhelmed are commonly reported in the research literature relating to the carer population. This was evident in the present study; 14 (24.6%) of participants agreed they were overwhelmed, and 8 (14%) strongly agreed they were overwhelmed.

Additionally a high proportion of the participants reported feeling emotionally strained; 26 (45%) agreed and 11 (19.3%) strongly agreed that they were emotionally strained. Furthermore considering the statistically significant correlation between living arrangements and how long the person had been caring on overall QOL, physical wellbeing and psychological wellbeing, when dealing with an unpredictable disease trajectory, the accumulative effect over several years poses a risk to carer psychological wellbeing.

However, a dichotomy exists when considering uncertainty in HF and how to apply a principle of early palliative care as recommended by Murray et al. (2017). As shown in the findings, many carers coped by living day to day but also described a need for timely information to help them cope. Thus if a palliative care ethos is to be embedded in HF care delivery to support patient and carers, it is necessary to consider how information is provided in a proactive manner in order to meet the multidimensional needs of the patient-carer dyad. As outlined in chapter three, there is a recurrent issue associated with the principle of early palliative care in the context of life-limiting conditions. Despite initiatives to improve communication with both patients and carers, for example the Gold Standards Framework (2006), this study demonstrated persistent practicalities in embedding a palliative care philosophy in a timely manner. Barnes et al. (2006) found that health care professionals working with HF patients and their carers tried to improve communication by personalising the information to the individual's needs and to consider the nature and level of information the person and their carer may want to hear. Dionne-Odom et al. (2014) evaluated the effectiveness of cancer palliative care intervention when used with HF patients and their carers. The evaluation demonstrated that the difficulty with prognostication made it difficult to implement the model of care. The authors concluded that many patients and carers did not recognise the poor prognosis of HF and, as a consequence, discussions relating to palliative care did not occur until late in the disease trajectory. Whilst Murray et al. (2017) advocate that information and discussions relating to expectations of what may happen in the future should be instigated early, the authors acknowledge that this process, in being initiated early, differs from the process of breaking bad news. The dialogue must unfold and evolve relating to the patient's condition, and this approach demands a tailored, person-centred approach to the delivery

of information. The evidence from this thesis indicates the HFN is well placed to offer this model of care to carers of HF patients.

12.1.4 Information needs

A key finding from this study indicated that the information needs of carers of HF patients were not adequately met. There was a particular risk of a breakdown in information provision during the transition between hospital and home. Participants articulated that when the person they were caring for came home they were often unaware of the services available to them and they were left alone to deal with the practicalities of daily life. Most carers in the study had to actively seek out information relating to the condition and support services available. Findings from the survey also demonstrated that 38% of participants were overwhelmed in their caring role. It could be proposed that providing information in a timely manner would reduce such feelings, and carers expressed a desire for clear information to assist them to anticipate what they should expect in order to reduce the uncertainty.

Hanratty et al. (2011) compared the experiences of patients with cancer, HF, stroke and neurological conditions in relation to receiving the news of their diagnosis. The study found that whilst most patients received information about the condition and its treatment early in the disease trajectory, people with HF had the diagnosis and prognosis discussed to a much lesser degree. HF patients did not receive a full explanation at diagnosis and did not tend to access the information they needed to understand their condition. This lack of information is replicated in the carer population. For example, Doherty et al. (2016) conducted a narrative review of carers' needs in the context of advanced HF. Carers identified the requirement of increased information early in the disease pathway and desired the information to be tailored to their individual circumstances and condition of the person they were caring for. As regards the information provided by health care professionals, carers reported they wanted information to be delivered in a manner they could understand without the use of medical jargon (Doherty et al., 2016). This supports the

theory of illness uncertainty as presented by Mishel (1999) in section 12.1.3 which suggested that information should be provided at a level desired by the person.

Hupcey et al. (2011) conducted a qualitative study with 45 spousal carers of HF patients receiving support from specialist HF clinics in the USA. Their findings indicated that all participants had unmet information needs, including those who considered themselves as expert carers. Importantly, the findings of the study showed how information needs are continuous due to the progressive nature of HF; carers are required to manage new medications and/or devices as the patient's condition fluctuates. Interestingly, participants in the Hupcey et al. (2011) study described how during an exacerbation of the condition they required information that focused on what they had to deal with in that instance rather than being overwhelmed with too much information about what might be to come. When the patients stabilised, carers recounted how they could then focus on future plans including medications and dietary management (Hupcey et al., 2011). The study affirms the findings from the present study that the information needs of carers fluctuate in a similar manner to the disease trajectory. Carers require both proactive and personalised information.

Findings from this thesis highlighted issues associated with the transition between secondary care and primary care. For some participants, crucial assistance and information was obtained from social care and the voluntary sector early in the trajectory in an absence of specialist services. Whilst the participants found this support valuable, access to these services was ad hoc and illustrated how there was confusion about the accountability of differing services. Participants talked about having to battle to get information and access to services they needed. This finding mirrors the findings of Gott et al. (2007), which revealed that there was lack of information about how to access social services and what provision services offered. Additionally, the participants in the Gott et al. (2007) study reported difficulties in making contact with social care providers. Kitko and Hupcey (2013) conducted a study based in Pennsylvania with 18 patient-carer dyads; a common finding was the difficulties encountered when 'navigating the system'. The system in the study referred to complex health care systems and welfare benefits services; negotiating with a range of service providers was described by Kitko and Hupcey (2013) as a

source of great angst for carers. These studies and the findings of the present study confirm the earlier research by Murray et al. (2002) indicating that people with HF experience poorer coordination of health and social care services in comparison to other life-limiting illness trajectories.

The concept of a CSP (Appendix Three) initiative was welcomed by the participants in this study as an effective way to provide proactive information about supportive services. The CSP is intended to outline to carers a range of services available in the locality in order to provide the necessary information but also to offer carers the opportunity to access services when they choose to do so, depending on their individual needs. It is important to indicate that the CSP provides information about services that are already locally available but, as indicated from the study data, carers are commonly not aware of. It was evident in this study that carers were unclear about the differing roles of service providers and at times recognised the limitation of the capacity of some care providers. One participant spoke about how services can only do what is within their remit, and for the family this may not be enough. Quantitative findings showed 39% of the study population agreed or strongly agreed that they felt overwhelmed with the responsibility of caring and 45% agreed or strongly agreed they were emotionally exhausted. To improve carer experience and reduce associated feelings of being overwhelmed and anxiety, the findings of this study demonstrate the importance of tailored information that is responsive to the fluctuating needs of carers throughout the disease trajectory. Integral to the CSP initiative is recognition that carers benefit from a palliative care ethos early in their caring experience. Murray et al. (2017) emphasise that early conversations are crucial to assist patients and carers consider what might happen in the future and what might help. The CSP could assist to facilitate such conversations and aim to ensure that carers are informed about what can help if or when they encounter a situation when they may not be able to cope.

12.1.5 Younger carers

HF is typically associated with the older population, and commonly older spousal carers provide support (van Riet et al., 2016). In the present study, however, it was evident that consideration needs to be given to the younger carer population offering assistance to spouses, parents or grandparents with HF. Five of the participants in the study were under the age of 50, with the youngest being aged 37. Whilst these participants reported similar issues to older carers in the study, they also raised important considerations of the different issues they experienced

Younger carers receiving the diagnosis of HF face living with the implication of the condition being 'lifelong'; this impacted on their physical and emotional health with social and financial implications. Yet despite these difficulties younger carers viewed their role as fundamental to their relationship, something they would do without question and unconditionally. As younger carers, the perspective was that their situation had become ordinary for their family and had re-established the focus within their relationship; their old life was left behind.

Young spousal carers described dealing with an interrupted life course as difficult but, as previously mentioned, considered their circumstances as fundamental to their relationship. Nolan et al. (1996) refers to this as 'reconstructive care' which builds on the existing relationship to create a new dynamic to recognise the new roles required. In the present study, living as a carer became the normality of their daily lives, a new chapter in their relationship. In this manner, the study findings reflected the work of Barnes (2006) with family carers which demonstrated caring was accepted as part of ordinary life; despite the difficulties encountered, carers' lives are interwoven with an awareness of and concerns about family members.

Frustrations of participants were associated with information and support services and how these did not consider the needs of younger carers. Doherty et al. (2016) proposed that research evidence indicates a need for information

to be fitting for the patient and the stage of the HF. In the absence of such provision, in the present study younger spousal carers actively sought out information relevant to them and their family via alternative networks, for example social media. Participants felt that HF was commonly associated with older people, and therefore there was a lack of understanding from friends and family of the nature of HF in younger people. One participant was frustrated that there was a lack of public information and awareness about the condition and compared the public perception of a cancer diagnosis to that of an HF diagnosis. Participants were saddened that people did not understand that the diagnosis was life-limiting and lifelong and lacked understanding of the implications of this for younger people and their families living with the condition. Thus the participants used social media including cardiomyopathy forums to access peer support and information that was fitting to their particular situation. It could be proposed that use of social media by participants in the present study addressed issues of social isolation in younger carers. Quantitative findings demonstrated that 29.8% agreed and 8.8% strongly agreed with feeling socially isolated. The importance of social media in helping younger carers link to information and peer support was evident in the interviews with some of the younger participants in the present study. A systematic review of the usefulness of social media in health communication conducted by Moorhead et al. (2013) demonstrated this mode of communicating increased interactions with others in a similar situation, and provided accessible and tailored information and peer, social and emotional support. Social media has been shown to be a useful means of conveying information and support in other chronic conditions affecting younger people and their carers. Muhammed et al. (2014) described an initiative in which patients and carers developed an online support group for people living with chronic kidney disease. A voluntary Facebook group was developed by two patients and one carer and currently has an international following with over 5,000 members. The group offer the opportunity of 'real time' lived experiences, alongside online education and updates on research (Muhammed et al., 2014). To date, the Facebook page has been shown to help patients and carers access information relating to chronic kidney disease including coping, wellbeing and social care.

Similarly a Facebook initiative was developed in Australia for people and their families living with young onset dementia. Craig and Strivens (2016) explored the support available from the Young Onset Dementia Support Group community page. Whilst the research focused on patients, it is of relevance as these patients faced similar challenges to the younger participants in the present study. They described lack of access to age-appropriate support, higher levels of unmet needs and financial responsibilities including loss of employment and mortgages. Craig and Strivens (2016) reported the community page has 900 international followers, with 44% of followers in the 35-54-year-old age range. Users of the Facebook page reported the forum provided opportunity for raising awareness, support and expression of concerns, to have a voice beyond close and reducing networks; for carers it was an opportunity to engage with the perspectives of other people and their carers of living with dementia (Craig and Strivens, 2016). To provide tailored information in a proactive, accessible manner, it seems that social media is a conduit worthy of further research in the HF carer population. I think it is particularly necessary to consider this in the younger adult caregiver population to meet existing unmet needs and to provide age-appropriate support, information and access to people living in similar circumstances.

Additionally, the HFN was thought to demonstrate understanding, and younger carers considered the nurse to be a peer who demonstrated empathy and insight into the complexity of the situation. Again, this contrasts with the experience of the carers in the Gusdal et al (2016) study, who reported a lack of opportunity to talk to health professionals about the emotional and relational consequences of HF.

Both the younger spousal carers in this study had young families, and this added to the complexity of their situations. The participants experienced financial difficulties due to reduced capacity to work and desired information on financial support they could access. The findings of the study showed one carer received financial information in an opportunistic manner through a voluntary service for drug users; the other carer had resorted to doorstep loan providers when she was forced to stop work. As stated, there is limited research literature relating to younger carers in the context of HF, but the study undertaken by Kimbell et al. (2015) with patients and carers living with advanced liver failure

included younger carers. They reported similar findings to the present study as regards employment, the inability of the patient to work and the subsequent financial pressures this caused.

They did not engage with local support groups as they perceived people that attended the groups were older than them with differing personal circumstances.

In the same manner as the adult child carers in the Retrum et al. (2013) study, younger spousal carers also desired practical information tailored to their needs that could help them with physical tasks. This highlights how assumptions should not be made that younger carers do not need assistance with physical tasks based on the likelihood that they are fitter than older carers.

Daughters and a granddaughter providing support similarly described managing work, families and caring commitments causing great difficulties. As with young spousal carers, these participants sought practical assistance, but additionally they described feelings of expectation that in turn led to feelings of guilt. One daughter who visited her mother every day described how, whilst she was physically exhausted, it was easier to visit than cope with the emotional guilt she felt if she had not visited. Another daughter similarly talked about the expectation that she should go to her mother's several times a day with shopping that her mother had forgotten to ask for. This offers insight into the gender expectations of daughters and granddaughters. These findings add to those of Williams et al.'s (2017) explorations of gender in end-of-life care; as in the present study, female participants spoke of feeling guilty about putting their needs before their mothers'. The daughters and granddaughter in this study, as previously stated, spoke of a need to show that their relative had their personal care needs dealt with in a dignified manner as failing to do so would reflect on them poorly. This affirms the findings of Williams et al. (2017), whose participants described desiring to fulfil their duty as a good daughter. Interestingly however in this study population female carers had better spiritual wellbeing than male carers. The items in the FAMQOL spiritual domain measures positive outcomes, namely caring adds purpose or mission to my life, adds to my feelings of inner strength, adds to my feelings of inner peace and gives meaning to my life. As shown in the quantitative findings in chapter seven,

male carers expressed lower spiritual wellbeing. Thus whilst consideration is required as to the high expectations daughters and granddaughters may place upon themselves further investigation is needed as to why, despite these expectations, female carers may gain more satisfaction than male carers.

The findings of the present study add new knowledge to the understanding of differing challenges facing younger carers, both spousal and adult children, providing care. Younger carers desire access to information that is tailored to their situation with recognition of the differing expectations they fulfil when compared to older carers, including recognition of financial concerns. Peer support, access to dedicated benefits advice and use of social media should be considered as models to provide support and signpost to information for this group of carers. Over the next few years, younger people will be working longer due to increasing retirement age, and commonly families do not live in close proximity due to changes in the societal framework. It is timely therefore to reflect on how this will impact on the expectations of younger carers in the context of HF. Changes to health and social care provision requires increased emphasis to be placed on informal carers providing support in the community. Whilst research with carers of HF patients indicates the difficulties and complexities associated with this, overwhelmingly these studies have focused on carers aged 60 and above (Doherty et al., 2016).

12.1.6 The role of community-based specialist HF nurses

The present study explored positive and negative influences on carers' perception of being a carer for a patient with advanced HF and how the carer experience can be improved. As such it is one of the first studies highlighting the role of HFNs in relation to the support they offer carers. To date, evidence-based research exploring the impact of HFN services has focused on patient outcomes (Takeda et al., 2012, Holland et al., 2012). Findings from the thesis add to this existing evidence base by demonstrating the importance of the HFN role in helping carers cope with their responsibilities.

When the patient-carer dyads interviewed were receiving the support of the community HFN, the participants overwhelmingly reported a positive experience

of the support provided. This mirrors the positive patient experiences of the HFN service as outlined in chapter three, section 3.4.1 (Takeda et al.,2012,Jolly, 2002;). Carers in the present study viewed the HFN as a coordinator of care, able to provide physical and psychosocial interventions to improve the patient and their own quality of life. In doing so, carers felt reassured and reported increased understanding of the condition and how they could manage it on a day-to-day basis. Participants described HFNs being central as a point of contact to whom they could turn to ask for advice and who could offer ongoing support. The quantitative findings illustrated that social isolation was a key issue, with 17 (29.8%) of carers agreeing and 5 (8.8%) strongly agreeing that they felt socially isolated. As the HFN was considered by all carers interviewed as an essential point of contact it could be argued that the nurse offers a way to reduce feelings of isolation in this carer population and in doing so can improve the carer experience.

Additionally the HFN was considered to be a reliable source of information. Importantly, due the model of care delivery, carers had opportunity to develop a rapport with the HFN; this allowed carers to trust the knowledge and expertise of the HFN. Additionally, carers described how the information the HFN offered was appropriate to address their individual circumstances. This was particularly important for the younger carers interviewed who, experienced frustrations with lack of tailored information to meet their specific requirements. The community-based nature of the service meant the nurse was accessible and flexible to meet the questions and queries carers had at differing stages in the patient's illness, with carers recounting how the HFN had reassured them by being readily available when issues arose. Consequently, proactive information provided to meet the specific carer requirements served to help carers live with the uncertainty and unpredictability of the condition.

A qualitative study conducted by Gusdal et al. (2016) in Sweden had a similar aim to this thesis of exploring informal carers' experiences and needs when caring for a person with HF in their own home. Fourteen carers, comprising male and female spouses and daughters, were interviewed in their own homes using semi-structured interviews. The findings of the Gusdal et al.'s (2016) study reported that participants felt they were rarely asked by health care professionals how they were coping and sought an open dialogue about their

supportive needs. However, the HFN service patients and carers were receiving in the Gusdal et al. (2016) study differed to the present study; the HFN was based in an outpatient setting, and patients received routine telephone follow-up three days post discharge. The service also offered a telephone helpline for patients and carers to speak to an HFN. A limitation of the study was that it did not specify the health professionals participants were referring to; however, it did report that carers expressed a need for separate meeting with a nurse with specialist knowledge in HF.

Liljeroos et al. (2014) conducted a qualitative study in Sweden with HF patient-carer dyads to explore their perceived caring needs. Nineteen dyads were interviewed about their perceptions of caring needs in HF. The findings of the study indicated that dyads expressed the need to learn about HF in order to manage everyday life. Participants required continuous information throughout the disease trajectory due to the fluctuating condition of the patient, which meant new questions were often arising (Liljeroos et al., 2014). In order to feel in control and competent, carers required regular information and having someone to directly address their questions to. As in the findings from this thesis, the participants in the Liljeroos et al. (2014) study valued the role of the HFN and similarly to this study alluded to the nurse being the only health professional that took an interest in their wellbeing. However, as in the Gusdal et al. (2016) study, the nurse was only available in an outpatient clinic setting, and once the clinic visits were completed, the carers reported that they had no one to contact.

Pihl et al (2010) conducted a study in Sweden to explore the impact of the physical limitations of HF for the carer. The HFN was based in an outpatient clinic in a hospital setting and participants were recruited to the study by the HFN. Similarly to Gusdal et al. (2016) and Liljeroos et al. (2014), the findings described how carers felt that health care professionals did not focus on their needs but exclusively focused on the needs of the patient; in this way carers were not viewed as a resource.

Pihl et al. (2010) contradicts findings from this thesis, which produced evidence to show carers felt included and involved in the dialogue with the HFN and viewed the HFN as a point of contact they could call on if they had any

concerns. However, an important difference in the HFN services in the present study was that this UK-based study explored the experiences of carers who were receiving a community-based HFN service which offered home visits.

The additional benefits for carers of a community-based HFN service offering home visits were transparent in this thesis. Carers considered the HFN role as offering continuity and consistency to both themselves and the patient. As specialist nurses, HFNs were able to provide advanced clinical and communication skills; carers valued this expertise and the information provided, which enabled them to become knowledgeable care providers. Carers actively engaged with the HFN during the home visits to increase their awareness of the condition and its management.

All the participants in the present study described the HFN as being pivotal to helping them understand the condition and increasing their confidence. As phase one of the present study showed, feelings of being overwhelmed were high in the study population; 14 (24.6%) of participants agreed they were overwhelmed, and 8 (14.0%) strongly agreed they were overwhelmed. Participants were emotionally strained, 26 (45.6%) and 20 (35.1%) carers agreed they felt selfish when considering their own needs. The qualitative findings established that central to the intervention of the HFN was the carer being acknowledged as imperative in supporting and managing the patient. Carers were encouraged to be present during the nurse's visits, and by doing so the HFN demonstrated respect for the interventions of the carer, which is evident when participants described feeling validated and their own requirements being recognised in the discussions they had with the nurse. Thus the involvement of the carer in the dialogue with the HFN offers the opportunity to acknowledge the carer's issues and reduce concerns about feeling selfish about raising their own issues.

The benefits that community-based specialist nurses offer to carers is mirrored in other long-term conditions. Bunn et al. (2016) reviewed the evidence for specialist nursing support for carers of people living with dementia, known as Admiral Nurses. The role of the Admiral Nurse is to offer emotional and psychosocial support to family carers. The review found that carers considered the Admiral Nurse a credible source of information, providing practical support

and access to services. The role was highlighted for its carer-centred approach with evidence that carers embraced a service which focused on them as well as the patient (Bunn et al., 2016). The review concluded that community-based specialist nurse services report high levels of carer satisfaction (Bunn et al., 2016). Kimbell et al. (2015) conducted a qualitative study with 11 carers of people with advanced liver failure. Findings indicated the need for access to a single specialist health care professional to act as care coordinator, bridging the gaps between primary and secondary care and offering proactive management throughout the disease trajectory.

Conversely it could be argued that whilst participants in this study valued the clinical expertise of the HFN, other attributes of the role they appreciated including accessibility, continuity of care and opportunity to develop a rapport may be provided by other community-based roles. This was reflected in some participants' experiences of formal care services highlighted in findings from this thesis.

In an earlier study, Gott et al. (2007) explored the experiences of social services provision amongst an HF population in the UK. As part of the MM study design, qualitative interviews were conducted with 40 patients with HF. Several participants reported they had negative expectations of the quality of social services support based on the experiences of their friends. A key issue in the Gott et al. (2007) study related to a lack of continuity in the home care providers; participants spoke about how they were aware of people who had been receiving care from the same home carers for several years and then without notice the home carer was changed. Additionally, people spoke of home care services that did not listen to the person's needs in relation to their personal care. The findings in the present study differ as the home carers were perceived to go '*above and beyond*' what was required of them. Participants expressed appreciation at the manner in which home carers addressed the individual needs of the person rather than merely following designated tasks they had been allocated. Such an approach is fitting within the ethic of a care model in that it focuses on the particulars of care required in everyday life. Barnes (2012) calls for increased recognition of how an ethic of care philosophy influences the development of practices that respect and are inclusive of those being cared for in the relationship with the care provider. A key component of

the quality care in this study was the continuous relationship with the home carers. One participant spoke positively about the two home carers who looked after her grandmother; these carers offered ongoing support up to the end of the grandmother's life. In this manner, the grandmother and the home carers were able to develop a relationship and rapport that enabled a respectful, reciprocal connection.

Considering the current challenges associated with health service provision in the UK, specialist nurse services are under increasing evaluation as regards cost effectiveness, and there is the requirement to develop services that are fit for purpose to meet the needs of increasing numbers of people living with complex long-term conditions. Whilst there is clear empirical evidence to indicate the benefits of community-based service specialist HFN services for patient outcomes, this thesis proposes the service is additionally imperative to facilitate provision for carers who are supported to cope with the responsibility of caring. By virtue of the service being delivered in the community, with nurses conducting home visits during which the carer is present, this study demonstrates how this specialist role ensures carers are supported and valued as providing competent, high-quality care. Carers desire access to a health professional who offers a supportive, continuing relationship with them (Boyd et al., 2009). The intervention of the HFN experienced by the participants in the thesis embeds these principles and shows the meaningfulness of hearing the carer's voice. Additionally, some participants found formal care services provided opportunity to develop a rapport with the person who was supporting them and their family. For both HFN services and formal care services, the essential element was time to develop a trusting relationship, and carers expressed how ongoing intervention from the same person facilitated this process. Additionally, by visiting patients and carers in their own homes, HFN services and home carers recognised the impact of living with HF within the social fabric of people's lives.

The thesis highlights that within community care a quality that is viewed as imperative is continuity of contact; this was evident in relation to both the HFN and the home carers. I propose that new community-based roles specific to addressing carer needs are developed to complement existing HFN and formal

care services. Further details on this new role are presented in implications for policy and practice in section 12.4.1.

12.1.7 Caring as integral to relationships

As presented in chapter three, the underpinning theoretical models which influenced this study promote an understanding of caring with a focus on the particularities of day-to-day interactions, understanding of care being given and received and the positivity associated with being a carer (Nolan et al., 2003, Barnes, 2012). Caring can bind families and communities together and is integral to the social fabric (Daly and Lewis, 2000). Barnes (2012) proposes caring is fundamental to human nature; as we age and through situations we face during our life course it is likely that we will experience episodes of illness, physical or emotional, during which we will need the support and help of others. For people and their family and friends living with HF as in this study, caring is enduring. A key finding from the present study demonstrated how solidity in the social fabric encircling carers positively influenced the caring experience but advocates that recognition is given to carers with disparate social relationships; these principles are critiqued in the context of this study's findings.

It was apparent that the majority of the participants viewed caring as integral to their relationship with the person they were caring for. In this manner, there was an awareness and recognition of a need to care which reflects the principle of attentiveness (Tronto, 1993). In showing attentiveness Tronto (1993) advocates it is necessary to acknowledge the needs of others. When asked about aspects of caring they found rewarding, attentiveness was apparent in participants' dialogue. Overwhelmingly, participants did not consider taking on a caring role as an additional expectation; rather it was within the components of their relationship. The quantitative findings showed that a proportion of participants found rewards in caring; 40.4% of carers reported that the role added purpose to their lives and 36.8% that it gave meaning to their life. Importantly, attentiveness to care did not apply only within the confines of a family dyad as illustrated by support provided by neighbours. Thus this demonstrates how attentiveness can be instigated by recognition of the needs of those in our communities with whom we have close ties (Barnes, 2012).

Connected to the expression of attentiveness is the ability to suspend one's own goals, ambitions, plans of life and concerns (Tronto, 1993). This was an important consideration in the context of the participants' experiences of feeling out of control and the unpredictability of the HF disease trajectory. In the study conducted by Pihl et al. (2010), findings relating to how the physical limitations of the condition impacted on the daily life of the spouse showed they became accustomed to dealing with problems when they arose instead of worrying about when they may occur. The Gusdal et al. (2016) study also showed participants had an attitude of one day at a time, a '*seize the day*' mentality. Thus evidence indicates carers need the emotional capacity to put their own lives 'on hold'.

Carers' proficiency to manage the interruption in their assumed life course was apparent in the findings from this thesis. For example, participants recounted how they became accustomed to each day being different and no longer anticipated how their lives, in the context of caring for a person with HF, would evolve. Dealing with an interrupted life course, however, differed for individual participants. For several of the participants, it had been necessary for them to make adjustments to their working and home situations to meet the changing circumstances. Three participants interviewed had moved house, and several others described adjusting working hours or giving up work as they were unable to cope with the competing demands. In this way their experiences reflected 'anticipatory care' as described by Nolan et al. (1996) which focuses on anticipating future needs and changing aspects of day-to-day life in the caring dyad to proactively address what may occur in the future. Most participants alluded to valuing the time they had with the person they were caring for, with acknowledgement of the inevitable outcome of HF, albeit difficult to predict when this may occur. Living as a carer became the normality of their daily lives, a new chapter in their relationship.

By accepting a need to care, carers in this study showed the principle of 'responsibility' as described in the ethic of care model. Tronto (1993) defines responsibility as accepting action is required in response to a need. Notably responsibility differs from obligation, in that responsibility is not a pre-determined expectation; rather it is grounded in the special relationship with family and friends (Engster, 2007). It is important to acknowledge that in order

for carers to take on caring responsibilities, a capacity to understand and to be in a position to respond to the needs of the individual must be evident. I propose that responsibility is linked to the principles of responsiveness, trust and respect, and competence within the concept of an ethic of care and will therefore consider these principles together in the context of findings from this study.

Responsibility for caring relates to special relationships with others in society and is integral to societal expectations. In this manner, in being part of a family there is the expectation that older members will be cared for within the family with adult children caring for elderly parents and spouses caring for each other (Tronto, 1993). Engster (2007) extends this responsibility beyond family boundaries to people with whom there is a special kinship and those in a shared close proximity or a social relationship. This is applicable to this study with participants comprising spouses, adult children, best friends and neighbours (see Table 2). As stated, responsibility should not be viewed as the same as obligation; it was evident in this study that the majority of carers offered support because they chose to rather than they were obliged to. They spoke about caring being natural to them and something from which they gained satisfaction. A finding of note was that two participants had taken on additional caring responsibilities for a neighbour and grandchild respectively. Despite the increased demands this placed on their lives, they enjoyed helping, which supports Engster's (2007) principle of kinship in caring in that there is an instinctive desire to care which prompts a feeling of responsibility.

Responsiveness refers to how the person responds to the care given. The principle recognises the risk of inequity and vulnerability in the caring dyad and, in the case of HF, due to physical and emotional limitations of HF, patients are dependent on their carers, both informal and formal (Barnes, 2006., Tronto, 1993). Benner and Wrubel (1989) assert that responsiveness is an essential element of the moral quality in caring; there must be a balance between the needs of the carers and cared for. Similarly Nolan et al. (1996) describe preservative care, which shows equality in the dyad to preserve the dignity, hope and control of the person being cared for. Participants in the Gusdal et al. (2016) study described solidarity in the caring dyad; they cared for one another and took turns in being the carer and cared for. The reciprocity of care allowed

the dyad to have an understanding of each person's perspective. The present study adds to this evidence as participants spoke of working as a team and undertaking daily tasks together. There was recognition by several participants that the person they were caring for tried to do as much as they could for themselves whilst they, as the carer, were watching over them to make sure they were safe. Thus there was a sense of a shared respect and congruence in the relationship with acknowledgement of each person's needs.

Embedded in congruent caring relationships is trust and respect; congruence is considered as a partnership in which there is an understanding of the patient's needs and a mutual consistency as regards the implications of the condition (Retrum et al., 2013). Congruence in the dyad has been shown to have a positive impact on the patient and carer. Nolan et al. (1996) assert carers can view the reconstructed focus within their relationship with the person they are caring for as something which engenders reciprocity and congruence. The importance of the nature and quality of the relationship in the patient-carer dyad rather than practical caring tasks can be correlated to carers' satisfaction (Nolan et al., 1996).

Lyons et al. (2015) examined the individual elements of patient-carer dyads in relation to confidence in managing the condition. In total, 329 dyads participated in the study; participants completed a 6-item Self-Care of HF Index. The findings indicated that the quality of the relationship influenced confidence levels in managing the illness. Lyons et al. (2015) concluded that congruent relationships encompass open communication and ongoing dialogue about the symptoms and in this manner there is shared decision making. The present study demonstrated similar findings with several participants speaking about the trust and respect in the relationship they had with the person they were caring for. Older carers showed acceptance of the support offered as part of the natural progression within their relationship and a partnership. Younger carers, however, also alluded to the fact that the illness had brought them closer together and made their relationships stronger but recognised how it was important to have been in a loving relationship at the beginning of the illness in order to manage the emotional challenges.

The findings of this thesis are mirrored in research relating to dyads in cancer. Li and Loke (2014) conducted a systematic review examining the mutual impact of spousal carer and cancer patient dyads. The review found effective communication within the relationship related to reduced distress and improved adjustment to living with the disease. This was associated with a heightened appreciation of the time together and increased closeness. Couples dealing with breast cancer described struggling through with the help of mutual support, sharing of personal thoughts and concerns. Dyads used the word 'we' to describe their experiences, including the uncertainty and facing the future; to cope, dyads searched for shared meanings and understanding and tried to retain a positive outlook (Li and Loke, 2014). These strategies were evident in this present study and in particular the dialogue of the younger spousal carers who felt they could cope because they were still '*strong*' as a couple despite the consequences of the condition.

Lyons et al. (2015) indicated that social support facilitated increased trust within the patient-carer dyad. The authors proposed that this demonstrates the importance of wider relationships with family, friends and work colleagues in sustaining a positive and congruent caring relationship by patients and carers having trust in one another. The findings of this thesis affirm this; participants alluded to the importance of their family, friends, work colleagues and the interventions of formal services, including the HFN, in facilitating their confidence and competence. In the quantitative phase of the study working or having previously worked showed statistical significance on social wellbeing; carers who were working reported higher levels of social wellbeing (mean 3.37) as compared to carers who had never worked (mean 2.38). It is proposed that this relates to the social contact and associated support networks work colleagues offer. This was evident for one of the younger male carers whose employer provided flexible working in relation to his circumstances but also colleagues assisted in signposting him to counselling services.

For those participants with limited networks they described how they relied on the input of formal service providers to validate their role. Congruence with paid home carers and the voluntary sector services was also shown to be meaningful for this study's participants. As discussed in section 12.1.6, the HFN was trusted and respected by carers, but additionally the high-quality care

provided by some home carers and unpaid volunteers was valued by participants. These experiences show the principle of trust and respect in practice as described by Barnes (2012). Formal care providers considered the needs of the cared for, thus ensuring both the patient and the carer felt worthy of attention and reassured that consideration was given to their individual needs.

Encompassing trust and respect, carers need to feel confident of their competence to deliver what is expected of them. Gardner and Kramer (2009) conducted a qualitative study with 10 patient-carer dyads to explore areas relating to congruence and incongruence; participants included carers of people with end-stage heart disease. Carers reported they felt most difficulties were associated with managing and providing adequate care. Sullivan et al. (2015) explored the needs of carers of people with HF and their concerns as regards their competence and compassion. Sixty-three carers were interviewed, the majority of whom were spousal carers; findings indicated carers' competence concerns were their ability to deal with the needs of the patient at home. Family carers wanted reassurance that they were safely performing tasks and sought this assurance from health professionals. Participants in the Sullivan et al. (2015) study wanted a dialogue with a 'knowledgeable other', but this was lacking, and the authors call for consideration of a nurse-led intervention to answer specific questions, to ease stress and build confidence and engender trust in the dyad.

Importantly, the present study demonstrated the role of the HFN in facilitating carer competence and confidence which assisted trust and respect between the carers and cared for. As stated previously, the HFN was considered to offer expertise as regards the condition and networks to additional supportive services. Considering competence in the context of caring, the thesis showed interesting perspectives from carers as regards the manner in which they engaged with caring tasks. Some participants described how they managed the day-to-day life as a carer in a similar way they would manage a job or project. Two participants utilised their previous health care knowledge and one participant spoke about using project management skills as an experienced engineer to help prioritise care management. Others positively embraced the challenge of acquiring new knowledge and skills, with the HFN considered a

conduit to competence. The quantitative data affirms these findings in that carers who had previously worked in paid employment expressed higher overall FAMQOL QOL scores, indicating that increased competence gained through working experience may lead to a lesser negative impact on carer quality of life.

12.1.8 Incongruence

Whilst participants in the study showed empathy, compassion and consideration to the person being cared for, it is necessary to highlight some of the difficulties within relationships in the context of the study findings. The perspective of incongruence in the present study is considered as differences in decisions, behaviour and attitudes (Kitko et al., 2014). One participant, caring for her elderly husband, found it difficult that he did not acknowledge the help and support provided, and she sought recognition of her own health issues. Despite quantitative data demonstrating 57.9% of participants agreeing they could get to health checks, carers with their own health issues showed lower scores in social wellbeing in the quantitative data; health issues and social isolation demonstrated statistical significance. Carers who had no health issues expressed higher overall social wellbeing than carers with health issues. Furthermore when considering the relationship of carer to the person being cared for, a statistically significant difference was shown for spousal carers; spousal carers expressed lower social wellbeing than non-spousal carers ($p=0.06$).

These findings echo the findings of a recent study conducted by Williams et al. (2017) exploring gender norms in older women's views about appropriate roles of men and women in the context of caring. A relevant finding that is emulated in the present study was the perception that it is an expectation and duty of women to care. Participants interviewed by Williams et al. (2017) believed caring was normal for women and they were experienced to fulfil the role; additionally, they spoke of putting their caring duties before their own health needs despite having chronic health issues. The findings of this thesis demonstrated similar carer perceptions with several female spouses describing maintaining their caring duties despite chronic health issues.

However it is important to note that in the present study, male participants showed similar perceptions to those of female carers in the Williams et al. study (2017). The qualitative findings demonstrated two male participants alluded to a lack of recognition of their own needs and how the enduring demands of the caring role were impacting on their own wellbeing. The quantitative data added

to this finding with a statistically significant difference in spiritual wellbeing, representing positive aspects of caring, with male participants reporting lower spiritual wellbeing than female participants (Table 10). Thus as outlined in section 3.1 this finding highlights the need to move beyond boundaries of gender and caring but considering care as a normal aspect of human existence with recognition of the associated challenges that should be addressed from an individualised rather than gendered perspective.

Considering incongruence in relation to type of carer dyads, this study showed that it was evident during the caring trajectory for both male and female carers inclusive of spousal and adult child carers. For adult daughters and granddaughter, a particular sensitivity was conflicting information given by the patient to the home carers as compared to what they reported to the family carer. This related to the level of personal care required and caused embarrassment for the participants, who felt it reflected poorly on them as a daughter and granddaughter. The findings support Kitko et al. (2014), who explored incongruence in HF carer dyads as part of a larger longitudinal study. The study showed incongruence was present in participants in relation to health care issues including home care requirements.

Retrum et al. (2013) conducted a qualitative study with 17 HF dyads to explore the presence of congruence and incongruence; the sample included spousal and adult children carers. The findings showed specific issues caused incongruence in differing dyads. Spousal dyads reported increased psychosocial concerns whereas participants who were adult children wanted more assistance with tangible elements of caring including the practical help that was available to them. The authors considered this related to adult children having reduced time to provide care due to other demands including work and children. Again, the findings in the present study demonstrated similarities with this research. The adult child carers articulated practical difficulties with dealing with the physical care of their mother/grandmother and needing more assistance with personal care. Spousal carers described feeling overwhelmed, emotionally exhausted and socially isolated. Notably this was validated by the quantitative findings, which demonstrated that spousal carers had lower social wellbeing than non-spousal carers (Table 8). Retrum et al. (2013) further concluded that the age of the patient and carer influence the perceptions of HF

leading to congruence as regards acceptance of end-of-life care. The authors propose that older dyads recognise they are in the latter stages of life and therefore have agreement in the timeliness of discussions. The Retrum et al. (2013) study indicated such congruence was not evident in the adult child carers, which they related to a reluctance to have end-of-life conversations. The findings of the present study, however, are in contrast to Retrum et al.'s (2013) findings, with both younger spousal carers and adult child carers describing a realistic view of facing the future.

Further investigation should be considered for carers who have their own health concerns, are socially isolated and may experience incongruence in their relationships to mitigate against negative aspects of caring.

12.2 Methodological implications

Milne and Larkin (2015) carried out a critical analysis of recent research conducted with carers in the UK and considered the knowledge generated from the differing research paradigms. They proposed that two definitive paradigms exist: gathering and evaluating, and conceptualising and theorising. Gathering and evaluating is concerned with assessing the impact of caring and evaluates the effectiveness of policies/services in place to support carers. Conceptualising and theorising endeavours to extend the knowledge base to consider the multi-dimensional aspects of caring within the context of relationships. The analysis of carer-related research undertaken by Milne and Larkin (2015) indicated a plethora of research conducted to date belongs to one of these two research paradigms. The authors propose that this limits the understanding of caring in a social context and conclude that there is a need for an eclectic research methodology that can truly capture the complex nature of caring in the 21st century (Milne and Larkin, 2015).

The present study reflects this recommendation and implemented an innovative approach utilising MM; empirical quality of life data was enriched with an in-depth exploration of the lived experiences of caring and the similarities and differences in these experiences were analysed. The study has shown varied findings that add to the theoretical evidence base of caring for a person with

advanced HF. Moreover, the study highlights important methodological issues when conducting MM research with carers, which now will be presented.

The challenges of recruiting participants to the quantitative phase of the study are presented chapter five. In this study the HFN acted as gatekeeper to the carers of patients on their caseload; in this manner, they identified the carer, but this presented challenges in achieving a higher number of participants.

A further methodological consideration is the language used in carer research that may limit engagement with the target research population. Molyneaux et al. (2011) undertook a critique of the term '*carer*' and the implications for how people identify with this term. The critique proposes that the term carer evolved from the historical feminist perspective of the role of women in undervalued caring roles. From this perspective developed social and political bodies which aimed to raise awareness and lobby with the desire to improve support for carers and cared for. Whilst Molyneaux et al. (2011) recognise the language of caring and carer can be a means to gain access to salient services, they advocate it is necessary to revisit the term to consider if it encapsulates the people whose needs we are trying to address. From a critique of carer research literature, Molyneaux et al. (2011) propose that people do not consider themselves as carers but describe performing caring tasks as part of their relationship. Furthermore, they propose labelling people as carers can lead to a loss of their own identity. This resonates in the present study; some participants did not view their role as a carer; they described 'watching over' the person they lived with but considered this as something they would do as part of their relationship with the person.

Ribeiro and Nogueira (2008) undertook a study with older males, and again participants did not refer to themselves as carers; rather they spoke of being husbands. The male participants in this study affirm this and viewed the tasks required of them as being what they should do as a husband; they described it as part of their marriage contract, '*for better or worse*'.

Molyneaux et al. (2011) concluded that people are reticent to consider themselves as carers and do not see the support they provide as beyond the bounds of their relationships and roles. The authors advocate that in the ethos of person-centred care, in which individual circumstances are acknowledged,

each caring dyad should be defined according to the relationship. Thus the person is recognised as a spouse, partner, son, daughter or friend; by being identified in this manner the emphasis is on relationship-based caring. I propose that applying this principle utilises the conceptual model of an ethic of care in which people consider the *'responsibility'* to care as central to their relationships.

12.3 Strengths and limitations

12.3.1 Quantitative component

The present study demonstrated that the FAMQOL instrument was a valid instrument in an HF carer population; quantitative findings provided beneficial data relating to this carer population. The self-administered questionnaire with a prepaid return envelope was shown to be an appropriate quantitative method to obtain measurable data from the research population, and the return rate of completed questionnaire from those who received them was high, demonstrating the usability of the instrument.

The issues relating to low numbers of carers recruited into the quantitative phase is acknowledged as a limitation of the overall study methodology. This was due to difficulties in the HFN service, chosen to access carers, identifying and recruiting participants into the research. However, using clinical staff as gatekeepers proved to be both problematic and advantageous.

With regards to sampling bias, it was possible that the HFN may have filtered who they felt was appropriate for the study by their own interpretation of the inclusion criteria. In the context of this study, the HFN may have determined which patients were palliative and in doing so potentially excluded carers who would have been appropriate to be involved. There is also an issue with gatekeepers subconsciously selecting those carers who they believe are most likely to complete the questionnaire and/or participate in an interview. There were clear systematic differences in the distribution rates between the eight HFNs. This could be associated with workload demands meaning individual HFNs may not have necessarily prioritised the research study. Finally,

consideration should be given to which carers were more likely to be willing to be involved in the study. It is acknowledged that the possibility could be that carers providing intensive support, older carers or those from a lower educational background may not consider they have capacity to participate. However, in the present study the findings clearly demonstrate diversity in the participants' experiences.

As a single-centre study, there was a limit to the numbers of carers that could be accessed through the HFN service, and it was acknowledged that this would impact on the number of questionnaire returns. Whilst questionnaires are commonly associated with low response rates (Bowling 2009), a further exploration was made as to why the response rate of the questionnaires was gradual. It became evident that the low response rate was associated with the distribution of the questionnaires by the HFN rather than non-completion of the questionnaires.

By offering a case management model of nursing, the HFN is a care coordinator; this involves continual communication with patients and their carers throughout the disease trajectory. A typical caseload of each HFN was 40 patients, of which approximately half had a carer. New referrals to the service were triaged to a waiting list, and therefore the HFN may have been visiting the same patients and carers for a number of months. The nurses were distributing the questionnaires when they came into contact with the carers during home visits to the patient. It transpired that due to the nature of the service delivery, on average each nurse distributed five questionnaires during a three-month period. Thus, due to the manner in which they visited patients and carers, there were clear implications for how this would impact on the length of the data collection in phase one of the study.

The following actions were implemented by the researcher and supervisory team to overcome the challenges posed in the study and to maintain the sequential design: a set end date was agreed for the quantitative phase of the study; ensuring the HFN was aware of and updated regarding the study time line, questionnaire returns and recruitment of carers for the second phase of the study; and writing to all carers who expressed an interest in being interviewed to

provide a realistic estimate of when they could be expected to be contacted about being interviewed.

12.3.2 Qualitative component

Qualitative findings added to measurable data to offer an in-depth understanding of the complexities of caring at an individual level. A strength of the qualitative data was a heterogeneous sample with diversity in age, relationship and level of caring each participant was providing. In this manner, the sample offered insights into the diverse experiences of carers to explore the particularities of caring as described in the underpinning carer theory (Barnes, 2012., Nolan et al., 2003). The semi-structured interview schedule allowed for key domains that emerged from the quantitative findings to be addressed but incorporated flexibility for participants to discuss wider experiences they wanted to share. As all the interviews were conducted in the participants' homes, this facilitated an open dialogue during the interview as the participants felt comfortable with the surroundings. For some participants, this was of particular importance as they wanted to be nearby the person they were caring for in case they were needed. The setting therefore enabled participants to offer their time without concerns about leaving their own home and caring responsibilities.

A limitation of the qualitative component of the study was the recruitment of carers. The intention at the outset of the study was to use purposive sampling for maximum diversity selected from the questionnaire responses. However, due to the gradual returns of the questionnaires, there was concern that, if the first phase of the study extended over a lengthy period, there was the risk that those participants who had agreed to be interviewed may no longer be interested or indeed, due to the nature of HF, no longer be caring for the person as the patient may have died. It was decided to contact those carers who had expressed an interest in being interviewed to set up interview dates rather than risk losing them due to a lengthy time lapse. Consequently all 14 carers who agreed to be interviewed participated in the second phase of the study; thus it could be proposed that the sample was in fact a convenience sample. Nevertheless, the sample did demonstrate variability in the characteristics of the study participants as outlined in chapter eight.

12.3.3 Mixed methods approach

O’Cathain et al. (2008) recommend that the reporting of MM studies should be inclusive of the principles shown in Box 3.

Box 3 Good Reporting of a MM Study (GRAMMS)

Describe the justification for using a MM approach to the research question.

Describe the design in terms of the purpose, priority and sequence of methods.

Details of each method in terms of sampling, data collection and analysis

Description of where integration occurred, how it occurred and who has participated in it.

Description of any limitations of one method associated with the present of the other method.

Description of any insights gained from mixing or integrating methods.

The study used a MM design to obtain measurable data of the impact of caring on physical, psychological, social and emotional wellbeing and to explore individual carers’ experiences and how their circumstances may influence these domains. The quantitative phase of the study was the supplemental phase, and the qualitative phase was the core component of the study. The results from the quantitative phase were influential in confirming and developing the domains for the qualitative phase of the study.

Strengths of the present study include a robust rationale for the MM study with a clear, transparent methodology fitting to address the research question.

Limitations were encountered, however, with regard to integration of data.

Due to the difficulties associated with the recruitment of participants to phase one of the study, the quantitative sample did not allow for regression analysis, which was the intention at the outset of the study. Additionally, the statistical

analysis of the 57 respondents' data showed limited statistical significance. The sample size has low power to detect effects; therefore even if an association exists, it would not show statistical significance. A strength of the present study was the novel approach in this research population, and the methodology has been published as a case study for nurse researchers (Whittingham et al., 2017).

It is acknowledged that a further limitation was that the study was conducted in one UK setting and may therefore not be representative of other geographical locations. It is recommended that multi-site research following the same study design as the present study should be considered to produce rigorous and generalisable data.

12.4 Unique contribution to knowledge

This thesis used MM approach to explore factors influential to carers' perceptions of caring, appropriateness of a Carer Support Plan (CSP) initiative and examined the impact of caring on QOL in carers supporting a person with advanced HF. Using an MM study design embedded measurable outcomes and individual carer voices in the study findings. Much of the research literature in the study population focuses on the negative aspects of caring, with instruments measuring carer burden and findings focusing on poor carer quality of life. This study appears to be the first UK-based study that has administered the FAMQOL in a carer population. This is a new instrument developed specifically for carers of HF patients, which captures both positive and negative aspects of caring stated, a particular interest of this research was and the FAMQOL, The quantitative results validate the usability of the instrument in a HF carer population. It was clear from the quantitative results that, as expected, carers reported negative impacts on quality of life dimensions. Additionally, however, many respondents also reported positive aspects including caring gave them a sense of purpose, feelings of inner peace and meaning to their life.

Added to the quantitative data, rich qualitative findings showed similarities and diversity in the participants' experiences. For example, it was evident that consideration needs to be given to the younger carer population offering

assistance to spouses, parents or grandparents with HF. Younger carers desired access to information that is tailored to their situation with recognition of the differing expectations they fulfil when compared to older carers, including recognition of financial concerns. Younger carers interviewed tended not engage with local support groups as they perceived people that attended the groups were older than them with differing personal circumstances. Consequently the importance of social media in helping younger carers link to information and peer support was apparent.

The findings showed that carers of patients with advanced HF have specific needs which differ from other carers of chronic conditions such as cancer and physical frailty. This study showed how the disease trajectory influences the carer experience in that the unpredictability associated with HF enhances the difficulties carers encountered. Many participants perceptions of their experience related to the difficulties of dealing with the unpredictability of the patients' condition. Despite capacity to encompass unpredictability into their everyday lives, it was also evident in the findings that the unpredictability of the disease trajectory was accompanied with feeling out of control leading to negative consequences for carer quality of life.

This is one of the first UK studies highlighting the role of HFNs in relation to the support they offer carers. Findings demonstrated the positive influence of the HFN in facilitating carer competence and confidence which assisted trust and respect between the carers and cared for. Younger carers considered the HFN to be a peer who demonstrated empathy and insight into the complexity of the situation. The community based care delivery offered by the HFN service was important for carers to establish a rapport that facilitated carer confidence. Furthermore whilst the study demonstrated the role of the HFN was key to supporting carers, findings suggest that this role could potentially be carried out by someone with less specialist clinical knowledge for example community based Carer Support Worker (CSW), lay workers or knowledgeable volunteers. Such roles offer opportunity to supplement the HFN role and the potential of such roles are worthy of high-quality research to explore the possibilities they could offer to this carer population.

Another key finding from this study indicated that the information needs of carers of HF patients were not adequately met. There was a particular risk of a breakdown in information provision during the transition between hospital and home. Dialogue from the participants indicated that the CSP was considered to be an acceptable initiative to facilitate timely dissemination of information.

Critically, the findings from the study show the essential dimensions to facilitate positivity in caring including compassion, thoughtfulness and understanding. Participants considered caring as integral to their relationships; the ability to cope was influenced by a range of attributes including quality of relationships in the carer/patient dyad and with formal care providers, access to tailored and timely information, and the role of the HFN. I recommend further consideration is given to the supportive needs of carers who do not experience congruence in relationships and individuals with limited social networks and support services.

12.5 Implications for policy and practice

12.5.1 New ways to deliver dedicated carer support

The findings of the thesis indicate that it is timely to consider new roles and models for offering carers support that could accompany current service provision. It is clear that the current provision is under increasing pressure and this situation is likely to persist, if not worsen, over the next years, due to changes in demographics and how health and social care is delivered. In 2013, the author Linda Pickard (Pickard, 2013) projected that by 2017 the demands for unpaid, family care would outweigh the capacity of carers and advocated that health and social care policy considered how to bridge the gap of unmet needs for carers. Important considerations for differing roles in health care practice have been highlighted, which are outlined below.

The positive impact of the HFN role should be acknowledged in terms of not only the patient experience but also the education and support provided to the carers and the manner in which this improves the carer experience. This role replicates a model of health care which addresses the patient and carer as a dyad (Doherty et al., 2016), but the challenge exists in current health and social

care provision as regards divisions in teams and budgets, increasing expectations and economic scrutiny of specialist nurse services.

I advocate that further exploration of new roles is required to improve the carer experience in an economically viable manner and recommend integrated health and social care teams with shared budgets are considered based on existing examples of best practice. One such example, based in a rural UK setting, offers support to carers of people living with cancer and other long-term conditions with palliative care needs (Nelson et al., 2017). The service employed a full time CSW who conducted a comprehensive carer assessment and signposted them to available resources. Critically, the service provided a holistic and integrated package of support that aimed to improve coordination between carers, health, social care and voluntary services (Nelson et al., 2017). An evaluation of the service indicated that it appeared to be addressing a gap in the absence of other services and that the continual contact offered reassurance without which carers reported their situation would have been difficult to deal with.

In the present study, carers spoke of the importance of the accessibility of the HFN as a point of contact and the care coordinator. I consider the role of a CSW outlined by Nelson et al. (2017) an initiative to supplement the carer support specialist HFN teams are currently providing. However, it is essential that the CSW role is not viewed as replacing the specialist clinical role provided by the HFN; indeed, it was evident from participants' accounts in this study that they required the clinical expertise to increase their own confidence in their knowledge to manage the patient's condition. Rather, the CSW role could serve to reduce workload demands on the HFNs by taking responsibility to address carer issues. I propose that a CSW role should be incorporated into the HFN service as recommended by Nelson et al. (2017). This would allow for effective integration and communication of both patient and carer needs. Carers of HF patients are a diverse population with a wide range of differing issues and often do not consider their own needs due to the responsibilities of caring. Additionally, theoretical literature presented in chapter three, section 3.1, illustrates how caring exists in our everyday lives, and as such many people who are providing care do not consider themselves as carers. By integrating the

role of CSW into the specialist HFN team, support can be offered proactively and tailored to meet the fluctuating requirements of the patient-carer dyad.

The characteristics of the CSW role call for further debate. In the study by Nelson et al. (2017), the CSW was part of the local carer support service, Carers Connect, with a professional background in social services. In a recent paper, Farquhar and Moore (2017) argue it is timely to explore a new nursing role dedicated to carers. The authors suggest the role should be a registered nurse in order to address physical and psychological health needs. However, a concern regarding a clinical role is the potential blurring of boundaries; carers could effectively become 'patients'.

Rather than a clinical role, I advocate that, additional to the CSW model, models successfully utilising lay workers and volunteers to assist nursing teams in meeting the needs of patients and their carers with complex health needs are worthy of future research. Candy et al. (2015) conducted a systematic review examining the effectiveness in the provision of volunteers supporting patients and their families living with life-limiting disease in relation to wellbeing. The review included services provided by volunteers to patients and families in their own homes. The authors concluded that in most studies volunteers took a complementary role rather than acting as a substitute for the nurse. The review findings indicated that patients and carers valued the companionship offered by the volunteer and that the role facilitated liaison between families and formal care services (Candy et al., 2015). The authors highlight that a noteworthy finding was objective evidence of a positive effect that patients cared for by their family in their own home and receiving the support of a volunteer on average lived longer than those not receiving the volunteer service. Candy et al. (2015) propose this is worthy of further investigation as it suggests that volunteer support may have improved family carer wellbeing, which may have increased patient longevity by enhancing the quality of support carers were able to provide. A study conducted by Litzelman et al. (2017) in the USA explored the role of Community Health Workers (CHWs) for ageing people with chronic conditions. The role of the CHW was to bridge the gap in the shortage of health care providers; CHWs were recruited from local communities and worked in close partnership with registered nurse care coordinators and social care. The findings indicated the service was received well by both patients and their

carers. When reflecting on the present study's findings, the value of volunteers as a carer advocate for those who are socially isolated with limited social networks and those patient-carer dyads who experience incongruence is a further innovative role that could be incorporated into specialist teams. The impact of the role could serve to reduce the workload of the HFNs with potential to be cost-effective.

The King's Fund produced the report "Volunteering in health and social care: securing a sustainable future" (Naylor et al., 2013), which set out the need for new strategies to deal with the increasing demands on health and social care. Additionally, the European World Congress established a task force in 2013 to explore the roles undertaken by volunteers in hospice and palliative care in Europe. The group aims to consider how volunteering is managed; what training is offered to volunteers; what the challenges are for volunteers, managers and organisations; and the numbers of volunteers involved in each participating country (<http://www.eapcnet.eu/Themes/Organisation/Volunteering.aspx>).

In the context of the findings of the present study, I consider that the roles of the CSW and knowledgeable volunteers could offer dedicated, ongoing and proactive support to carers to supplement the role of the HFN. Thus these innovative ways to meet the increasing demands on health and social care services are potential areas for future research.

12.5.2 Carer Support Plan

It is evident from the present study findings that the support carers require is unique and individual to each person's changing situation. The participants in this study desired practical information, but many did not allude to increased access to respite care or breaks from caring. Rather, they wanted continuity and high quality from care providers, practical advice and someone to offer them recognition and hear the carer's voice. The CSP was readily received by the participants in the present study as a means of conveying information about services available locally. It is recognised, however, that a difficulty in disseminating the CSP is effective engagement with the initiative with formal care providers.

The intention for the initiative would be for the HFN to outline the information in the CSP at the beginning of the disease trajectory during an assessment visit. Carers can choose to request access to supportive services as they require during the fluctuating disease trajectory. I acknowledge that the challenge with the CSP initiative is the changing and increasing demands on service provisions. It is crucial that carers are not offered supportive interventions that cannot be met when the need arises; rather, the CSP can be considered as an instrument that outlines what are realistic expectations of local services with clear details on what differing services provide.

12.6 Directions for future research

The present study findings add to the existing research literature on the experiences of being a carer for a person with advanced HF; new avenues are advocated for future research and are outlined below.

12.6.1 Exploring the needs of younger carers

The experiences of younger adult carers are not currently a well-researched field in the context of HF. The younger participants in this study described differing challenges and a need for tailored information to meet their specific circumstances. I propose that, with changes in population demographics and increased demands on health and social care provision, there will be greater expectations of family carers, a consequence of which is that the numbers of younger adult carers will increase in subsequent years. Additionally, the findings relating to the younger male carer's experience advocates further research is considered with male carers to explore differing gender expectations and how these may limit the support offered to male carers.

In order to meet the needs of this carer population, research should consider how to address the specific requirements of this carer population and look to best-practice examples from the younger carer population in other life-limiting conditions.

12.6.2 Social media as a supportive network

Participants in the present study spoke of the use of social media as a means of information and support. Social media is a constantly evolving resource; it shapes information and forms support networks in our social fabric. Exploration of the usefulness of this mode of communication and support is a potentially innovative research project with capacity to improve carer networks not only for younger carers but also for carers who are socially isolated. Additionally, findings in the present study relating to the use of social media may have applicability to carers of people with life-limiting conditions other than HF.

12.6.3 Carer Support Plan pilot

The Carer Support Plan was viewed by participants in the present study as an acceptable instrument to improve carer understanding of the support available. The findings from research studies examining the effectiveness of the Carer Support Needs Assessment Tool (Knighting et al., 2015) demonstrate positive engagement of service providers with the initiative is critical to successful implementation. I propose a pilot of the CSP initiative by community-based HFN services could be considered as part of a wider research project examining the use of social media as a mode of information sharing. Additionally, future research could measure the effectiveness of the CSP with carers of people with other life-limiting conditions.

12.6.4 Carer Support Workers

The present study demonstrated unequivocally the importance of the community-based HFN as a support to carers. To complement the role of specialists in palliative care, the role of CSW, lay workers and volunteers should be considered as part of future mainstream services. Current research is being conducted by the European Association of Palliative Care Task Force on Volunteering to explore the possibilities of this resource. The experiences of the participants in the present study are a valuable insight into attributes of the community-based services that are perceived as positive quality support. Future research should be conducted to explore how these services can be accompanied by new roles to meet the increasing demands on existing service provision.

12.6.5 Conclusion

Overall the thesis has added to the existing evidence base by highlighting the individual dimensions of caring, and this challenges health and social care providers to develop supportive services that acknowledge the uniqueness of each carer's circumstances. Expectations of our carer population are increasing; caring is considered as integral to the social fabric. It is therefore timely and necessary in the current health and social care climate to explore new and innovative ways of working with this population in order to provide personalised, proactive supportive initiatives.

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Appendix One: Matrix of studies included in the narrative review

| Author and year | Aims | Participants/sample | Study setting | Method/intervention | Description of tool used to measure caregiver burden/QOL | Relevant findings |
|----------------------|---|--|--|---|--|--|
| Agren et al. (2010) | To describe the levels of carer burden and identify independent predictors of caregiver burden in partners of patients with HF. | 135 dyads participated in the study. Both patients and carers completed the questionnaire. | Acute hospital and outpatient HF clinic. | Descriptive correlational cross-sectional study over 3-year period. A questionnaire packet was sent to the partner and patient who had agreed to participate. | Caregiver burden scale, Short Form (SF)36, Beck Depression Inventory, Control Attitudes Scale, Knowledge Questionnaire (RAND), Charlson Comorbidity Index. | 68% of carers reported low levels of carer burden, 30% reported medium and 2% high levels of caregiver burden. Medium and high levels were correlated with poor physical condition of the patient alongside poor functioning and mental health of the carer. |
| Bakas et al. (2006a) | To examine relationships amongst age, perceived control over managing heart problems, perceived difficulty with tasks, perceived outcomes and perceived mental and general health amongst caregivers of persons with HF, describe caregivers' perceptions of control over managing heart problems; describe the tasks and outcomes perceived as being difficult and negative by caregivers. | 21 family caregivers. | Primary care medicine outpatient clinic. | Non-experimental, exploratory, descriptive design. Questionnaire using tools listed. | Control Attitudes Scale, Oberst Caregiving Burden Scale, Bakas Caregiving Outcomes Scale, SF36. | 43% caregivers perceived a lack of control in relation to the patients' HF problems, younger carers perceived tasks to be more difficult and indicated poorer mental health, 47% reported difficulty in managing household tasks, 57% reported that they felt that their emotional wellbeing had been affected by being a carer. |

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| Chung et al. (2009) | To examine the effect of patients' and partners' depressive symptoms and anxiety on QOL in patient-spouse dyads. | 58 dyads participated in the study. | Outpatient HF clinic. | Cross-sectional, descriptive study in which depressive symptoms, QOL and anxiety were assessed concurrently in patients and spouses using tools listed. | Brief Symptom Inventory, Minnesota Living with HF questionnaire (modified version for carers). | Dyads showed greater depressive symptoms and anxiety than the mean reported in healthy communities. No significant gender differences in anxiety and depression. Spousal caregivers' depression and anxiety correlated with their own QOL but not with their partners. This had a direct negative impact on the patients' QOL. |
| Dracup et al. (2004) | To describe the emotional wellbeing of spouses of patients with HF, to identify factors associated | 69 spouses of patients with HF. | Outpatient HF clinic. | Cross-sectional correlational design using questionnaire incorporating the tools listed. | SF36 Control Attitudes Scale – Family Version, Caregiver Appraisal Tool | SF36 scores showed lower levels of QOL and poorer mental wellbeing when compared the general |

² Appendix One

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| | with decreased emotional wellbeing and to compare wellbeing between spouses with higher and lower levels of perceived control. | | | | | <p>population; higher caregiver burden and lower perceived control led to increased distress.</p> <p>Higher levels of perceived control are linked to significantly higher levels of emotional wellbeing.</p> <p>Younger spouses found to be at increased risk of poor emotional wellbeing.</p> |
| Evangelista et al. (2002) | <p>To describe and compare the emotional wellbeing of HF patients and their caregivers, identify gender differences in emotional wellbeing of patients and caregivers, identify factors associated with emotional wellbeing of HF patients.</p> | 103 dyads participated in the study. | Outpatient HF clinic. | Prospective, comparative design using questionnaires incorporating the SF 12. Convenience sample. | 12-item short form (SF12). | Caregivers had a significantly higher emotional wellbeing than patients. Authors allude to the higher levels of emotional wellbeing as a result of the positive association of being a carer and the responsibility that the roles can bring. Relates to the commitment and satisfaction. |

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|---------------------|---|--|--|---|--|---|
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| Fried et al. (2005) | To examine the adequacy of caregiver–patient communication in serious illness and its relationship to caregiver burden. | 193 caregivers and 33 patients participated in the study. COPD and HF patient and caregivers participated in the study. Caregivers for HF (n= 52). | Participants were recruited from an outpatient clinic. Interviews were conducted in the participants' own homes (carers and patients were interviewed separately). | Cross-sectional cohort study. Telephone screening to ascertain number of ADLs patient needed support with. Carer interview using tools listed. | Zarit Burden Inventory, | The relationship between the desire for communication and caregiver burden was examined – 93.8% of caregivers and 88.6% of patients recognised that it was important to talk to each other about the illness, 39.9% of caregivers desired more communication with patients and 37.35% found communication with the patient difficult. The need for more communication with the patients was linked to higher levels of carer burden and emotional stress. NB Overall the level of emotional burden reported by caregivers was low – this highlights that caregiving has both positive and negative aspects. |
| Garlo et al. (2010) | To examine caregiver burden over time in caregivers of patients with advanced HF. | 179 caregivers of patients with COPD, cancer and HF. | Recruited from acute and outpatient settings. Participants interviewed in own homes at 3- and 12-month periods. | Longitudinal cohort study over 12-month period. Interviews using Zarit Burden Inventory. | Zarit Burden Inventory. | 23% of carers for HF patients reported needing help with daily tasks; this was higher than other caregivers. Strong association between carer perceived need for social support and higher levels of burden. |
| Hwang et al. (2011) | To identify factors associated with the impact of caregiving. | 76 dyads of patients with HF. | Participants recruited from outpatient HF clinics. | Cross-sectional descriptive design using a convenience sample. Participants given opportunity to complete the questionnaire on their own | Charlson Comorbidity Index, Dutch Objective Burden Inventory, Medical Outcomes Study, Social Support Survey, Control | Lack of family support for caregivers was associated with patients' NYHA class, relationship to the patient, caregivers' perceived control |

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| | | | | or by interview (in person or over the telephone). If they completed it independently, they were asked to do so by themselves with no discussion with their partner. | Attitudes Scale – revised, Caregiver Reaction Assessment, SF36, Patient Health Questionnaire (carer focused). | and social support. Many family caregivers reported that caregiving had impacted negatively on their health. Findings were comparable to carers of patients with colorectal cancer. The caregiving experience was more positive when social support was readily available. It was seen as vital that carer needs were assessed immediately after patient's discharge from hospital. |
| Hooley et al. (2005) | To describe levels of caregiver burden and depressive symptoms and correlate this to patients' QOL and depression. | 50 patient-carer dyads. | Participants recruited from outpatient HF clinics. Participants completed a self-administered questionnaire. NB Patients and carers completed the questionnaire in separate rooms in the clinic. | Self-administered questionnaire implementing validated tools. Linear correlation to examine the carer burden score with the 3 other questionnaires scores. NB Does not state the time period over which the study was conducted. | Patients – Minnesota Living with HF, Beck Depression Inventory, Carers – Zarit Caregiver Burden Inventory and Beck Depression Inventory. | Caregiver burden is related to the levels of depression and poor QOL in the patients they are caring for. Whilst carers of HF patients do experience huge burden (ZCB 16), this is lower than carers of patients with cognitive impairment. |
| Iqbal et al. (2010) | To assess factors affecting health-related QOL in HF patients and their carers. | 179 patients and 131 carers. | Cardiology wards on discharge (n=101) or outpatients clinic (n=78). | Self-administered questionnaires completed at 1 month post-discharge or in the outpatient clinic. | Patients – QOL (EQ-5D), Minnesota Living with HF. Carers – QOL (EQ-5D). Scottish Index of Multiple Deprivation. | QOL of carers correlated to QOL of the patients' QOL was lower in female carers than male, NYHA class, socio-economic status correlated to lower QOL. |

| | | | | | | |
|------------------------|---|---|---|---|---|---|
| Luttik et al. (2009) | To investigate QOL in partners of people with congestive cardiac failure in comparison to individuals living with a healthy partner. | 303 partners of people with congestive cardiac failure. | Recruited from a larger RCT conducted in 17 cardiology centres. | Cross-sectional comparative design. Population was compared to an age- and gender-matched control group selected from the general population. Conducted over 3-year period. | RAND 36, Cantril's Ladder of Life (measure of global wellbeing), Dutch Objective Burden Inventory (measure of tasks carer conducts). | Small differences in QOL between carer population and general population, female carers had lower scores than male carers in QOL measures, variations in carer QOL correlated to the severity of the patient's disease. |
| Makdessi et al. (2011) | To examine the effectiveness of a disease-specific tool to measure carer burden. | 88 caregivers. | Participants were carers attending an outpatient HF clinic with the patient. | Cross-sectional descriptive design. Self-administered questionnaire. Carers completed questionnaire independently and returned it in a stamped addressed envelope. | Dutch Objective Burden Inventory (DOBI), Caregiver Reaction Assessment, Hospital Anxiety and Depression Scale. | Responses to the DOBI provided new insight into frequency of caregiving tasks. Study recommended further research into the psychometric properties of the tool. |
| Molloy et al. (2008) | The study aimed to examine the effectiveness of the demand-control model to predict caregiver burden and satisfaction. | 60 caregiver/patient dyads. | Participants were recruited from an older persons' day hospital and outpatient HF clinic. | Cross-sectional design. Caregivers interviewed independently of the patient. Interviews conducted in the carers' own homes or by self-reported questionnaire when an interview was not possible. | Care Work Strain Scale and carer satisfaction (subscales of the Impact of Informal Caring Scale) NB Scale acknowledges the positive aspects of caring. | Findings showed no supporting evidence for predictions of the demand-control model in predicting caregiver satisfaction. Control was the strongest predictor of caregiver burden. |
| Nauser et al. (2011) | To evaluate the psychometric properties of the Family Caregiver Quality of Life Scale (FAMQOL designed to assess the physical, psychological, social and spiritual dimensions of QOL amongst caregivers of HF patients. | 100 HF caregivers. | Inpatient and outpatient cardiology settings. | Cross-sectional study, convenience sample. Carers recruited if they met 2 or more of the task criteria on the Oberst Caregiving Burden Scale. Questionnaires administered by telephone interview followed by a 2-week test-retest. NB The FAMQOL can be also be self-administered. | FAMQOL, plus the following additional measures to evaluate construct and criteria validity: 19-item Medical Outcomes Study Social Support Survey – to measure social support. Patient cognition measured by 8-item Cognitive Status Scale, Oberst Caregiving Burden Scale – subscale used to measure caregiving tasks | Item to total correlations were examined for the individual domains. Findings indicate that the 16-item FAMQOL tool has validity and reliability; 7 experts assessed the tool's content validity, strong evidence of internal consistency reliability and test-retest reliability. Brief and easy tool to administer. Participants were predominantly women. |

| | | | | | | |
|------------------------|---|--------------------------------|--|--|---|--|
| | | | | | difficulty, 31-item Parents' Perception of Uncertainty in Illness Scale for family members, Appraisal of Caregiving Scale, 9-item depression scale of Primary Health Questionnaire (PHQ), Bakas Caregiving Outcomes Scale, SF36. | |
| Pressler et al. (2009) | To determine predictors of family caregiving outcomes amongst caregivers of patients with HF and to identify the tasks reported as most difficult and most negative outcomes. | 63 patients and 63 caregivers. | Outpatient HF clinic. | Prospective study, caregivers completed the questionnaire face-to-face with an interviewer or by telephone; interviews conducted at 4 and 8 months were done by telephone. Convenience sample – names were put forward for caregivers to participate by clinic staff. | Bakas Caregiving Outcomes Scale, SF12, Charlson Comorbidity Index (assesses medical health of the carers), Family Assessment Device (brief version), Control Attitudes Scale, Patient Health Questionnaire, Brief Symptom Inventory (measure of levels of anxiety in carers), Oberst Caregiving Burden Scale. | Caregivers reported moderately poor physical and emotional health related QOL; carers reporting depressive symptoms at baseline were more likely to report that their lives had changed for the worse at 4 months. Pre-existing carer medical conditions and perceived difficulty of caregiving tasks were predictors of physical health related QOL at 4 months; at 4 and 8 months depressive symptoms were predictors of emotional health related to QOL. |
| Saunders (2008)(| A study examining the association of caregiver characteristics and the caregiving environment on caregiver burden. | 55 caregivers and 41 patients. | Participants identified and recruited from the caseload of 2 community-based HFNs over a period of 4 months. | Cross-sectional, non-experimental design. Caregivers were interviewed face-to-face at the homes of the patients using a structured format. | The Centre for Epidemiological Studies Short Depression Scale (CES-D) – depression screen for carers, CRA main tool in study NYHA to assess patients' clinical status. | Higher levels of burden in Caucasian caregivers, those caring for other relatives, unemployed caregivers, older carers, higher numbers of carer hours, poor carer health and depression in carers were all associated with higher levels of burden. |

Appendix Two: Quality of Life Questionnaire (FAMQOL)

This group of questions is about you. Please tick the box for your response.

1. Date of birth

...../...../.....

2. Gender (please tick)

Male

Female

3. Partnership status (please tick)

Married

Civil Partnership

Widowed

Divorced

Single

4. Ethnic origin (please tick)

White

Mixed

Asian or Asian British

Black or Black British

Chinese

Any other ethnic background

5. What was your last job? (please write in the space provided)

6. Living arrangements (please tick)

I live with other people

I live alone

7. Do you have any children? (please tick)

Yes

No

If yes, how many?

8. What is your relationship to the patient?

9. Could you tell me the amount of contact you have with the patient?
(please tick)

Daily

At least weekly

Monthly

Yearly

10. How long have you known the patient? (please tick)

More than 25 years

10-25 years

5-9 years

Less than 5 years

11. How long have you been supporting the patient? (please tick)

More than 10 years

10-5 years

5-1 years

Less than 1 year

12. Have you any health problems at the moment?

Yes

No

If yes, can you please list them in the space provided.

The following questions are about you as a carer and how this affects your life.

Can you please circle your responses to the following statements:

| 13. As a caregiver | Strongly Disagree | Disagree | Neither Disagree or Agree | Agree | Strongly Agree |
|---|--------------------------|-----------------|----------------------------------|--------------|-----------------------|
| I seem to get sick more often. | 1 | 2 | 3 | 4 | 5 |
| I am overwhelmed. | 1 | 2 | 3 | 4 | 5 |
| I feel selfish when considering my own needs. | 1 | 2 | 3 | 4 | 5 |
| 14. Because of caregiving | Strongly Disagree | Disagree | Neither Disagree or Agree | Agree | Strongly Agree |
| I am tired. | 1 | 2 | 3 | 4 | 5 |
| My physical health has suffered. | 1 | 2 | 3 | 4 | 5 |
| I am strained emotionally. | 1 | 2 | 3 | 4 | 5 |
| I am socially isolated. | 1 | 2 | 3 | 4 | 5 |

| 15. Even though I am a caregiver | Strongly Disagree | Disagree | Neither Disagree or Agree | Agree | Strongly Agree |
|--|--------------------------|-----------------|----------------------------------|--------------|-----------------------|
| I am still able to exercise like I want. | 1 | 2 | 3 | 4 | 5 |
| I am able to get to my own check-ups with doctors, dentists and other health care providers. | 1 | 2 | 3 | 4 | 5 |
| I am able to participate in enjoyable activities. | 1 | 2 | 3 | 4 | 5 |
| I am able to maintain personal relationships with others. | 1 | 2 | 3 | 4 | 5 |
| I am able to practise religious activities if I want to. | 1 | 2 | 3 | 4 | 5 |

| 16. Caregiving | Strongly Disagree | Disagree | Neither Disagree or Agree | Agree | Strongly Agree |
|--|--------------------------|-----------------|----------------------------------|--------------|-----------------------|
| Adds to my purpose or mission in life. | 1 | 2 | 3 | 4 | 5 |
| Adds to my feelings of inner strength. | 1 | 2 | 3 | 4 | 5 |
| Gives me a sense of inner peace. | 1 | 2 | 3 | 4 | 5 |
| Gives meaning to my life. | 1 | 2 | 3 | 4 | 5 |

Thank you for taking the time to complete this questionnaire. Please can you return it in the envelope provided by *date*. If you need any help to complete the questionnaire, please telephone the researcher using the number provided on the information sheet.

Thank you.

Appendix Three: Carer Support Plan

The Carer Support Plan is intended to help you consider what options you would prefer to be put in place should you feel you need additional support in your caring role. Reasons for you needing to use the Carer Support Plan may include feeling increasingly tired, you may be experiencing illness yourself so cannot cope as well, or the person you are caring for may be needing increased support.

The options that are available to provide additional support are listed.

At times, there may be a delay in accessing the service due to service availability, but we will endeavour to provide a prompt response.

Your name:

Name of person you are caring for:

Assessor's name:

Signature:

Next review:

I/we confirm that I have been fully involved in my Carers Support Plan

I/We agree to copies of the Carers Support Plan being sent to:

GP Person of the person being cared for

Other *please specify:*

(e.g. specialist heart failure nurse, district nurse, End of Life team)

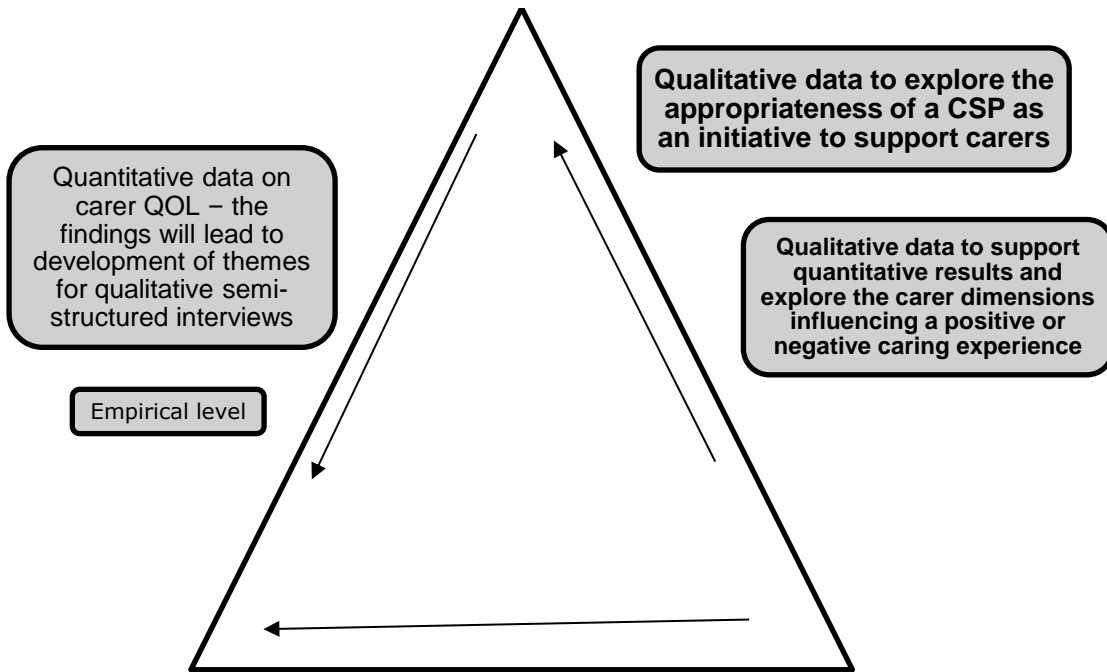
Name:

Signature:

Date and time:

| |
|---|
| <u>Preferred option</u> |
| Contact a named relative/friend <input type="checkbox"/> |
| Give details: |
| Increase nursing management at home <input type="checkbox"/> |
| Increase social support: Hospice at Home <input type="checkbox"/> Crossroads <input type="checkbox"/> Social services <input type="checkbox"/> |
| Arrange respite admission to Virtual Hospice bed <input type="checkbox"/> |

Appendix Four: Methodological triangulation



Appendix Five: Participant Information Sheet Phase One

Study Title: The impact of being a carer for a person with heart failure

We would like to invite you to take part in a research study. Before you decide, it is important that you understand why this research study is being carried out, and what it would involve for you. Please take time to read the following information carefully. Talk to others about the research study if you wish. Ask us if there is anything that is not clear, or if you would like more information; our contact details are at the end of this sheet. Take time to decide whether or not you wish to take part.

What is the purpose of the research study?

The research is exploring your experiences of looking after someone with heart failure and how it affects you as a carer. There are no right or wrong answers; we are interested in **your** views as a carer. The results of the questionnaire will help provide information about carers of patients with heart failure in Nottinghamshire.

Why have I been invited to take part?

You have been approached to take part as a carer who is already known to the heart failure nurse in Nottinghamshire.

What will happen to me if I take part?

If you agree to participate in the research study, we would be grateful if you could fill in the questionnaire. Please can you complete it following the instructions provided. Once you have completed the questionnaire, can you please post it to the researcher using the envelope provided. If you would like help to fill the questionnaire in, please contact Katharine Whittingham (contact details at the bottom of this sheet).

By returning the questionnaire you are agreeing that your responses can be used in the research study.

We request that you return the questionnaire by *date*.

What happens when the questionnaire is completed?

The heart failure nurse and any services you are currently receiving will continue to be available you in the same way. We will analyse the results from your questionnaire for the purpose of the research study.

Confidentiality

All the information we collect will be treated as confidential and will only be given to the research team. There will be no reference to you by name or in any way that could personally identify you on the questionnaires. The completed questionnaires will be stored securely.

What if there is a problem?

Many people welcome the opportunity to think about their caring role. However, you are entitled to decline to complete the questionnaire.

If you have a concern about any aspect of this research project, you should ask to speak to the researcher, who will do her best to answer your questions (contact details at the bottom of this sheet). If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure or your local Patient Advisory Liaison Service (PALS).

What will happen to the results of this research project?

Your views will be kept entirely private, and although some information may be used in publications, these will be anonymous and no one would be able to be identified from any of the information used. The final results of this research project will be circulated to those involved in providing the heart failure nurse service in order to help them provide the best service for you as a carer.

The research is a two-part study. The first part involves completing the questionnaire.

The second part of the study will involve the researcher, Katharine Whittingham, interviewing carers about their experiences. The interview can be done in the carer's own home. If you would like to be involved in the second part of the study, please can you complete the tear-off slip at the bottom of this page and return it with your completed questionnaire in the envelope provided.

By taking part in the research, you will be contributing to the ongoing development of services to support carers.

Contacting us

If you have questions or want more information about the research project, please contact the researcher – Katharine Whittingham – telephone 0115 823 0924 (answerphone connected).

Katharine.whittingham@nottingham.ac.uk

If you are interested in being interviewed in part 2 of the study, please provide your contact details and return the slip with the completed questionnaire in the envelope provided.

Name

Address

Daytime contact number

Mobile

Appendix Six: Interview schedule

The participant will be welcomed and thanked for agreeing to participate in the interview. The researcher will explain the purpose of the study and the interview. The participant will be informed that whilst there are some questions the researcher will ask, the interview will also provide an opportunity for them to talk freely about their experiences of being a carer.

The researcher will explain that the interview can last between 30 and 60 minutes and that the interview will be recorded using a digital recorder. The participant will be informed that the researcher will identify when the digital recorder is switched on. The researcher will inform the participant that, at any point during the interview, should the participant wish to suspend the interview they can inform the researcher and the interview and digital recording will be stopped until the participant identifies that they are willing to recommence the interview.

The participant will be reassured that should they find any of the questions difficult to answer they are under no obligation to give a response and they control the information that they are willing to share with the researcher.

The participant will be informed that the interview will be transcribed but responses will be anonymised.

The participant will be informed that they can withdraw from the interview and study at any point.

The participant will be asked if they have any questions prior to commencing the interview.

Social context

Can you begin by describing who you care for and what you do as a carer?

Can you tell me about your family situation?

Prompt

Have you been married/living together for long?

Do you have children or family living nearby?

Have you worked and/or are you still working?

Clinical indicators

Can you tell me about when your husband/wife became unwell?

Prompt: How long ago was that? When you began to care for your husband/wife?

Being a carer

Can you explain to me if you found anything to be rewarding/good about caring for your husband/wife?

What about anything particularly difficult?

Prompt: physically or emotionally? Any health issues the carer may have?

Has caring for your husband/wife had any impact on your health?

Prompts: physical health or mental health

Has caring for your husband/wife had any impact on your social life?

Prompts: relations with family and friends

What sort of impact has caring for your husband/wife had on your quality of life?

Can you tell me about any support you have to look after your husband/wife?

What sort of support would be most helpful to you, in caring for your husband/wife?

Do you think there is anything that would improve your caring experience?

What sort of concerns do you have (if any) about caring for your husband/wife in the years to come?

I am interested in your thoughts about the Carer Support Plan initiative. The Carer Support Plan asks you to tell the HFN about support you feel you may need if you begin to feel you are struggling in your caring role. This may be additional help from friends or family, respite care for your husband/wife/mother/father or increased support from services. The HFN would ask you

before you feel you are struggling so you are aware of the support available,
and the nurse is also aware of what help you think would be useful for you.

Would you find something like this initiative useful/acceptable?

Do you think you may use it?

If not, can you explain why?

Is there anything else you would like to say?

Thank you for your time today.

Appendix Seven: Meeting with Heart Failure Patient and Carer Group (HOPE) Lincolnshire based

HOPE is a support group for patients, carers and their families living with heart failure in Lincolnshire. The group meets weekly at the Cathedral Centre, Lincoln, and is run by volunteers. The group was initially established by a carer who through her own experiences recognised the need for a support network for both patients and their carers.

Whilst the group is for both patients and carers, following brief introductions and a catch-up, the carers then meet in a separate room to discuss their own issues and concerns. The group includes bereaved carers as there is no formal exit policy from HOPE, and carers can continue to attend if they feel they benefit from doing so.

HOPE has been running for seven years and currently has eighteen members registered with the group (six patients and twelve carers).

I joined four carers for their meeting and talked to them about the research proposal. They felt that the research was an important issue to be addressed and talked openly about their current situations. I presented the draft questionnaire and interview schedule. The carers felt that the questionnaire would be feasible for them to complete although they all agreed that the results may be different on a day-to-day basis. One carer had had a particularly difficult morning and said that her result would be very negative today but may be better the next day! They discussed that they felt that carers may feel completing the questionnaire would be helpful for them to think about what they do as a carer as many do not think of themselves as carers.

The semi-structured interview schedule was discussed, and again the 4 carers identified how they would be pleased to be asked about their experiences and to identify what they have found to help them.

One carer discussed how the programme run by HOPE, *'WHO cares 4 YOU! A programme of information and inspiration'*, had been very beneficial to her. The programme runs for eight weeks and involves two hour sessions which include

advice on how to manage time and resources effectively in the caring role. I am planning to meet with Diane Moon, who facilitates the course, to ascertain further information regarding the programme

All the carers and patients at HOPE were supported by a heart failure specialist nurse.

The carers I spoke to were all enthusiastic about being involved in the research, and I thanked them for their time. I explained that it is currently envisaged that the study will be conducted in Nottinghamshire but I would like to meet with them again to outline how the research is progressing and to explore the possibility of further research in the Lincolnshire area.

Appendix Eight: Participant Information Sheet Phase Two

Study Title: The impact of being a carer for a person with heart failure

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the research study if you wish. Ask us if there is anything that is not clear, or if you would like more information; our contact details are at the end of this sheet. Take time to decide whether or not you wish to take part.

What is the purpose of the research study?

The research is exploring your experiences of looking after someone with heart failure, how it affects you as a carer and what you think about the idea of a Carer Support Plan. There are no right or wrong answers; we are interested in **your** views and experiences as a carer.

Why have I been invited to take part?

You have been approached to take part as a carer who is already known to the heart failure nurse service in Nottinghamshire.

Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you or the person you are caring for receives.

What will happen to me if I take part?

If you agree to participate in the interview, we would be grateful if you could:

1. Read this participant information sheet. If you have any questions, please telephone the researcher – details given at the end of this sheet.
2. When the interviewer (Katharine Whittingham) contacts you, she will ask if you are still willing to participate in the research study. If you are, she will arrange a convenient date and time for you to participate in an interview. This

will be face-to-face either at your home or other convenient place for you. The interview will take approximately 30-60 minutes to complete. The interview will be digitally recorded and typed up in full.

3. It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and asked to sign a consent form prior to the interview commencing. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you or your family receive.

What happens when the interview is finished?

The heart failure nurse and any services you are currently receiving will continue to be available to you in the same way. We will analyse your experiences from the interview, which will help to plan future services to support carers of people with heart failure.

Confidentiality

All the information we collect will be treated as confidential and will only be given to the research team. The digital recording will be deleted as soon as the interview has been typed up. There will be no reference to you by name or in any way that could personally identify you on the typed interviews. The typed interview transcripts will be stored securely.

What if there is a problem?

Many people welcome the opportunity to talk freely about their caring role. However, should any difficulties arise the interviewer will offer the appropriate support and reassurance during the interview. If necessary, the interviewer can offer advice and information about where you can access further support.

The interviewer will be aware and respond appropriately to such discussions. However, you are entitled to stop the interview whenever you wish.

If you have a concern about any aspect of this research study, you should ask to speak to the interviewer, who will do her best to answer your questions (contact details at the bottom of this sheet). If you remain unhappy and wish to

complain formally, you can do this through the NHS complaints procedure or your local PALS service.

What will happen to the results of this research study?

Your views will be kept entirely private, and although some quotes may be used in publications, these will be anonymous and no one would be able to be identified from any of the quotes used. The final results of this research study will be circulated to those involved in providing the heart failure nurse service in order to help them provide the best service for you as a carer. If you would like a brief summary of the results, please tick the box on the consent form.

By taking part in the study, you will be contributing to the knowledge that we have about carers' experiences and aspects of services that best helps to support carers like you. A summary of the interview findings and recommendations will be offered to all carers taking part.

Contacting us

If you have questions or want more information about the research study, please contact the researcher – Katharine Whittingham – on telephone number 0115 823 0924 (answerphone connected).

Thank you for taking the time to read this information sheet.

Appendix Nine: Consent to take part in an interview

Participant Identification Number:

Title of Project:

Name of Researcher:

Please initial box.

1. I confirm that I have read and understood the information sheet about taking part in an interview for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I understand that the interviews will be digitally recorded and I give my permission for anonymous quotes from this interview to be used in any publications/reports that might result from this study.
4. I would like to have a summary of the interview findings resulting from the study.
5. I agree to take part in the above study.

Name of Participant
Signature

Date

Name of Person Taking Consent
Signature

Date

Appendix Ten: Meeting with Head of Research Management and Governance

I arranged to meet with the Head of Governance in the community Trusts in which I will be conducting the research. The Head of Governance informed me that the department has a cross-county function for Nottinghamshire health care providers and therefore will only need to complete one form for Governance purposes.

Key issues that were discussed:

Consent

Consent for questionnaire – this will be implied consent and therefore a formal consent form does not have to be completed by participants prior to completing the questionnaire.

Consent for the interviews can be obtained face-to-face using a formal consent form prior to the interview being conducted.

Complaints procedure

The information sheets for participants should direct participants to the local PALS service and/or the usual NHS complaints procedure.

Research passport

A research passport application must be submitted to the University of Sheffield prior to the data collection phase commencing. The completed application should then be sent to the Head of Governance.

Authorisation

Final authorisation must be given by Heads of Service in CityCare and Michelle County Partnerships. This can be done in the form of an email and copied into the Head of Governance.

Storage of data

Data should be stored securely following the guidance of the University of Sheffield.