Ulster University

Improved identification, communication and service provision needed to relieve caregiver burden in advanced heart failure in Ireland:

a mixed methods study

AIIHPC
All Ireland Institute of Hospice and Palliative Care

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Abbreviations

ACP	Advance Care Planning
AIIHPC	All Ireland Institute for Hospice & Palliative Care
BHSCT	Belfast Health & Social Care Trust
CSNAT	Carers Support Needs Assessment Tool
GAD	Generalised Anxiety Scale
HF	Heart Failure
MLHFQ	Minnesota Living with Heart Failure Questionnaire
MSPSS	Multidimensional Scale of Perceived Social Support
NI	Northern Ireland
NYHA	New York Heart Association
OT	Occupational Therapist
PCRN	Palliative Care Research Network
PHQ	Patient Health Questionnaire
PRISMA	Preferred Reporting Items for Systematic Reviews
QoL	Quality of Life
ROI	Republic of Ireland
RR	Response rate
SCHFI	Self-Care in Heart Failure Index
SD	Standard deviation
SEHSCT	South Eastern Health & Social Care Trust
SIBHF	Survey of Illness Beliefs in Heart Failure
UK	United Kingdom
USA	United States of America
ZBI	Zarit Burden Scale

1. Introduction

Heart failure (HF) is the inability of the heart to eject blood around the body sufficiently and is caused by structural abnormalities or cardiac dysfunction. Patients often experience clinical symptoms such as dyspnoea, oedema, fatigue and uncontrolled pain[1, 2] and HF is considered as having the greatest negative impact on quality of life (QoL) when compared with other major chronic diseases[3]. The disease trajectory is typically characterised by periods of decompensation followed by periods of stability and according to Goodlin (2009) it can be described in 5 phases: (1) onset, diagnosis and initiation of medical treatment; (2) stable period; (3) periods of instability due to symptom reoccurrence as heart function deteriorates; (4) symptoms increase and are associated with declining physical capacity, despite optimal therapy; (5) marked deterioration and increasing symptoms[4].

The long-term prognosis of HF is worse than that associated with the majority of cancers. For example, in HF there is a 38% mortality rate in the first year following diagnosis[5] with 50% of HF patients dying within 4 years of diagnosis. In this context prognostication can present practical challenges[6] and the symptom burden associated with HF makes it a complex condition for health care professionals to clinically manage. While death can be sudden, a significant proportion faces the progressive deterioration of a terminal illness[7].

HF is reaching epidemic proportions in Ireland and throughout the developed world. According to estimates from the European Heart Failure Association, there are over 26 million people around the world living with HF[8] and over 3.5 million new patients are diagnosed every year in Europe alone[3]. In 2016, the number of people in Northern Ireland (NI) thought to be living with HF was 15,702 equating to 1% of the population[9], similar to that of Western European populations with prevalence rates estimated to range from 1% to 2%[1]. There is a 1 in 5 lifetime risk of developing HF[3] and the growing prevalence of HF could reflect an aging population.

The proportion of the population aged 65 years and older in NI is steadily increasing. In 2014 16% of the population were 65 years+ and projections suggest this will increase to 25% by 2039[10]. In Ireland there is a predicted doubling of numbers for those aged 85 years by 2021[11] and in the UK a 17% increase in the annual number of deaths is expected, along with an increase in the percentage of deaths of those aged 85 years or older to reach 44% by 2030[12].

International and National evidence indicated that given a choice, most people would prefer to be cared for and die at home[13-15]. Despite this, the majority of people in Ireland still continue to die in acute hospitals or long-stay facilities, with only 25% dying at home[16]. Within NI, the Transforming Your Care agenda, emphasised the importance of care in the community[17], yet this is challenging for the HF population due to the unpredictable disease trajectory and high symptom burden.

Palliative care, by definition, is a holistic approach to care that seeks to improve a patient's QoL through the prevention and relief of suffering. Evidence suggests palliative care has the potential to address the complex needs of the HF patient and has been shown to improve the patient and caregiver experience[18]. The World Health Organisation advocated that palliative care should seek to improve QoL for patients and their families and ensuring that family caregivers' needs are appropriately assessed

is one of the top ten quality markers for palliative care strategies[19]. In addition the need to focus on non-malignant diseases was recently identified as one of the top ten research priorities for palliative and end of life care in the UK and Ireland[20]. A number of recent guidelines highlighted the contribution palliative care can have to the care of HF patients and recommended the need to seek to integrate a palliative approach within the overall clinical management of HF[21-23].

Given the aging population and demand for palliative care for the older population, it is not surprising that HF patients remain disadvantaged when it comes to accessing palliative care services with as little as 4-7% of patients receiving a palliative care referral, many of which occur in the last week of life[24, 25]. Disparities in access to palliative care still remain, a National survey for referrals to specialist palliative care services in England, Wales and Northern Ireland reported the majority of referrals were for people with a cancer diagnosis, although the number of new referrals for non-cancer conditions is on the rise[26]. Social justice in health is a view that everyone should be entitled to the same level of care regardless of their socioeconomic status, yet it is evident heart failure patients are disadvantaged in relation to accessing palliative support. In addition, heart failure patients are often cared for by their informal caregiver in the community, where social deprivation amongst other factors may limit access to various healthcare services[27].

The importance of informal caregivers in the care of HF patients cannot be underestimated and their involvement has the potential to enhance palliative care services for HF patients living in the community[28]. Providing care for a loved one with a life limiting condition can be challenging, caregivers are responsible for various aspects of the patients' care such as support with self-care, including, medication management, diet adherence and symptom monitoring as well as providing physical support with aspects of daily living and emotional support[29, 30]. Aadapting to role reversal, financial difficulties[31, 32], providing continuity of care at home[33] and navigating the healthcare systems[34, 35] can all be burdensome. Informal caregivers of people with HF are often the spouse who may be of a similar age with their own health concerns[36] and can often become socially isolated[37]. Carers frequently experience depressive symptoms[38], anxiety[39] and burden[40, 41] as well as reduced QoL[40] and research has suggested caregiving may impinge on the caregivers own health. Results from the REGARDS study suggest perceived burden was associated with an increase in all-cause mortality[42]. It has been noted that supporting family caregivers can not only improve the wellbeing for patients[43, 44], but also reduce the impact from caregiving for carers[45]. Therefore, identifying ways to provide psychosocial and practical support for this group of carers to maintain some sense of normal living and reduce caregiver burden is needed[34, 46].

1.1 Study rationale

Research has indicated HF patients and their caregivers are less likely to access palliative care services compared to other life-limiting conditions, despite having similar needs[47]. Several recent studies have examined the palliative care needs of HF patients and provide preliminary evidence that such an approach is feasible and acceptable to patients[48, 49]. Furthermore, enhancing palliative care services and support to family members caring for HF patients has the potential to improve care and QoL for the patient, reduce caregiver burden and in addition reduce healthcare costs. Therefore, it is vital that the needs of people living with heart failure and their caregivers are examined in order to inform future interventions and services for these individuals.

1.2 Study aims and objectives

The aim of this work package was to examine the palliative care needs of caregiver's of people living with advanced HF in Ireland and to explore any relationship between this and a range of other factors including the patient's clinical profile and support available.

The objectives of the study are:

- To undertake a systematic review of the literature relating to the physical and psychosocial needs of caregivers' of people living with advanced HF.
- To identify an appropriate cohort of patients and caregivers of people with advanced HF by profiling the HF databases in NI and the Republic of Ireland (ROI) and recruiting a sample of eligible patient-caregiver dyads.
- To evaluate the dimensions of inequality in the population of patients and caregivers and relate this to their health outcomes, QoL and caregivers perceived burden.
- To explore the experience of current caregivers of people with HF, elucidating their needs and identifying the skills and resources they perceive necessary to enable them to effectively support their loved one towards the end of life.
- To explore the end of life experience of bereaved caregivers when caring for a loved one with HF and identify their palliative care needs.

2. Background literature

A summary of the published systematic narrative review is included in this report and access to the full article can be obtained in the European Journal of Cardiovascular Nursing[46].

2.1 Introduction

The benefit of palliative care for patients living with HF and their families has been acknowledged, leading to research exploring their needs and the benefits of incorporating palliative care alongside HF specialties. The majority of research has focused on the patients' needs, albeit more recently caregivers are being recognised for the role they play in providing care for the patient. This has led to an emerging evidence base surrounding caregivers' needs and the objective of this systematic narrative review was to explore the literature reporting the palliative care needs expressed by caregivers caring for a loved one with advanced HF.

2.2 Methods

A systematic approach was undertaken according to the PRISMA guidelines[50]. Five electronic databases were searched (CINAHL PLUS, EMBASE, Medline, PsychInfo, and SCOPUS) and keywords were grouped into three concepts; HF, palliative care and caregivers. Multiple key words within each concept were included to capture as many relevant articles as possible. Articles were included for review if they met the inclusion criteria: (1) peer-reviews articles (2) published between January 2003 and June 2014 (3) English language (4) original research exploring the palliative care needs expressed by informal caregivers of HF patients using a qualitative methodology. There were 316 articles identified which were screened by the researcher (LD) in a stepwise manner, screening titles followed by abstracts and full text. Consensus was obtained by two researchers (LD & SMcI) and fifteen articles were deemed suitable for inclusion in the review. Study quality was assessed using the McMaster University critical appraisal form, albeit no article was excluded. Data was extracted from each article using an inductive methodology for the thematic analysis and 10 broad categories were identified. Concept mapping of these lead to three main themes; psychosocial support to help maintain a sense of normalcy; support with daily living; support navigating the healthcare system; which were verified by the research team (LD, SMcI & DF).

2.3 Results

A short summary of each theme is below.

Psychosocial support to help maintain a sense of normalcy.

This included social, emotional and spiritual needs. Caregivers expressed a need to continue with normal living, having time away from caregiving so they could maintain social activities and often reported wanting more support from family members. Some suggested having a support group or respite care as beneficial. Those caregivers with poor family support seemed to draw comfort from their spiritual faith. A number of studies reported caregivers wanting somebody to talk to; to share their concerns. Bereaved caregivers in particular mentioned counselling would be beneficial to them when their loved one was at the end of life.

Support with daily living

Caregivers reported needing support with practical issues when helping the patient with activities of daily living, such as medication management and symptom control. Role reversal was common and some caregivers sacrificed their jobs in order to care full time and others found it difficult to attend to their own healthcare needs.

Support navigating the healthcare system

A lack of information from healthcare professionals was a consistent finding in the articles. Caregivers need information early in the patients' disease course regarding symptoms, treatments and the future, albeit, information needs to be tailored to the individual patient-caregiver dyads preference. Caregivers felt they had insufficient time with HF specialists to discuss the patients' condition and that information needed to be communicated to them without the use of jargon. Preference for end of life conversations varied; nevertheless, there is a need for supporting patients and caregivers to have these conversations.

2.4 Implications for practice

- **The needs identified here could form the basis of a framework to ensure caregivers palliative care needs are addressed.**
- **Healthcare professionals need to acknowledge the role caregivers play and involve them in the care of the patient.**
- **Research is warranted to determine the best way of providing information to caregivers and to evaluate these methods for their potential to ease caregiver burden.**

3. Research approach & methodology

3.1 Study design

A sequential confirmatory mixed methods study was undertaken with 3 key phases in line with the study objectives (figure 1). The results from each of these phases will be presented in the subsequent chapters of the report.

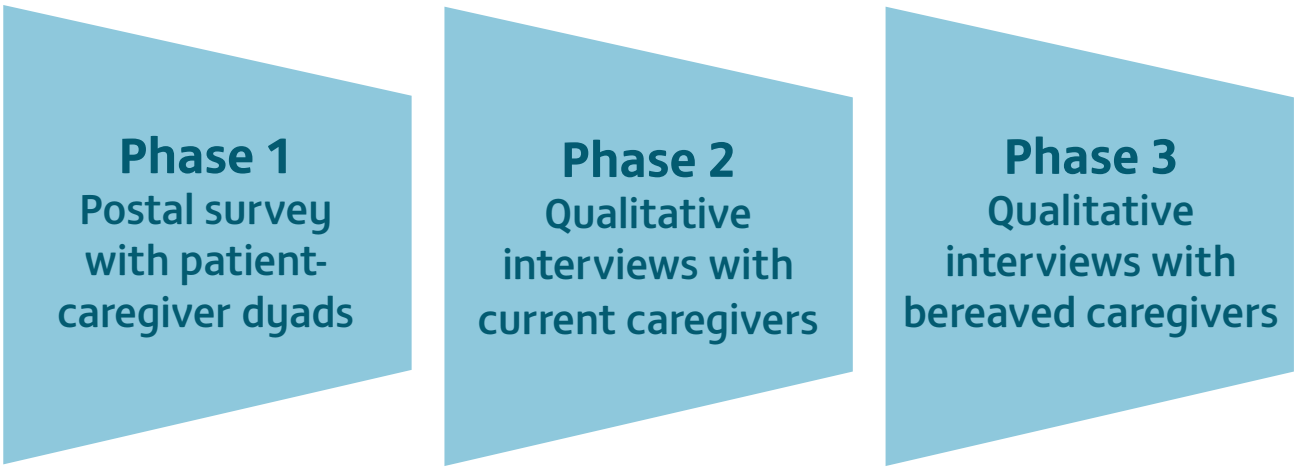

Figure 1 Research study design

3.2 Ethical approval

This research study was internally reviewed within the Institute of Nursing and Health Research, Ulster University and ethical approval was granted by the Office of Research Ethics Committees Northern Ireland (13/NI/0186) and St Vincent's Healthcare Group Limited, Ethics and Medical Research Committee, University College Dublin.

3.3 Phase 1: Postal survey with patient-caregiver dyads

3.3.1 Recruitment

Patients with a HF diagnosis under the care of the Cardiology teams within the Belfast Health & Social Care Trust (BHSCT) and the South Eastern Health & Social Care Trust (SEHSCT) NI and St Vincent's Healthcare Group, Dublin, Ireland, were assessed by the clinical team to establish whether they met the inclusion criteria (table 1). A member of the clinical team introduced the research study to the patient and sough verbal agreement from them, to be contacted by a member of the research team. At this stage the clinical team were able to ascertain whether the patient had a caregiver, and was mentally suitable, therefore, fulfilling the requirements of the study. Access to the caregiver was negotiated through the patient to ensure the profiles of the dyads could be matched and so patients who gave verbal consent to the clinical team were posted study packs for both themselves and their caregiver. The packs consisted of an invitation letter, participant information sheet, opt out slip and questionnaire packs for both the patient and their informal caregiver. Additionally, the caregiver pack contained an opt-in slip for the caregiver to complete if they were interested in finding out more about another aspect to the study (phase 2: qualitative interview with current caregivers).

3.3.2 Patient inclusion exclusion criteria

In order to identify advanced HF patients likely to be in last year of life, with palliative care needs, we applied the following inclusion exclusion criteria.

Table 1 Patient inclusion exclusion criteria

Patient inclusion criteria	Patient exclusion criteria
Aged 18 years or older	< 18 years
NYHA classification III or IV	NYHA class I-II
Ejection Fraction ≤ 40%	Ejection Fraction >40%
Deemed physically and mentally suitable	Deemed mentally unsuitable to take part (memory concerns reported or dementia diagnosis)
Have an informal caregiver (individual not associated with a formal caregiving service)	
Able and willing to give informed consent	Patients residing in residential care homes in receipt of formal caregiving
AND meet any ONE of the following: Brain natriuretic peptide (BNP) > 400 pg/ml or NTproBNP > 2000 pg/ml ≥ 1 unscheduled hospital admission 12 months prior to the study recruitment phase On IV diuretics during the previous 12 months	

3.3.3 Caregiver inclusion exclusion criteria

Caregivers were included if they were; aged 18 years or older; an informal caregiver to the HF patient (identified by the patient as the main person who provides physical and/or psychological care to the patient); and able and willing to provide informed consent.

3.3.4 Data collection

The validated instruments for use in this survey have been carefully selected based on those previously used in the literature (table 2). In addition, the research team collected demographic information, self-reported time spent on caregiving roles and patients' self-reported contact with healthcare professionals in the previous 6 months.

Table 2 Summary of the validated tools employed in the patient-caregiver postal survey

Tool	Outcome measure	Scoring, domains & interpretation
Patient Health Questionnaire (PHQ-9)[51]	Depression	Total score calculated ranging 0-27 1-4 mild depression 5-9 moderate depression 10-14 moderately severe depression 15-19 severe depression Score ≥ 10 indicates the need for clinical assessment
General Anxiety Disorder (GAD-7)[52, 53]	Anxiety	Total score calculated ranging 0-21 0-5 mild anxiety 6-10 moderate anxiety >10 severe anxiety ≥10 further evaluation recommended
Minnesota Living with Heart Failure Questionnaire (MLHFQ)[54, 55]	Quality of life (QoL)	Total score calculated ranging 0-105 2 domains: Physical (summing of items 2-7, 12,13) Emotional (summing of items 17-21) <24 good QoL 24-45 moderate QoL >45 poor QoL
Self-Care in Heart Failure Index (SCHFI)[56]	Patients' self-care	Recommend reporting 3 domains separately: Maintenance (summing of items 1-10 and then standardized to a 0-100 range) Management (summing of items 11-16 then standardized to a 0-100 range) appropriate only in patients who have been symptomatic Confidence (summing of items 17-22 and then standardized to a 0-100 range)
Multidimensional Scale of Perceived Social Support (MSPSS)[57]	Social support	Total score & 3 domains: Perceptions of support from: Family (summing items 3,4,8 & 11) Friends (summing items 6,7,9 and 12) Significant other (summing items 1,2,5 & 10)
Survey of illness beliefs in Heart Failure (SIBHF)[58]	Patients' accuracy & certainty of illness beliefs	Mean score calculated ≥ 3represents accurate knowledge < 3 represents inaccurate knowledge
Zarit Burden Interview (ZBI)[59]	Caregiver burden	Total score calculated ranging 0-88 Score> 24 indicates greater distress
Preparedness for Caregiving[60, 61]	Caregivers preparedness for caregiving tasks	Mean score calculated ranging 0-4
Carer Support Needs Assessment Tool (CSNAT)	Caregivers support needs	Total score calculated ranging 0–56 Each domain is scored (0=no more support needed; 1=a little more; 2=quite a bit more and 4=very much more)

3.3.5 Quantitative data analysis

All statistical analysis was performed using the Statistical Package for Social Sciences (IBM SPSS V22). Data were expressed as means and standard deviations (SD). Correlation analysis was performed using Pearson's Correlation Coefficient to examine the relationship between continuous variables. Comparisons of continuous variables between two groups were performed using the two tailed Independent t-test. Univariate analysis between nominal variables was performed by Chi Square analysis. One way analysis of variance was conducted to explore dimensions of inequality (financial stability and education level) on health outcomes (depression and anxiety), QoL and burden. Inequality was assessed by the financial stability question in the demographics questionnaire "How well would you say you manage financially". Fewer respondents reported finding it difficult to manage financially and quite difficult, therefore for the purpose of statistical analysis the responses for these were combined generating four response groups (Finding it difficult/very difficult, just about getting by, doing alright and living comfortably). Three models of multiple regression analysis were conducted to predict caregiver burden. Variables included in model 1 included caregiver PHQ, GAD, MSPSS and the preparedness for caregiving scale. Patient variables included in model 2 to predict caregiver burden included patient PHQ and GAD and in model 3 patient MSPSS, SCHFI and SIBHF were included. P value ≤ 0.05 was regarded as significant.

3.4 Phase 2: Qualitative interviews with current caregivers

3.4.1 Recruitment

Caregivers who returned an opt-in form from phase 1 expressing an interest in a face-to-face interview were posted a letter of invitation and participant information sheet detailing phase 2 of the research. The caregiver was given a minimum of 48 hours to read and carefully consider taking part and then a member of the research team contacted them to answer any questions and ascertain interest in taking part in the interview. Caregivers were selected for interview using a purposive sampling strategy taking into account geographical spread, gender and relationship to the patient.

3.4.2 Caregiver inclusion exclusion criteria

Caregivers were recruited if they were; aged 18 years or older; an informal caregiver as nominated by the patient; and able and willing to provide informed consent. Formal caregivers (an individual associated with a formal service system, whether a paid worker or volunteer) and those younger than 18 years were excluded.

3.4.3 Data collection

Face-to-face interviews were conducted by a trained member of the research team who gained written informed consent prior to the interview. Additionally, process consent was followed throughout each interview, whereby the researcher regularly evaluated the comfort of the participant, and if or where appropriate, offered them the option to decline to answer specific questions or terminate the interview at any time. The interviews were semi-structured following an interview guide (figure 2) and followed an inductive approach so that the content of the interviews was guided by the caregivers' responses.

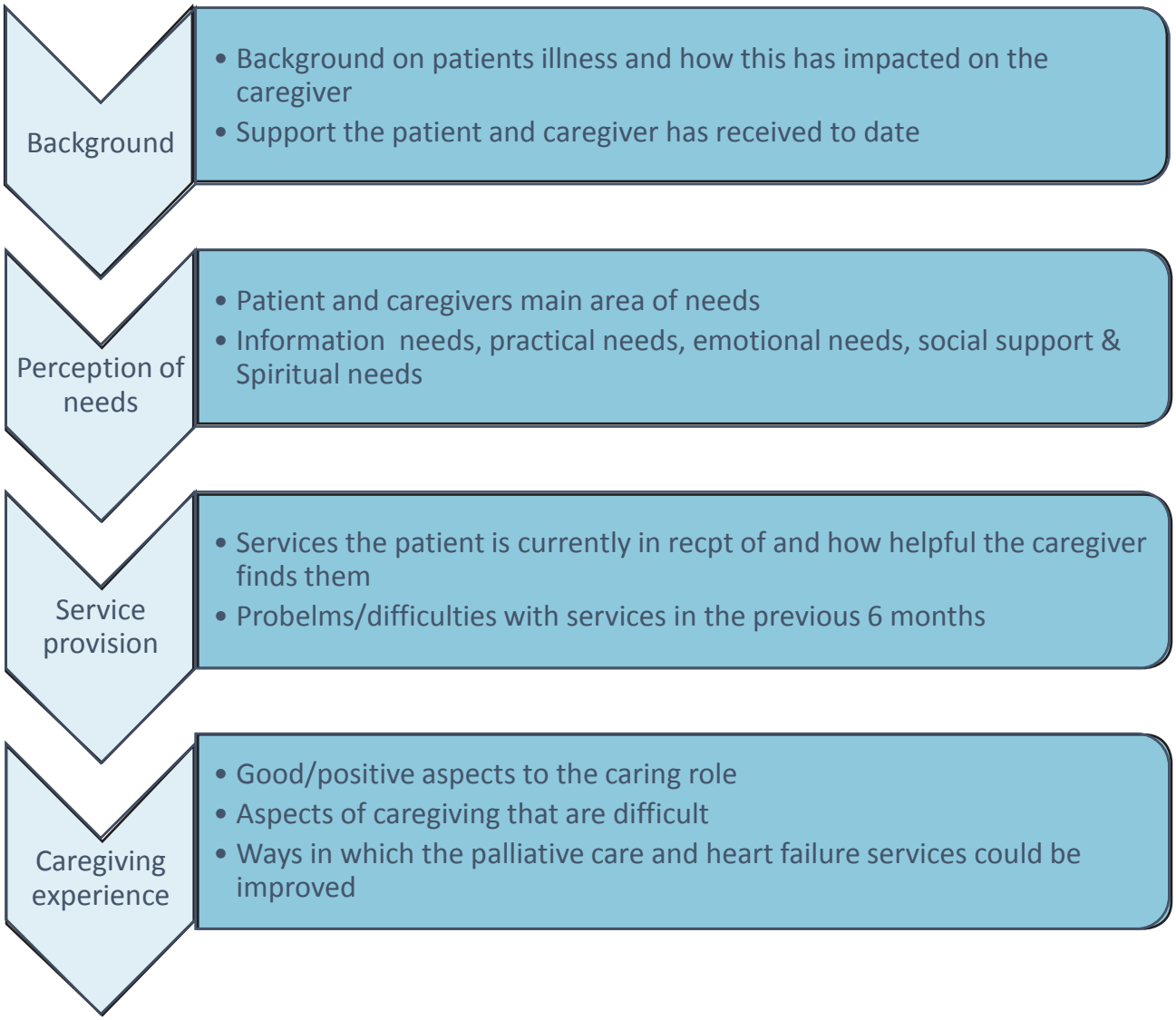

Figure 2 Semi structured interview schedule with current caregivers

3.4.4 Qualitative data analysis

The interviews were digitally recorded and transcribed verbatim. All transcripts were imported into NVivo 10 for data management and an inductive analysis of the data was undertaken using Braun & Clarke (2006) six phases of thematic analysis[62]. Phase 1: the researcher (LD) carried out the interviews, read the transcripts to become familiar with the data. Phase 2: initial codes were generated inductively. Phase 3: initial searching for themes involved a more in-depth recoding to combine codes and form overarching themes. Phase 4: themes were reviewed and refined by the research team (LD, SMcI & DF) leading to Phase 5: naming and defining the agreed themes and sub themes followed by Phase 6: producing the report.

3.5 Phase 3: Interviews with bereaved caregivers

3.5.1 Recruitment

Bereaved caregivers were recruited with the assistance of Northern Ireland Chest Heart and Stroke who provided information pertaining to the research on their website and social media. Information was displayed on the BHSCT staff hub and an email was circulated to Ulster University staff. Bereaved caregivers interested in the research contacted the research team, were provided with additional information and given the opportunity to ask questions.

3.5.2 Caregiver inclusion exclusion criteria

Caregivers were recruited if they were; 18 years or older; informal caregiver who cared for a loved one with HF; able and willing to provide informed consent. Caregivers were excluded if they were bereaved in the previous 6 months and if they were bereaved more than 5 years.

3.5.3 Data collection

Data was collected by a trained researcher (MM) using face-to-face interviews. The bereaved caregiver interviews were carried out in a similar way to phase 2, following a comparable semi-structured interview schedule noted previously.

3.5.4 Qualitative data analysis

The interviews were digitally recorded and transcribed verbatim. Thematic analysis[62] using a framework approach was undertaken using the themes from phase 2.

4. Results from phase 1: Postal survey with patient-caregiver dyads

4.1 Response rate

Of the 201 patient and 176 caregiver questionnaires posted, 112 and 86 patient and caregiver questionnaires were returned, representing a 56% and 49% response rate respectively. The proportion of patients and caregivers recruited from NI and the ROI is reported in table 3. There were significantly more patients recruited from NI (n=68) compared to the ROI (n=44) (P=0.023). However as noted in table 3 the response rate was higher in the ROI with 75% of patients and 72% of caregivers returning completed questionnaire packs.

Table 3 Recruitment response rate

	Northern Ireland			Republic of Ireland			Total		
	Posted	Returned	RR	Posted	Returned	RR	Posted	Returned	RR
Patients	142	68	48%	59	44	75%	201	112	56%
Caregivers	126	50	40%	50	36	72%	176	86	49%

RR: Response rate

4.2 Demographics

Patient and caregiver demographic data from both NI and ROI were combined and outlined in table 4. The patients and caregivers had a mean (SD) age of 74.9 (9.88) years and 63.9 (14.30) years respectively. As expected the majority of the patients were male (73%) and caregivers were predominantly female (80%). A large proportion of patients (65%) and caregivers (88%) were married/cohabitating and almost all patients (96%) and caregivers (92%) reported having someone who they could confide in. The majority of patients (88%) and caregivers (89%) reported having a religious/spiritual faith and (88%) and (87%) patients and caregivers respectively, drew comfort from their faith. Most caregivers were married or partners of the patient (n=58) followed by a son or daughter (n=24). Some seven patients were cared for by their sibling or a member of their siblings' family (i.e niece). One caregiver was a friend of the patient and seven of the patients reported their caregiver to be a combination of different people rather than one individual.

Table 4 Patient and caregiver demographics

	Patients		Caregivers	
	n	(%)	n	(%)
Gender				
Males	82	(73)	17	(20)
Females	30	(27)	67	(80)
Marital status				
Single	10	(9)	7	(8)
Divorced/separated	4	(4)	2	(3)
Married	71	(64)	74	(88)
Co-Habiting	1	(1)	-	-
Widowed	25	(22)	1	(1)
Education				
Primary	30	(27)	10	(12)
Secondary	66	(59)	52	(63)
University	16	(14)	21	(25)
Employment				
Employed	3	(3)	24	(29)
Sick leave/disability	8	(7)	4	(5)
Retired	91	(81)	38	(46)
Unemployed	1	(1)	2	(3)
Homemaker	9	(8)	14	(17)
Financial stability				
Living comfortably	43	(40)	28	(33)
Doing alright	39	(36)	29	(35)
Just about getting by	18	(17)	17	(20)
Find it quite difficult	4	(4)	8	(10)
Finding it very difficult	3	(3)	2	(2)
Smoking status				
Smoker	5	(5)	7	(8)
Never smoked	48	(44)	55	(66)
Ex-smoker	55	(51)	22	(26)

4.3 Time caregivers spent caring

It was found that over half the caregivers spent an excess of 50 hours a week, in general, with the patient and a great deal of the caregivers (84%) spent up to 10 hours a week attending medical appointments with the patient, as reported in table 5.

Table 5 Time caregivers spent on caregiving activities 4.4 Questionnaire tools

Hours per week	Household tasks		General time		Attending medical appointments	
	n	(%)	n	(%)	n	(%)
< 5	9	(11)	4	(5)	41	(50)
5-9	17	(21)	8	(10)	28	(34)
10-19	13	(16)	7	(9)	3	(4)
20-49	23	(28)	14	(17)	3	(4)
50+	21	(25)	49	(60)	7	(9)

A comparison of patient and caregiver scores for each of the questionnaire tools is presented in table 6. It was found that patients were older, more depressed (PHQ-9) and had poorer QoL (MLHFQ) than the caregivers. In particular, the patients' physical QoL (MLHFQ) was significantly poorer than the caregivers', albeit, there was no difference in their emotional QoL (MLHFQ), suggesting the condition had a similar impact on the patients' and caregivers' emotional QoL.

Table 6 Differences in patient and caregiver results from validated tools

	Patients		Caregivers		
	Mean	(SD)	Mean	(SD)	P-value
Age	74.9	(9.88)	63.9	(14.30)	<0001
PHQ-9	8.5	(6.69)	5.2	(5.72)	0.001
GAD-7	5.4	(5.45)	6.6	(6.62)	0.201
MLHFQ total	53.6	(25.18)	34.9	(31.09)	<0001
MLHFQ physical	26.6	(11.07)	14.8	(13.17)	0.001
MLHFQ emotional	10.2	(7.95)	9.3	(7.63)	0.414
MSPSS	5.4	(1.44)	4.9	(1.96)	0.069
Self-care maintenance	57.5	(15.89)			
Self-care management	50.8	(21.10)			
Self-care confidence	57.1	(21.42)			
SIBHF	40.3	(4.35)			
ZBI			27.5	(19.27)	
Preparedness for caregiving			2.4	(0.99)	
CSNAT total			8.5	(7.30)	

SD: Standard deviation; PHQ: Patient Health Questionnaire; GAD: Generalized Anxiety Disorder; MLHFQ: Minnesota Living with Heart Failure questionnaire; MSPSS: Multidimensional Scale of Perceived Social Support; SIBHF: Survey of Illness Beliefs in Heart Failure; ZBI: Zarit Burden Interview; CSNAT: Carers Support Needs Assessment Tool

4.5 Social Inequality:

4.5.1 Impact of financial stability on health outcomes

Financial instability appears to be associated with poorer health outcomes for both the patients and caregivers in relation to depression and anxiety. Depression scores were significantly higher for those "just about getting by" compared to those "living comfortably", (mean (SD) PHQ-9 score 13.9 (7.21) vs. 5.7 (5.08) P<0.001). The results were similar for patients' anxiety scores with those reporting "just about getting by" having significantly higher anxiety scores compared to those "living comfortably" (mean (SD) GAD-7 score 8.5 (622) vs. 4.0 (5.31) P=0.020). The results for the caregivers were similar with a significant difference in caregivers' depression and anxiety scores between financial stability groups. Post hoc analysis indicated significantly higher depression scores for caregivers who reported "finding it difficult/very difficult" compared to those who were "living comfortably" (mean (SD) PHQ-9 8.6 (6.96) vs. 2.18 (2.52) respectively P=0.014) and similarly significantly higher anxiety scores for the same group of caregivers (mean (SD) GAD-7 9.6 (6.62) vs. 3.1 (3.02) P=0.040).

4.5.2 Impact of financial stability on QoL and burden

There was a significant difference in the overall QoL of patients who reported "living comfortably" compared to the other financial stability groups (P<0.05). Similarly, there was a significant difference in the emotional Qol and physical QoL between those "living comfortably" and all the other groups (P<0.05). This suggests better overall, emotional and physical QoL for those "living comfortably". Table mean (SD) Qol scores for each of the patient's financial stability groups are presented in table 7.

Table 7 Patients' Qol results for each financial stability group

	Overall QoL (MLHFQ)		Physical QoL (MLHFQ)		Emotional QoL (MLHFQ)	
Financial stability	Mean	(SD)	Mean	(SD)	Mean	(SD)
Living comfortably	35.3	(25.42)	20.5	(12.03)	5.48	(6.60)
Doing alright	55.4	(19.85)	29.0	(9.12)	11.19	(7.42)
Just about getting by	70.7	(15.96)	30.4	(9.19)	14.43	(5.77)
Finding it difficult/ very difficult	73.4	(13.32)	34.5	(3.78)	15.56	(7.08)

MLHFQ: Minnesota Living with Heart Failure Questionnaire

Financial strain appeared to have a similar impact on caregivers QoL. There was a significant difference in the overall and physical QoL of the caregivers who reported "living comfortably" compared to all other financial stability groups (P<0.05). Caregivers emotional QoL only differed significantly between the "living comfortably" and "just about getting by" groups (P=0.001). The mean scores for all the financial stability sub groups on the QoL scales are shown in table 8. Financial stability was also shown to be associated with caregiver burden (ZBI) and caregivers "just about getting by" had significantly higher burden scores compared to those "living comfortably" (mean (SD) ZBI 38.6 (20.44) vs. 18.8 (11.94) P=0.007).

Table 8 Caregivers' QoI results for each financial stability group

	Overall QoL (MLHFQ)		Physical QoL (MLHFQ)		Emotional QoL (MLHFQ)	
Financial stability	Mean	(SD)	Mean	(SD)	Mean	(SD)
Living comfortably	14.3	(15.08)	5.6	(6.06)	5.5	(5.89)
Doing alright	36.6	(31.08)	17.8	(14.12)	9.4	(7.81)
Just about getting by	61.6	(26.19)	23.0	(11.75)	14.6	(6.73)
Finding it difficult/ very difficult	49.7	(37.04)	17.8	(13.61)	11.1	(8.20)

MLHFQ: Minnesota Living with Heart Failure Questionnaire

4.5.3 Impact of education on health outcomes and QoL

Interestingly a large proportion of this cohort of patients and caregivers were educated to secondary or university level as is reported in table 4 and analysis of variance did not indicate any difference in health outcomes or QoL for each of the education levels.

4.6 Depression, anxiety and quality of life

The results from the depression scale show 19 (20%) patients and 6 (9%) caregivers had a score warranting further clinical evaluation for depression and 19 (19%) patients and 18 (24%) caregivers had an anxiety score warranting further evaluation on the GAD-7 scale (table 9).

As a measure of QoL, patients were asked to answer 21 questions to gauge how their condition prevented them from living as they would want in the previous month and commonly used cut-offs were applied to identify those with poor QoL (67%). Although, when patients were asked to self-report their QoL at the end of the questionnaire only 27% patients self-reported their QoL as poor. This suggests patients were less reluctant to acknowledge their QoL was poor even though their responses on the questionnaire suggest it was.

Table 9 Proportion of depression and anxiety self-reported by patients and caregivers

	Patients		Caregivers	
	n	(%)	n	(%)
PHQ-9 Depression				
Minimal	31	(33)	41	(60)
Mild	30	(32)	15	(22)
Moderate	13	(14)	7	(10)
Moderately severe	10	(11)	5	(7)
Severe	9	(10)	1	(1)
GAD-7 Anxiety				
Mild	62	(61)	41	(56)
Moderate	21	(20)	15	(20)
Severe	19	(19)	18	(24)

PHQ: Patient Health Questionnaire; GAD: Generalized Anxiety Score

When patients were grouped based on their age, patients younger than 75 years were shown to have higher levels of depression (PHQ-9) (P=0.024) and anxiety (GAD-7) (P=0.005) and poorer QoL (MLHFQ) (P=0.005) compared to those aged ≥ 75 years. Correlation analysis was conducted to determine whether relationships existed between depression, anxiety and QoL. Results indicated patients' depression scores (PHQ-9) and their QoL (MLHFQ) (r=0.706 P<0.001) scores were related as were their anxiety (GAD-7) and QoL (MLHFQ) scores (r=0.529 P<01), suggesting patients who were more depressed and anxious had poorer QoL.

The results were similar for the caregivers, with those younger than 75 years having poorer QoL (MLHFQ P=0.035) compared to caregivers ≥ 75 years and similarly a relationship existed between caregivers' depression (PHQ-9) and QoL (MLHFQ) (r=0.743 P<001) and their anxiety (GAD-7) and QoL (MLHFQ) (r=0.806 P<0.001). Again this suggests caregivers who were more depressed and anxious had poorer QoL.

When patient and caregiver outcomes were correlated with each other, the findings suggested a relationship between patient-caregiver depression scores (PHQ-9) (r=0.522 P<0.001) and their anxiety scores (GAD-7) (r=0.460 P<0.001).

Patients were then grouped based on whether their anxiety score (GAD-7) warranted further evaluation and then their matched caregivers' QoL was evaluated. Results indicated that caregivers had poorer physical (P=0.002), emotional (P=0.010) and overall QoL (P=0.001), when caring for a loved one whose anxiety levels warranted clinical evaluation. The emotional and physical aspects associated with caring for an anxious patient with heart failure does appear to impact on the caregivers' overall QoL.

4.7 Patients' Illness beliefs and self-care

More than half the patients (n=59, 64%), were identified as having inaccurate knowledge of their condition. The patients were then grouped based on whether they had accurate or inaccurate

knowledge and their matched caregivers' health outcomes, QoL and burden were evaluated. Results showed patient's knowledge of their condition had no impact on caregiver outcomes as there was no significant difference in the caregiver depression, anxiety, Qol or burden scores. It was found that patients with inaccurate knowledge had significantly lower self-care maintenance scores (SCHFI maintenance mean (SD) 54.9 (14.72) vs. to 62.7 (15.71) P=0.109) and management scores (SCHFI management mean (SD) 45.6 (18.74) vs. 58.9 (20.58) P=0.034), which suggests patients with poorer knowledge of their condition have poorer self-care abilities.

It was found that patients from ROI scored statistically higher on the maintenance scale of the SCHFI compared to patients in NI (P= 0.001) and patients who were not married scored significantly higher on the self-management scale compared to those patients who were married (P=0.036). This would suggest that these patients would have better self-management of their condition.

There was a significant relationship between patient's self-care maintenance (SCHFI) score and caregiver depression (PHQ-9) scores (r=-0.356; P=0.003) and patients' self-care maintenance (SCHFI) and caregiver anxiety (GAD-7) score (r=-0.239 P=0.045). This would suggest caregivers were more likely to be depressed and experience anxiety when caring for patients with less self-care abilities.

4.8 Specialty services patients received

Patients were asked to self-report the number of appointments they had with healthcare professionals (GP, Consultant, Cardiologist, Heat Failure Nurse, Community/District nurse) in the previous 6 months. The results ranged from 1-51 appointments, with some 26 (25%) patients reporting they were not in receipt of any HF services in the previous 6 months.

There was a significant relationship between the number of visits patients had with healthcare professionals and both their overall QoL (MLHFQ) (r=0.294 P=0.017) and physical QoL (MLHFQ) (r=0.317 P=0.003). This suggested that patients' overall and physical QoL declined, the more frequently they attended appointments. However, correlation analysis also revealed patients had better scores on the self-care management scale, when they attended more medical appointments (r=0.275 P=0.035). This would suggest that whilst medical review appointments are required to assist in self-care management the frequency of these and accessibility can impact on patients overall and physical quality of life.

4.9 Burden and perceived social support

Results from the burden scale (ZBI) demonstrated that most carers 43 (57%) had some level of distress, 21 (28%) of which was graded as moderate to severe and more than half the caregivers 40 (53%) reported levels of distress that could be associated with depression.

There was a significant positive correlation between patients' level of depression (PHQ-9) and caregiver burden (ZBI) (r=0.456 P< 0.001) and patients' level of anxiety (GAD-7) and caregiver burden (ZBI) (r=0.366 P=0.002). This would suggest that caregivers experience greater burden when caring for patients with higher levels of depression and anxiety. Furthermore, there was a positive correlation between patients' QoL (MLHFQ) and caregiver burden (ZBI) (r=0.309 P=0.027), indicating greater caregiver burden when caring for patients' with poorer QoL (MLHFQ).
Caregivers with levels of distress associated with depression, had significantly lower support scores

from a significant other (mean (SD) MSPSS 4.6 (214) compared to 5.8 (2.05) P=0.027) and family (mean (SD) MSPSS 38 (210) compared to 5.2 (2.39) P=0.012). Therefore, improving support could have a positive effect of caregiver distress.

4.10 Predictors of caregiver burden

Various patient and caregiver items were entered into regression models to identify variables that predict caregiver burden (see section 3.3.5 quantitative data analysis for the variables included in the regression models). Caregiver anxiety (GAD-7) was a significant predictor of caregiver burden [(β=0.716 P<0.001) F(6,56)=11380 P<0007] and patient depression score (PHQ-9) was also a significant predictor of caregiver burden [(β=0.389 P=0.016) F(2,62)=8.373 P=0.001]. Patients' social support, illness beliefs or self-care scale did not predict caregiver burden.

4.11 Social support and QoL

Analysis was conducted to determine whether caregivers with varying levels of social support had different outcomes in relation to their QoL. Results indicated caregivers had better physical QoI (MLHFQ) when they had high levels of social support, compared to moderate levels of support (P=0.035).

4.12 Carers support needs assessment tool

The most reported support need was the domain focusing on the future, with 64% of caregivers expressing a need for more support in knowing what to expect in the future. More than half the caregivers also required more support in dealing with their own feelings and worries (58%), support to help them understand their relative's illness (57%), making time for themselves during the day (51%), looking after their own health (53%) and knowing who to contact if concerned about their relative (53%) (figure 3).

A total score was calculated for the CSNAT tool and it correlated positively with caregiver burden (ZBI) (r=0577 P<0001) suggesting caregivers with greater burden also reported needing more support. There was also a relationship between the CSNAT score and the preparedness for caregiving tool (r=-0.401 P<0.001), the MSPSS significant other (r=-0.315 P=0.008), the MSPSS family (r=-0.305 P=0.001) and the MSPSS friend (r=-0.391 P=0.001). These results would indicate that caregivers with less social support from a significant other, family and friends have greater needs according to the CSNAT tool.

4.13 Preparedness for caregiving

Caregivers cited "the Future" as the area they felt most unprepared for. Caregivers also reported wanting to be more prepared in relation to changes to medication, continence management and helping the patient get dressed and out for exercise.

The score from the caregiver's preparedness for caregiving scale was correlated with other caregiver outcomes and there was a significant positive relationship between the preparedness scale and caregiver burden (ZBI) (r=-0.452 P<0.001) and preparedness and QoL (MLHFQ) (r=-0.254 P=0.041). These results would indicate the more prepared caregivers were the less distress they experienced, with a subsequent impact on their QoL.

Furthermore, there was a significant positive correlation between preparedness and social support (MSPSS) (r=0.324 P=0.006), suggesting caregivers with more support felt more prepared for their role.

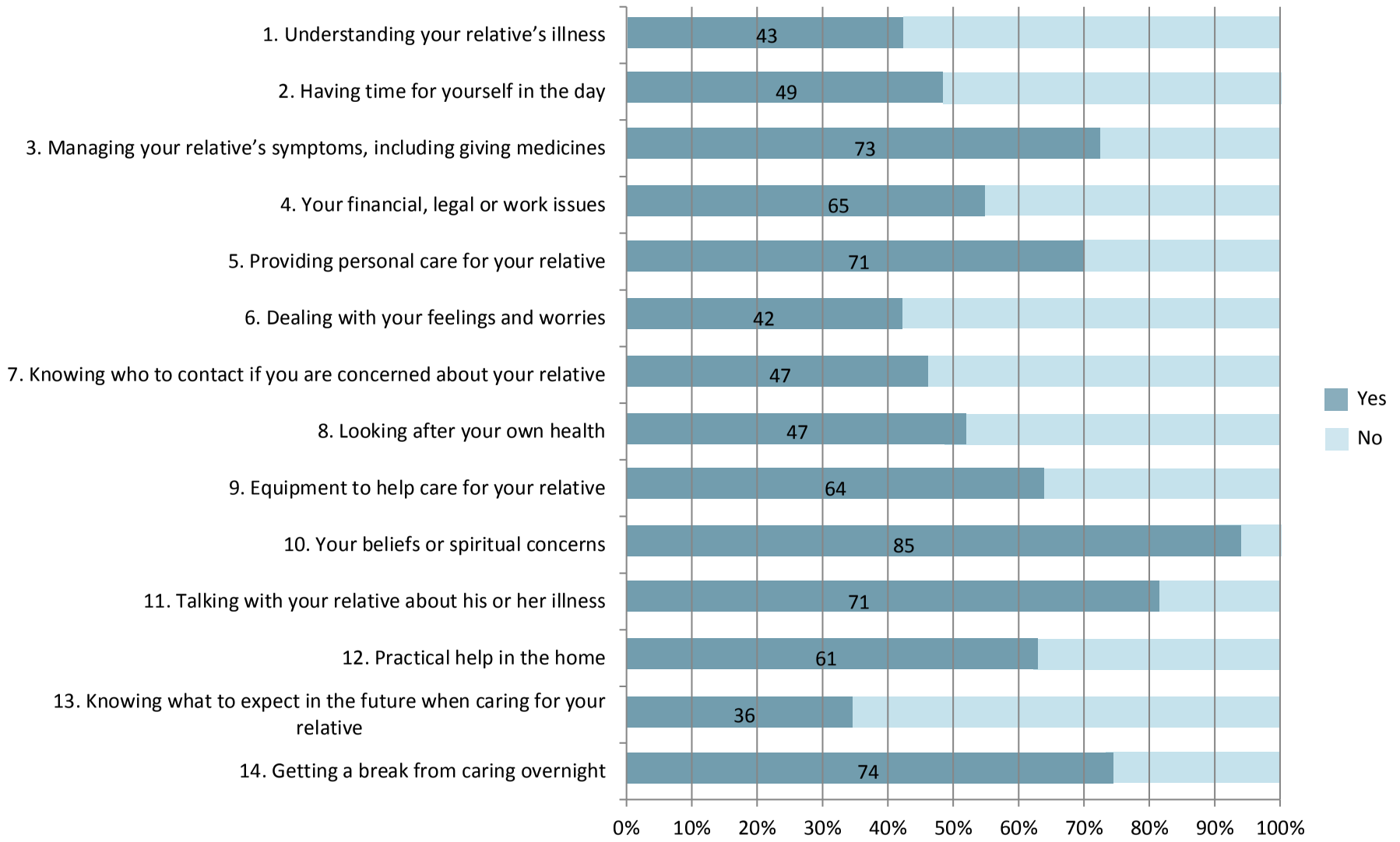

Figure 3 Results from the CSNAT reporting the proportion of caregivers expressing a need for more support with tasks associated with their caring role.

4.14 Summary of findings

- Financial strain was associated with poorer health outcomes (depression and anxiety) for the patients and caregivers
- Caregivers who were less financially stable had greater burden
- Education level had no impact on health outcomes or QoL for patients or caregivers
- Patients were more depressed and had poorer QoL compared to the caregivers
- Younger age (<75) was associated with poorer outcomes in relation to depression, anxiety and QoL
- Depression and anxiety impact on QoL for patients or caregivers
- Improving patient knowledge could lead to better self-care
- Patients managed their condition better when they interacted more with healthcare professionals, albeit, attending more appointments was associated with reduced QoL
- Caregivers anxiety score predicted burden.

Impact of caring on caregiver

- There was a greater impact on caregivers QoL when caring for patients who were more depressed and anxious
- Caregivers caring for patients with reduced QoL, greater depression and anxiety experienced greater caregiver burden
- Caregivers were more likely to be depressed and experience anxiety when caring for patients with less self-care abilities
- Patients depression contributed to caregiver burden
- Caring for a loved one with HF had less impact on caregiver physical QoL when they had high levels of social support

Caregiver support needs & preparedness

- Caregivers with levels of distress associated with depression had less support from a significant other or family
- Caregivers who expressed a need for more support according to the CSNAT had less social support from a significant other and family and have greater burden
- Caregivers with more support felt more prepared for their role
- Caregivers need support dealing with the future
- Caregivers who were more prepared for their role experienced less burden and caring impacted less on their QoL

5. Results from phase 2: Qualitative interviews with current caregivers

In this section the results are presented on the qualitative analysis of the current caregivers. A total of 20 face-to-face interviews were carried out on the Island of Ireland. The majority of caregivers were female (n=15), spousal caregivers (n=14), 1 sibling caring for her sister and 5 children caring for a parent. There was an even representation North and South of Ireland. The purpose of the analysis was to get an understanding of the caregivers QoL and identify common issues reported by the caregivers, where they would benefit from having more support. Figure 4 represents the three themes describing the context of the caregiving role, which has been described as 24-7, where their life is ruled by the condition and they experience a vast number of positive and negative emotions surrounding their role as a caregiver which has been described here as an emotional rollercoaster. In addition, two main themes of support needs have been included, which are a need for improved service provision and emotional support. Communication was the common aspect within the overarching seven sub-themes and it is clear that improved communication is a fundamental part of each of the support needs reported.

5.1 Context of the caregiving role

In the following section the context of the caregiving role is explained leading on to the support needs identified. All of these are supported with a number of quotes taken from the interviews and additional supporting quotes can be found in appendix I.

5.1.1 Theme 1: Its 24-7

All the caregivers reflected on their role as being "24-7". They are living with it 24 hours a day, there is no such thing as a day off and they are constantly watching the patient waiting for something to happen, which appears to be more of a burden for caregivers living with their loved one. The condition is so unpredictable the caregivers are afraid to leave the patient alone and if they do, they feel guilty. The following quotes reflect the caregiver's perception of their role being 24-7.

> ***"The whole life, from sitting watching, from the morning until he goes to bed at night, to him being sick. If I see a car pulling up, it is straight over, in case it is a doctor pulling up."*** (ID 1034)

> ***"I find that he is very unsteady on his feet so I am 24/7 keeping an eye on him. Where he is going, what he is doing."*** (ID 1138)

> ***"Sometimes I would love a break. But I go off and worry and it isn't worth it."*** (ID 1093)

Nevertheless, the majority of caregivers do this out of love and feel it is their duty as a spouse, sibling or child, to provide this care for their loved one, to motivate them to care for themselves.

> ***"we are still very much in love... I still care for her an awful lot and am happy doing it. There is a lot of satisfaction in it for me."*** (ID 1098)

Although caring for someone with HF can be 24-7 a number of the caregivers reported getting a great deal of satisfaction from caring and were accepting of their role.

5.1.2 Theme 2: My life is ruled by the condition

It was a common feeling among the caregivers that the patients' needs were their first priority and they often made reference to putting things on hold because of the patients' health. HF limits not only the patient's life, but also the caregivers which leads to caregivers feeling their life was no longer their own, but "ruled by the patient's condition". The following extracts reflect these feelings.

> ***"I don't have a life. My life is sitting in the chair watching."*** **(ID 1034)**

> ***"My life has gone on hold and I am much better able to go around and do things. There are things I would like to do but I can't always do them. I find it difficult to, I suppose a lot of the time..."*** **(ID 1098)**

Older caregivers seem to be more accepting of life's progression and seen the deterioration of health as a part of getting older, with younger caregivers finding their role more difficult.

> ***"Its no great hardship, when you have been with somebody and will be married coming 50 years this September, you expect to do that for one another."*** **(ID 1141)**

> ***"I am a bit younger than he is and I still have life in me. It does affect me. I would like to be doing more and feeling free, but I am not."*** **(ID 1114)**

This feeling that "life is ruled by the patient's condition", can lead to feelings of isolation, frustration and fear given the demanding nature of caring.

5.1.3 Theme 3: It's an emotional rollercoaster

There were a number of negative emotions surrounding the caregiving role, such as stress, worry, sadness, loneliness, fear, blame and denial. They felt problems were never ending and given how unpredictable HF symptoms can be, caregivers found it difficult to cope day-to-day when caring for a loved one living with HF. These emotions had a negative impact on their QoL and daily living, with sleep disturbances, depression and anxiety being reported. The following quotes explain the emotions surrounding caring.

> ***"just panic and hopelessness. Not able to do anything and sad, all the emotions that go with this I suppose."*** **(ID 1093)**

> ***"I get the tightness in my stomach. I get the feeling of dis-ease..."*** **(ID 1106)**

> ***"I was scared, I was angry.... Why is this happening to me, why is this happening to [patient]..."*** **(ID 1136)**

There were a number of positive comments in the data with reference to the support caregivers got from family, friends and neighbours, enabling them to get a break from their caring role to go for a walk, socialise or go shopping. Although, there were a similar number of caregivers who expressed a need for more support in order to help them on their caring journey.

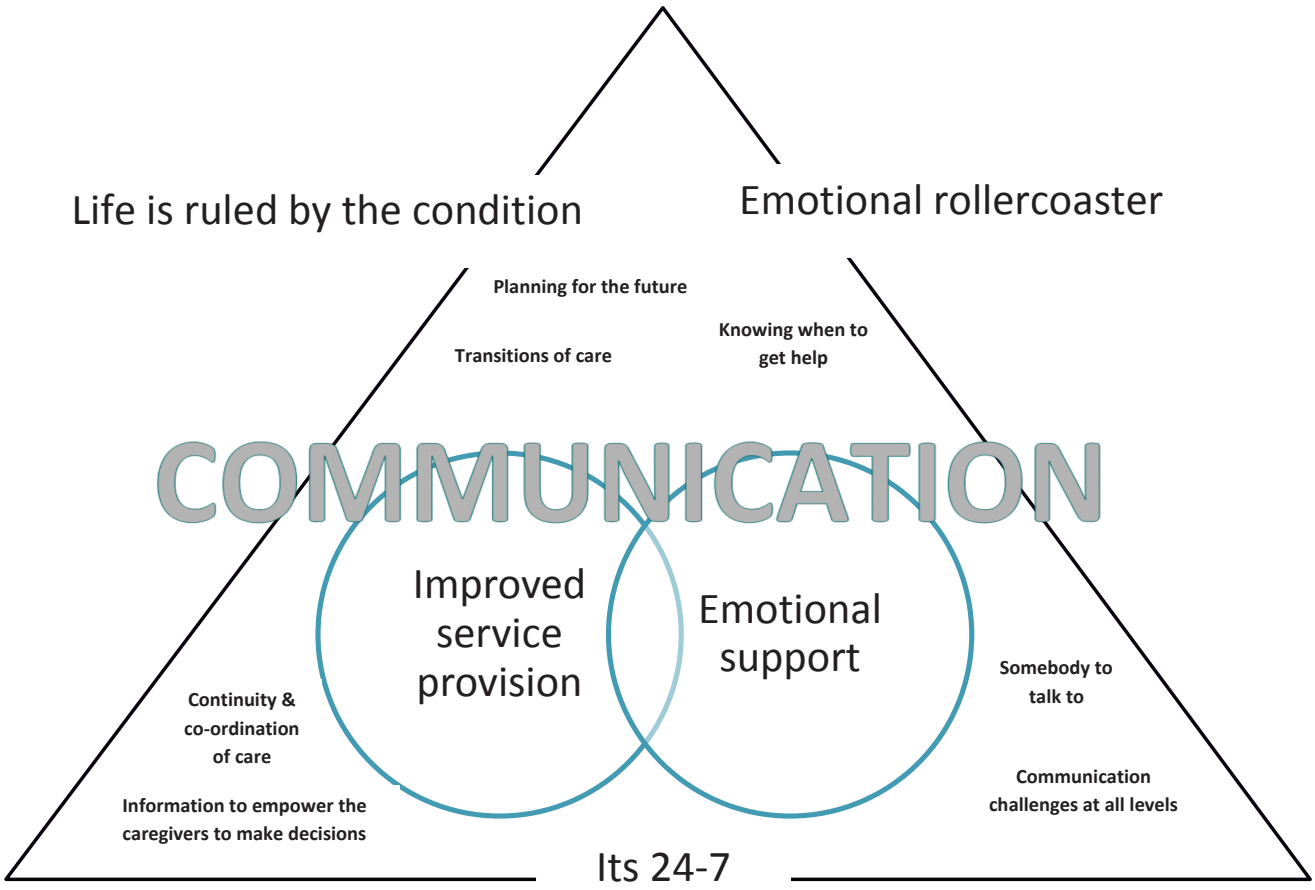

Figure 4: Context of the caregiving role and support needs identified

5.2 Caregivers' support needs

Caregivers support needs were categorised into two key themes and 7 sub categories. The two distinct themes were: improved service provision and emotional support. An overview of each subcategory and their supporting quotes are included in this section and additional quotes for each subtheme are included in appendix I.

5.2.1 Theme 1: Improved service provision

5.2.1.1 Planning for the future

5.2.1.2 Continuity and co-ordination of care

5.2.1.3 Transitions of care

5.2.1.4 Information to empower the caregivers to make decisions

5.2.2 Theme 2: Emotional support

5.2.2.1 Knowing when to get help

5.2.2.2 Somebody to talk to

5.2.2.3 Communication challenges at all levels

5.2.1 Theme 1: Improved Service provision

5.2.1.1 Planning for the future

Planning for the future included the "here and now" of how patients and caregivers manage on a daily basis as well as thinking into the future and issues surrounding end of life. The caregivers spoke about felling supported when they were provided with practical assistance to enable them to care for their loved one at home, to ensure the patient could manage with activities of daily living. In some instances, caregivers felt they were able to provide the care without any additional assistance, although, it would be beneficial for the caregiver, if they had information on the support available to them, so that they could seek support if and when they decide they needed it.

> ***"They got him a cane stick... we bought a wheelchair for him...eventually we did get a rolator for him...We're lucky in that our doctor gave us a disabled pass for him."*** (ID 1122)

A number of the caregiver's fears and anxieties were associated with the future and not knowing what to expect. They felt unprepared and expressed the need for information on knowing what to expect in regards to signs of deterioration and end of life issues. All the caregivers are thinking about issues surrounding their loved one's death and felt unprepared for the future.

> ***"I said Is that a sign? Is he just going to get cold? We don't know what you are supposed to do."*** (ID 1034)

> ***"I just would like to have some idea of how far down we are, down that sliding scale, I think we might be coming very close to that."*** (ID 1122)

Equally some caregivers were reluctant to think about or discuss the future; happy to take each day at a time and not dwell on the future. Each patient-caregiver dyad had different preferences in relation to the amount of information they wanted regarding how imminent end of life is.

> ***"I probably would. I am probably burying my head in the sand, I suppose. If I don't know, is it going to give him longer? Well, it is not really. It is just me, scared to know, probably more than anything."*** **(ID 1138)**

Each of these caregivers was caring for a loved one with advanced HF, yet none of them had been offered any palliative support. The caregivers noted that they only considered palliative care services as related to the care of cancer patients and did not consider palliative care could be available for patients with HF and their caregivers.

> ***"They are for cancer, really at the moment aren't they? The palliative care, is that just for cancer?"*** **(ID 1093)**

> ***"even to get information on palliative care would be something. What goes on, what it involves, to have that would be something."*** **(ID 1096)**

5.2.1.2 Continuity and co-ordination of care

Many of the caregivers described instances when they were unhappy with the care the patient received from healthcare professionals. They expressed the need for improved service provision, in particular better continuity of care within the HF services and better co-ordination between different disciplines. The following extracts highlighted situations whereby the caregivers felt care was inadequate.

> ***"And there was nothing really decided, no check-ups through the heart team unless he was rushed into hospital."*** **(ID 1034)**

> ***"The heart people, they put her on the warfarin and then they ask why she is on warfarin. They put her on it! You don't see the same one. I don't think she has ever saw the same one twice."*** **(ID 1038)**

> ***"Then you ring and one tries to pass it off to the other... One Dr says yes, one Dr says no, one Dr says yes, one says no."*** **(ID 1034)**

The majority of patients had comorbidities and were receiving specialist care from multiple disciplines, making caring for them at home more complex and the caregivers had expressed a need for better continuity and co-ordination of care.

5.2.1.3 Transitions of care

As HF has a very unpredictable trajectory, with the patient often experiencing periods of deterioration requiring hospitalisation, caregivers outlined that during these points of transition they required additional support. It was found that some caregivers considered a hospital admission as providing them with some respite, however for others hospital admissions became more time demanding. The

following quotes reflect how the caregivers felt during the patient's transition of care, highlighting their support needs during this time.

> *"When he comes home no, there's nothing in place... Now I lost it when he came home, I just exploded. Burst out into tears and really got very upset."* **(ID 1122)**

> *"And to get him into hospital was such a relief that somebody else had the responsibility because I couldn't do anything."* **(ID 1136)**

> *"the worst thing was getting across to the hospital and visiting. He likes me to visit and visiting twice a day for the first couple nearly killed me."* **(ID 1136)**

5.2.1.4 Information needs to empower the caregiver to make decisions

The caregivers had major information needs. These initiated when the patient was diagnosed and their frustration with the lack of information from healthcare professionals continued throughout the patient's disease trajectory. The caregivers expressed a need for more information on the patient's diagnosis and how to manage symptoms.

> *"the heart attack happened and then a few days after that we were given a booklet, a booklet was left with my husband which told him that he had heart failure...He'd been released from hospital, we'd been told he'd heart failure and that was it."* **(ID 1122)**

> *"You are helpless, you can't do anything. You don't get told anything."* **(ID 1034)**

> *"I think lack of information all along; it's lack of information from the staff."* **(ID 1136)**

In addition to receiving information regarding their loved one's condition, the caregivers noted the importance of sensitive communication.

> *"when I was in the hospital initially I spoke to one of the nurses. Anything I asked, I was given an answer. Whether I understood it or not, I was given an answer."* **(ID 1153)**

> *She said to him "You are in heart failure, it is a critical illness you know what is going to happen". She said, "you know we are all going to die at one point"."* **(ID 1034)**

5.2.2 Theme 2: Emotional support

It is clear from the data that the caregivers are living on egg shells dealing with this situation 24-7 and felt like they never got away from it. Caregivers need emotional support to help them make decisions relating to the patient's care, such as knowing when and where to get help, having someone to talk to who has walked the same journey and communication support to enable better patient-caregiver-family relationships.

5.2.2.1 Knowing when to get help

Caregiver's felt it was their responsibility to know when the patient's condition had deteriorated and warranted medical attention. This can be burdensome for caregivers and they expressed the need for support in managing the patients' condition, dealing with uncertainty and knowing when to get help.

> ***"I am always afraid something will happen in the middle of the night when it is dark and we are alone."*** **(ID 1093)**

> ***"if something happens, when he wakes up and he is not feeling great. Those kinds of things, those kind of decisions. I've usually been the one to make the decision; it is time to go the hospital."*** **(ID 1097)**

5.2.2.2 Someone to talk to who has walked the journey

In addition to having somebody to discuss the patient's medical condition with, the caregivers expressed the need for somebody to talk to on a more emotional level. They felt that nobody really understood what it is like, caring for the patient, unless they had been in a similar situation.

> ***"I suppose that sometimes I possibly like to chat with somebody who is in a similar situation. I have quite a number of friends but I am not sure if I want to start bleeding all over their day so to speak."*** **(ID 1102)**

> ***"there is no point in talking about it because to the outside world it doesn't look like that so what is the point in saying anything. Everyone thinks he is marvellous."*** **(ID 1114)**

5.2.2.3 Communication challenges at all levels

Challenges and barriers to communication can impact on relationships between the patient, caregiver, family and healthcare professionals. The caregivers were concerned that perhaps patients were not being honest about their condition and similarly the caregivers expressed reluctance to discuss their concerns with their loved one, their friends or family.

> ***"My only worries are if he's sick and he's not telling me, that's my only worry but that's his personality."*** **(ID 1096)**

> ***"I am trying to keep all this away from her because the doctors told me I have to keep her stress free... I could share it with her but I don't want to. Because it is stress."*** **(ID 1153)**

> ***"She said to him "You are in heart failure; it is a critical illness you know what is going to happen". She said "you know we are all going to die at one point"."*** **(ID 1034)**

5.3 Conclusion

HF has an unpredictable disease trajectory and patients often have complex medical needs. Being a caregiver for a patient living with HF can be over whelming. A lack of understanding, while feeling unsupported and alone, can increase caregiver burden. The results of this phase highlighted two major areas of support needs for these caregivers; improved service provision for the patient and emotional support for the caregiver and improved communication is central to meeting these support needs.

6. Results from phase 3: Qualitative Interviews with bereaved caregivers

In this section the results are presented on the qualitative analysis of the bereaved caregivers. Ten interviews were conducted in NI and all the caregivers were female. The majority of bereaved caregivers had cared for a parent (n=8) and two cared for a partner and other relative. The purpose of the analysis was to ascertain if the support caregivers received prior to the death of their loved one was adequate in helping them provide the best possible level of care at the end of life. All bereaved caregivers reported having no regrets about devoting so much time to caring for their loved one. Many felt that being able to care for their relative at home was in many ways difficult, however, the satisfaction that they felt in allowing the person to die at home and not in hospital surpassed any difficulties they encountered. There were two main themes in the data; Poor communication and Frustration.

6.1 Theme 1: Poor communication

The theme of 'poor communication' appeared in the data in all of the interviews with carers. Good communication between health care providers and caregivers is essential in allowing the caregiver to equip themselves both from a practical stance as well as enhancing psychological preparation for any health deterioration that their relative might experience. The theme of 'poor communication' has been refined into the following sub-sections as seen in figure 5.

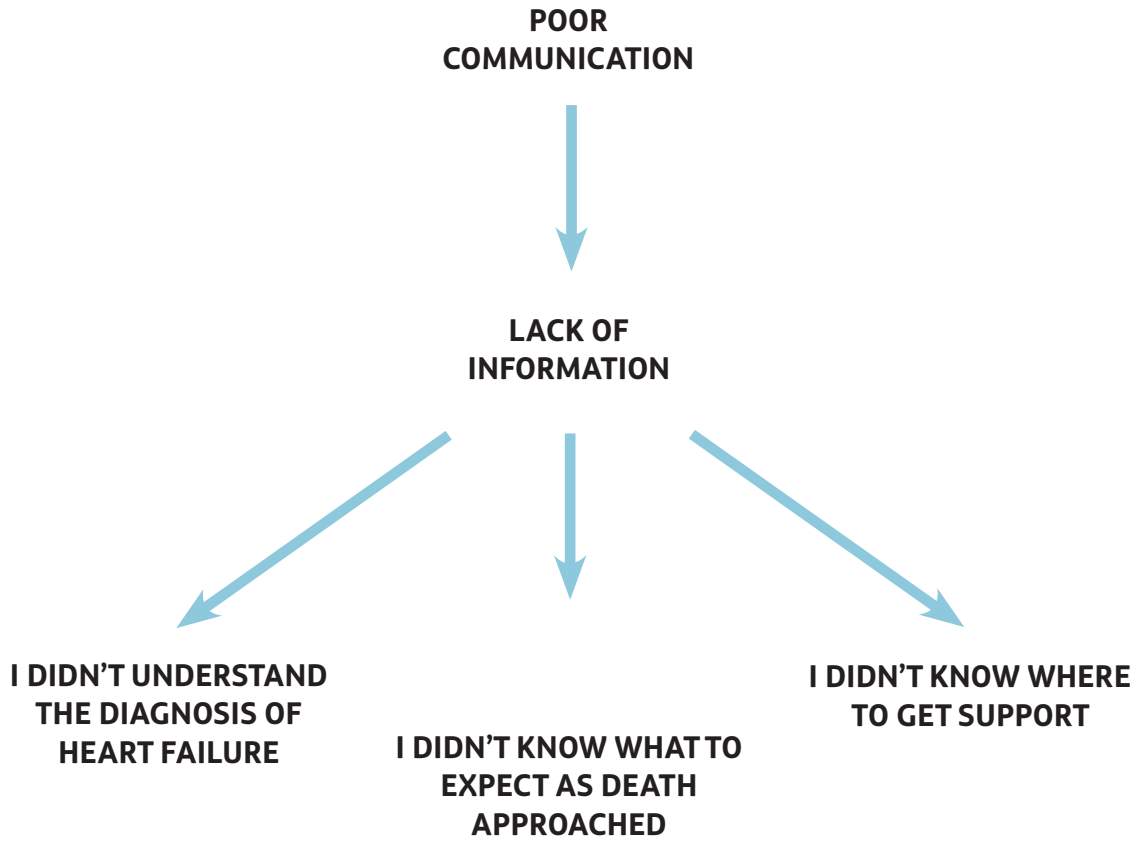

Figure 5 Theme 1: Poor communication

6.1.1 Lack of information

Caregivers were concerned with the lack of information they received from health care professionals, regarding their relative's condition.

> ***"Again I wasn't told very much. I found it frustrating."*** **(ID 01)**

This lack of information on occasions resulted in family members being unaware of their loved one's diagnosis and as a consequence, their poor prognosis.

> ***"They never told us. They never mentioned heart failure in the hospital."*** **(ID 03)**

> ***"Nobody would tell us that. Nobody ever once said, your mother is dying".*** **(ID 04)**

Many caregivers felt uncomfortable 'seeking out' information from nursing and medical staff. This was especially prevalent when their relative was hospitalised.

> ***"I think sometimes I think we were just too nice. I think we didn't assert, asking enough. I mean when the doctor wasn't on the ward and the nurse told us, we just thanked them. Maybe we should have said, "Well actually we would like to speak to the doctor". That was only Sunday and she was dead on Thursday."*** **(ID 03)**

There appeared to be an expectation among caregivers that information should be volunteered by nursing and medical staff, rather than the caregiver having to ask.

> **Researcher:** "Were you aware of her acute kidney injury at that time or afterwards?"

> ***"No afterwards, I paid £50 to get her records to find that out. Nobody has ever told me that."*** **(ID 02)**

> ***"I was relying on them to give me the information."*** **(ID 04)**

Caregivers needed honesty from healthcare professionals. This openness seemed an essential element in allowing the caregiver to face the reality of their loved one's guarded prognosis and by doing so allowing them to prepare both practically and emotionally for their eventual death.

> ***"Nobody said, "Your mother has progressive heart failure and is going to die."***

> ***"I think consultants need to be honest, stop being afraid, if your loved one is dying, then say it."*** **(ID 04)**

This lack of information also impacted on caregivers when preparing to take their relative home from hospital.

> *"The fact that no doctor would come and discuss his case and nobody would give us information to go home with."* **(ID 09)**

This lack of information resulted on occasions, in caregivers and patients not understanding the significance of the diagnosis of heart failure.

6.1.2 Not understanding heart failure

The data from the interviews suggested that on many occasions there was a distinct lack of knowledge regarding the long-term implications of a diagnosis of heart failure. This was evident both for the caregiver and their deceased relative.

> *"I don't know that my dad really knew what it meant. I don't think, to be fair, I don't think I knew what it meant. To be honest I just thought it was that he had a bit of fluid on his lungs, that he needed these tablets and that would keep it at bay."* **(ID 06)**

Some caregivers who had also experienced a close relative dying from cancer felt that a diagnosis of cancer was much worse than a diagnosis of heart failure. There was a sense of relief that their loved one did not have cancer.

> *"I think the cancer one probably had a bigger impact; more because of the whole societal thing about chemo and cancer."* **(ID 09)**

> *"The world and his wife wants to give you support when you have got cancer and if you have got heart failure you just get on with it because there is not much we can do anyway."* **(ID 06)**

> *"I went in thinking it was lung cancer and yes lung cancer in my view would be a worse diagnosis than heart failure."* **(ID 07)**

6.1.3 Not knowing what to expect near death

Many caregivers were concerned that they would not recognise the signs that death was approaching. This was especially prevalent for those who were caring for a relative at home.

> *"I didn't even know. I thought Jack would maybe go unconscious but he didn't. I didn't know what I was facing... The human body on its last legs is not a nice thing. You are really a baby in an adult body. I couple of her team were really very good. You always got, my overall impression of everybody, was don't ask too many questions. Maybe they thought I wasn't emotionally able to take it."* **(ID 01)**

Some caregivers had asked healthcare professionals what to expect, but reported being told that there could be any number of signs.

> *"He had obviously deteriorated but nobody was saying what the deterioration was or what to expect when he got home."* **(ID 08)**

> *"So, I was second-guessing how bad he was. It was a very, very stressful time. It was stressful because I felt completely, completely, alone. I felt completely responsible."* **(ID 06)**

This left many caregivers in a very vulnerable and unsure situation, and seemed to cause undue stress as they constantly worried about changing symptoms and their significance. They were unsure where to 'turn to' for help.

6.1.4 Not knowing how to get support

Caregivers struggled with knowing how and where to get help and advice during this very stressful time in their lives. This was especially so, when they were caring for their loved one towards the end of life, when their loved one's needs were changing as their condition deteriorated.

> *"I think I needed somebody to say, I wanted somebody to say, yes I think. I think I was at that stage where I wanted somebody to tell me what to do. I was too stressed, too emotional, too tired. I don't know what it was, everything I suppose."* **(ID 06)**

Healthcare professionals should be mindful that although caregivers are willingly caring for and tending to their ill relative, they have had no training to prepare them for such a role. They should not have to rely on some form of instinct to know what to do, but should instead be offered the support that is so essential at this emotional and stressful time.

> *"It is actually quite frightening that you're in charge of somebody so sick and you don't know what to do for them and you know they need serious medical help."* **(ID 09)**

> *"I think a definite diagnosis, if it is end of stage of life, I think family, whether they want to hear it or not, should be given contact numbers of every resource that is available to them; occupational therapy is a big one, for the wee practical things."* **(ID 08)**

This support may well improve the quality of life not just for the individual with heart failure, but also the caregiver.

> *"He would start sitting up in bed and get out of bed, but he couldn't stand so he would just fall on the floor. I am here on my own. I had nobody, no backup, no nothing and I had to sleep in here on the floor to stop him getting out of bed."* **(ID 09)**

Knowing how to get the correct support should result in caregivers feeling less isolated. Indeed, a minority of caregivers reported that eventually a particular member of the health care team arrived into their lives and made the caring experience much easier.

"He actually was referred to the heart failure specialist nurse who again was fantastic support to us. She really was super." **(ID 05)**

The following excerpt is referring to the first time a Marie Curie nurse arrived at their home.

"It was just like this angel had walked through the door. You knew, she came in and closed the curtains and did all sorts of wee things around the room, changed it and whatever and I just thought it was lovely. She made him very comfortable that night, there was something on his hands and she fixed it. it was just wee small things that very attentive and caring..." **(ID 09)**

There were also positive comments about the hospice coordinator after she had had a private chat with the patient.

"He was better. He was almost reassured. I don't know what she said to him. When she had come out for that initial visit just to make herself familiar, she left and she spoke to us all and she was a great source of contact for all of us. All of a sudden we had a hospital bed." **(ID 08)**

The following excerpt demonstrates how, lack of information and support can have financial consequences, as this lady's mother was purchasing incontinence pads from the Internet for her husband.

"I said, "Why are you paying £50 a box for incontinence pads?" She said she didn't care how much she had to pay. Mammy had actually mentioned it the carer girls. Mammy must have been running low on pads or something. She said, "Mine aren't coming for two days and I am going to run out." And the girls were saying, "What are you even doing buying them?" And all of a sudden we could have had pads galore, the house was coming down with them." **(ID 08)**

The data suggest that on occasions the needs of the caregiver are not met and this can result in a feeling of isolation, heightened anxiety and resulting stress. The two excerpts above suggest that having even one person that the caregiver can turn to for advice, may result in a better quality of life both for the patient and caregiver.

6.2 Theme 2: Frustration

The theme of 'frustration' appeared in many of the interviews. It was especially prevalent during hospital admissions. 'frustration' has been refined into the following sub-sections as seen in figure 6.

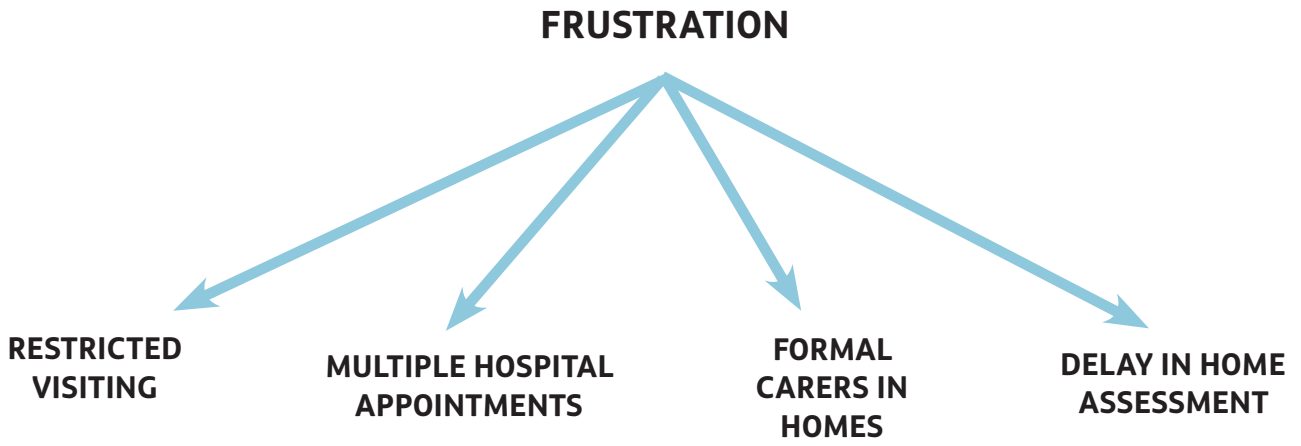

Figure 6 Theme 2: Frustration

6.2.1 Restricted visiting hours

Many of the caregivers reported their unhappiness and frustration at not being allowed to visit their relative outside set visiting hours. They did in fact understand the need for some restriction, especially during medical ward rounds. However, they could not comprehend why, as their relative's condition was deteriorating, that there was not more flexibility around visiting.

> ***"Easter Monday, visiting was 2-4 and 6-8 and we asked to get in on Easter Monday morning and they said, "No"."*** **(ID 03)**

> ***"As family we couldn't be in there 24/7. We were only allowed in at visiting times."*** **(ID 04)**

This restriction of visiting varied from ward to ward within the same hospital as the next excerpt demonstrates.

> ***"So they were very good and very accommodating. I got to spend that amount of time with him which I appreciated because on the other ward when I did spend extra time there, they said, "No, we can't have you obstructing our ward"."*** **(ID 06)**

This visitor restriction also had a direct 'knock-on' affect to their loved one's nutrition, as is clearly demonstrated below.

> ***"I think the nurses need to have more time on the wards, especially with elderly people whose appetite has gone. The dinners are put down in front of them and then the dinner staff are coming in and lifting that plate away and they are writing on the thing that she ate her dinner."*** **(ID 04)**

> ***"He had always been quite a slow eater anyway but we found we had to be there at lunchtime to feed him because it was kind of – if he said, "No I don't want that." Well that was fine, they just lifted the tray and walked away."*** **(ID 05)**

"He did need a bit of a hand with his food, he couldn't reach up to get a cup, he couldn't cut up his food and one day when I went up he said, Sure I had nothing to eat. They came and took it away again-I couldn't reach it." (ID 06)

6.2.2 Multiple hospital appointments

Journeys to various hospital appointments were reported as very difficult as the patient's condition deteriorated. Some respondents described having to bring their loved one to as many as three hospital appointments in one week. This included a warfarin clinic appointment; a heart failure nurse appointment and a cardiology appointment all on different days in one week.

> ***"Mammy had walked daddy in because his mobility was just awful near the end and he was on a wee frame. We had walked daddy in, he had lost an extortionate amount of weight and his legs were so fluid filled and he had difficulty breathing." (ID 08)***

> ***"Yet he would go to appointments, he maybe had four appointments a week which he wasn't fit to go to. He would go and I couldn't understand why people who are so ill, are asked to go to appointments." (ID 09)***

Despite the patient feeling extremely unwell, there seemed to be an element of 'doing what is felt to be expected by the doctor'

> ***"Should I have had to carry my father, my father had great respect. If you were told to go to an appointment, should you take me on your back Lorna, you go to them. They are busy."*** **(ID 08)**

> ***"It was absolute massive exercise because he was so poorly, but we got him into the car, got him on to a wheelchair at the hospital, got him into the hospital and they realised just how poorly he was."*** **(ID 06)**

There is no doubt that coordinating all appointments for one day would be difficult if not impossible. However, one has to wonder if there could be some adaptations made to allow for these very unwell individuals to condense appointments. This would also substantially reduce the onus that these multiple appointments place on caregivers.

6.2.3 Formal carers in the home

Some caregivers reported that their loved ones were unhappy about allowing 'strangers' into their home to help with care and as a result the family members shared the caregiving duties. This often involved creating a rota so that time spent away from other family members could be minimised. On many occasions the main caregiver had to reduce working hours or in some cases stopped work altogether (for a limited time). This no doubt had many implications including financial changes. In the following excerpt the caregiver reported being told by their GP that she was not entitled to any extra support. Following a visit by a district charge nurse things became better.

> ***"I wasn't entitled to anything. Then this guy had Marie Curie in, had this whole nurses, he had carers in, I didn't want carers but he was very astute. He said, Say yes to everything right now and then when they come in, if there is something you need from them, ask them and if you don't need them at that moment in time just say it is ok."*** **(ID 09)**

At times there seemed to be a dichotomy regarding the need for carers help versus maintaining dignity for their loved one.

> ***"So there would be three people standing watching him. Helping him up off the toilet in the morning to get his trousers pulled up and three women standing watching. Not very nice. It is quite degrading. From my point of view as a carer, I found them a little bit intrusive on my privacy in that they didn't seem to have any feeling that this was my home."*** **(ID 01)**

This same respondent reported that although she appreciated help, on occasions it was difficult coming to terms with strangers in their home.

> ***"They sat him down in his chair and he had his telly and his papers and he got a wee bite of tea and that was him until about 8.30pm 9pm, back they came again, another two, got him into his pyjamas and left him there. I paid somebody else to come in at 10.30pm to put him into bed. I paid £20 every night because Jack didn't want to go to bed at 8.30pm."*** **(ID 01)**

Concern was also expressed by caregivers at the length of time formal carers had, to attend to their loved ones.

> ***"Twice a day. Once in the morning for 15 minutes, that was to help get her up. And once in the evening for 15 minutes."*** **(ID 04)**

Many were concerned about the lack of consistency in formal caregivers delivering care to their loved on at home.

> ***"Then the staff kept changing and then she kept getting changed between services. There must have been some core group of people that came in and we got to know them quite well and then they were changed to somebody else and then she didn't know some of these people."*** **(ID 07)**

Despite feeling that at times, there were too many individuals coming into their home, there was a sense of loneliness following the death of their loved one. This loneliness was not only due to their bereavement but also due to the dramatic change in their circumstances as this following excerpt recalls.

> ***"Because I have gone from so many people across my door, to nobody. That sometimes is where the system fails. Everybody just walks away. It is not that I wanted anybody bowing and scraping to me. But nobody once came back to say, "Are you alright?" Suddenly everything just stopped."*** **(ID 01)**

6.2.4 Delayed home assessment

Many respondents were unhappy with the length of time it took to firstly get an occupational therapy (OT) assessment and then to have modifications made and appliances installed. Unfortunately, the first visit could occur after the individual had died.

> ***"An OT arrived at the door about a week after he died."*** **(ID 09)**

The following excerpt is from a caregiver who stated that is was four months from the time that the OT assessed her mother for a stair lift, until the stair lift was installed.

> ***"It was months and she was struggling to get up and down the stairs. She was breathless. Luckily she had a toilet down the stairs. So when she came down the stairs in the morning she never went back up again until the night."*** **(ID 04)**

Others reported similar delays that had an enormous effect on a daily basis.

> ***'At one stage we actually asked the social support if they could physically take her or I could take her to a nursing home, any random nursing home and actually pay for her to get a shower. That is the thing that frustrated us.'*** **(ID 07)**

In the following excerpt the caregiver reported that her father was assessed for a stair lift in January and died five months later whilst still waiting.

> ***"We had been assessed for a stair lift and we were waiting for that whole process. He got up to go to the toilet one night and he fell between the bed and locker. That was in the middle of April and I would say from that time my father was never the same man. And from that day that he fell, he never went back upstairs again."*** **(ID 08)**

6.2.5 Lack of understanding of palliative care

Another theme that was apparent in the data was the lack of understanding of palliative care. Many caregivers did not understand what palliative care was, with a perception that it was only available for patients suffering from cancer.

> ***"If she could have been moved to the hospice, it would have been wonderful because she would have had a nice dignified death. But I didn't know, because she didn't have cancer... you know... With cancer you are sort of given... well your mother is going to live for a few weeks. With this, there was no end to it. As a human being, you want to know, you want an end, you want to prepare."*** **(ID 04)**

This next excerpt recalls how shocked the caregiver was when palliative care was mentioned for the first time.

> ***"Strangely shocked and devastated. I suppose I had in my head I thought we were going to meet about something different. I thought we were meeting about where we go from here, what way we were going to do his medication. I had no indication, there was nothing, so it sort of hit me."*** **(ID 06)**

> ***"The palliative care nursing team came once every week. To this day, I don't know why they were here."*** **(ID 01)**

Indeed, there was also a lack of understanding from the patient in relation to the role of palliative care, which no doubt also had an effect on the caregiver.

> ***"He thought towards the end they will give you an injection of morphine and that is it, you are dead, they will kill you off. Basically he didn't understand. You probably would have needed to explain to him that it was to make him more comfortable."*** **(ID 09)**

These excerpts have demonstrated that healthcare professionals need to be mindful when introducing the notion of palliative care for the first time. A deeper explanation is required in order to prevent misconceptions about the role palliative care plays towards the end of life for those patients suffering from heart failure.

6.3 Conclusion

Bereaved caregivers recall having many needs that were unmet during their time when looking after a loved one with advanced heart failure. By far the most striking of these was the desire for better communication, regarding their loved one's condition and who to 'turn to' for help and support. Heath care professionals need to be mindful of the importance of keeping relatives informed of changes in the patient's condition as well as prognosis. The only exception to this would be if the patient explicitly asks that their condition is not discussed. It should be noted that this was not reported in any of the interviews.

There were occasions when the system worked well, such as when the Marie Curie nurse, Hospice co-ordinator or district charge nurse got involved in organising care. This positive slant only goes to highlight the fact that it is possible to provide better support and communication when someone is coordinating events. The heart failure nurse also provided welcome support. However, this was not always available in the community. Better communication may well lead to better care and support for both patient and caregiver.

7. Discussion and recommendations

7.1 Discussion

The findings from this report suggest caring for a patient with advanced HF can have a significant impact on the caregiver's overall QoL and they have a number of unmet needs. Caregivers expressed the need for improved service provision in the clinical care of their loved one, emotional support for them to cope with their caregiving role, improved communication from healthcare professionals and support communicating with the patient. It was found that the patient's level of depression and anxiety contributed to greater caregiver burden and poorer quality of life. Lack of support from friends and family was also associated with greater caregiver burden and having better support systems in place resulted in caregivers feeling more prepared for the future.

Identification of patients – 'hidden' group

Evidence would suggest the incidence and prevalence of HF is on the increase and this is compounded by an ageing population and challenges in terms of co-morbidities. Despite this however, there was a key challenge in clearly identifying patients who met the inclusion criteria, mainly due to a lack of existing databases containing clinical information pertaining to HF patients. This study illustrates that people with advanced HF at the end of life are substantially a hidden population. Evidence based inclusion criteria identified less than 15% in a population where we can expect an annual mortality rate of around 20%[63]. This raises a more substantive question around the clear identification of this population who have significant palliative care needs. Previous research by this team has evidenced the challenges of conducting palliative care research within heart failure[64], although initial consultation with cardiologists did not highlight any barriers to accessing advanced HF patients on the Island of Ireland. In addition, clinicians worked closely with us to refine the inclusion criteria around the available guidelines and evidence. Nevertheless, there were challenges and these patients in the advanced stage of their illness seem to be hidden within fragmented health service systems resulting in patients potentially being omitted when in fact they may have been in the last year of their life. Similar recruitment issues arose in the recruitment of HF patients from primary care[65], although GP surgeries tend to have well developed databases containing patient information and could potentially identify a greater number of advanced HF patients for research studies.

Identification of caregivers – 'hidden' group

It is generally family members who take up the role of informal caregiver, giving priority to the patient's health over their own and they have been described as "invisible" to healthcare systems[66]. Currently, no official register of informal caregivers, caring for heart failure patients in NI or the ROI exists, making access to this population a challenge for researchers. Access to the informal caregivers was via the patient, therefore, caregiver participation was mediated not only by the patient's gatekeepers but additionally by the patient themselves. Healthcare professionals do not always acknowledge the role caregivers play and this can lead to caregivers feeling powerless, if a positive relationship is not established with the healthcare professionals responsible for the patients care[67]. Caregivers need to identify themselves as "informal caregivers" and make themselves known to services with the first step being identifying themselves to their General Practitioner.

Challenges with prognostication

Prognostication in HF is widely acknowledged as a challenge, given the unique disease trajectory and complex nature of the condition to clinically manage and there is uncertainty surrounding appropriate criteria to identify HF patients who are at the end of life. Palliative care services have the potential to optimise care for HF patients by improving QoL without prognostic restrictions[68]. Both the European Association of Palliative Care and the European Society of Cardiology recommend integration of palliative care in HF[25, 69] and clinical standards for heart disease recommends use of the Gold Standard Framework Prognostic Indicator Guide (GSF) to correctly identify HF patients with advanced disease who would benefit from specialised palliative care[70]. The GSF guidelines include four criteria (1) the "surprise question - would you be surprised if this patient dies in the next 6-12 months" (2) does the patient have continued physical or psychological problems despite optimized treatment (3) NYHA classification III-IV (4) has the patients had ≥2 HF related hospital admissions in the previous 12 months[70]. To identify patients considered to be in the last year of their life, patients must fulfil two of the four criteria. Unfortunately, in a study examining the clinical utility of the GSF and the Seattle Heart Failure Model, neither accurately predicted HF patients in the last year of life[71]. Research indicates access to palliative care for HF patients is already suboptimal[72-74], putting a greater emphasis on the need for appropriate prognostic tools in HF, to ensure patients in the advanced stage of their illness are accurately identified and referred to specialist palliative care if required. Advanced patients at the end of life appear to be a difficult group to identify, therefore, their informal caregivers are an even harder to reach population.

Integrating heart failure and palliative care services

The caregivers in the current study expressed a need for improved service provision in the care of their loved one's heart failure condition in order to support them. As the patient's condition deteriorated towards the end of life, hospitalisation was common and often multiple healthcare professionals were involved in the care of the patient. Improvements in transitions of care as well as continuity and co-ordination of care are needed within existing systems, in order to facilitate the implementation of palliative care alongside HF management. However, integrating care across primary and secondary sectors and between specialties within secondary care is logistically challenging. Despite guidelines advocating integration of these specialist services[25, 75], very few HF patients are referred to palliative care[47]. A palliative approach should be adopted by healthcare professionals involved in the care of people living with HF, introducing aspects of palliative care early in the patient's disease trajectory and then making referrals to specialist palliative care services when the patient is in the advanced stage of their illness. A systematic review of palliative care models in cancer and chronic diseases in Europe, has proposed a generic framework for integrating palliative care in chronic diseases[76]. It recommends the development of a multidisciplinary palliative care trained team, with a focus on treatment, consultation and training[76]. Using the European Society of Cardiology guidelines of care[25], researchers from Sweden have developed and evaluated a new person-centred integrated model of care which has shown to be cost-effective with positive outcomes for the patient[77, 78]. The PREFER integrates both palliative advanced home care and HF care and QoL and symptom burden improvements were reported following the intervention[79]. The PREFER model incorporates an element of caregiver support, although evaluation did not extend to caregiver outcomes, therefore its potential to reduce caregiver burden has not been assessed.

Communication

In the current research, caregivers expressed having unmet information needs particularly surrounding the patient's diagnosis. There were occasions where the dyad learnt of the diagnosis because a leaflet was left with them in hospital, or the GP later mentioned it from reading notes following a hospital admission. Similar to our findings, patients and caregivers reported knowledge and understanding deficits as a barrier to quality care in HF[80]. The difficulties caregivers reported in the current study were predominantly related to poor communication from healthcare providers. Current caregivers expressed fear regarding "the future" and bereaved caregivers reported, on many occasions' healthcare professionals did not encourage open channels of communication relating to the deteriorating condition of their loved one. Many caregivers with hindsight wished that they themselves had been more pro-active in initiating these discussions, but at the time they did not feel comfortable in doing so. For successful integration of HF and palliative care services, roles and responsibilities for members of the multidisciplinary team need to be established. Research has indicated cardiologists are reluctant to initiate conversations with patients regarding the poor prognosis of their condition[81] and feel it is the role of the palliative care team to have discussions with the patient regarding poor prognosis[73]. The training needs of healthcare professionals responsible for the care of patients living with advanced HF need to be addressed, to ensure they have the necessary communication skills to initiate sensitive conversations surrounding advance care planning (ACP) and the poor prognosis that's inevitable in HF.

Advance Care planning

It can be argued that patients and caregivers understanding of the prognosis and development of goals of care can improve QoL for the dyad. This can be achieved through a process of ACP, which has been promoted globally as a central component of end-of-life policies[17, 82, 83]. It is an approach used to engage communication with patients and their family and health care professionals, to consider their preferences for care. It includes components such as an advance statement of preferences; an advance decision to refuse treatment; or to the appointment of someone with lasting power of attorney as well as aspects such as enabling patients and families to think ahead and consider future outcomes and eventualities within a safe environment in order to maximise life in the present[84]. A substantial body of research suggests that ACP reduces medical care and costs, enhances communication between patients and healthcare professionals and improves the quality of care at the end of life in different adult populations[85-89]. HF patients have shown a willingness to have discussions regarding prognosis and ACP[88, 90] and a number of ACP interventions have been developed for this population[88, 91-94]. ACP has been shown to be feasible in this population[91, 94] and results indicated patients were more informed[92] and there was better patient-caregiver congruence on treatment goals at the end-of-life[94]. It is the role of healthcare professionals to initiate conversations and support patient-caregiver dyads regarding ACP and shared decision making. The caregivers in the current study have expressed a need for emotional support and ACP could provide this, allowing caregivers to share their fears and concerns regarding the future and facilitate communication between the patient-caregiver dyad surrounding their uncertainty for the future. Similar to our findings, caregivers caring for a loved one with HF also reported uncertainty surrounding the patient's future[29, 95]. Research is warranted to determine whether implementation of ACP in the care of people living with HF has the potential to address uncertainty and support the patient-caregiver dyad.

Recognising caregivers needs

The prevalence of HF is increasing and this coupled with stable incidence rates, suggests a greater number of people living with HF. The economic impact of this is huge, putting additional strain on healthcare in particular HF and palliative care services. Not surprisingly, the burden of caring for this population of patients in the community falls to the informal caregiver and burden was evident in this cohort of caregivers. The evidence on whether burden is associated with caregiver mortality is conflicting[42, 96, 97], nevertheless, strain associated with caregiving is a significant health concern and highlights the need for targeted interventions to support this group of people. Our results indicate caregivers need accessible information relating to their loved one's condition and what to expect in the future as well as improved access to services. Similar to our findings, caregivers have consistently cited having unmet information needs, particularly surrounding the patient's prognosis and what to expect in the future[29, 46, 47, 80, 95]. Issues surrounding accessing and navigating complex healthcare systems have been reported previously[46, 80], similar to our findings and caregivers expressed needing a skill base to engage with social support, as often they were unaware what support was available to them and how to access it[29]. HF patients require their informal caregivers support to manage symptoms and recognise signs of deterioration[98, 99]. Caregivers are caring for a loved one 24-7 and are often responsible for making the decision to seek medical assistance, when the patient's health worsens, yet the caregivers in this study are unsure when to seek help and where, often relying on emergency services. Since the acknowledgement caregivers have unmet needs, research has moved to the development of interventions to support caregivers. Unfortunately, neither the COPE intervention for caregivers[100], nor an education and psychosocial intervention for dyads[101] reported improvements in caregiver outcomes. Preliminary results from the ENABLE model suggest small to medium effects for caregivers[72] and the FamHFcare intervention improved caregiver outcomes in relation to confidence and depression[102] and a multidisciplinary supportive intervention for caregivers had positive effects on caregiver burden and mental health[103]. Undoubtedly caregivers caring for patients living with HF require additional support and the results from the present study add to the emerging research in this area. These results can inform the development of effective interventions for this group of caregivers to ensure better health outcomes, reduced burden and improved QoL for caregivers, which in turn could benefit the patient and be more cost-effective for healthcare systems.

7.2 Recommendations

Based on the research findings the following recommendations are proposed. These recommendations will be further discussed at an "Evidence into Practice" workshop with key practitioners and a subsequent action plan will be developed.

Identification and prognostication:

There is a need for standardised documentation of clinical information in heart failure. Sensitive and specific prognostication tools need to be developed, implemented and evaluated as to whether they accurately identify patients with advanced HF needing palliative care.

Models of integration:

Models to integrate palliative care and HF need to be developed that incorporate the needs of informal caregivers. Within these models, clear referral criteria and pathways need to be decided upon and evaluated in relation to patient and caregiver outcomes.

Improved communication:

Communication training needs to be provided for healthcare professionals in order to address the lack of continuity and co-ordination between services reported here.

We need to develop an awareness surrounding the importance for healthcare professionals to initiate conversations regarding poor prognosis, goals of care and ACP. We need to acknowledge the barriers to initiating these sensitive conversations and provide better opportunities for healthcare professionals to facilitate open conversations with patients and their caregivers.

Advance care planning:

In order to successfully implement ACP for HF patients, we need an improved strategy to identify patients in need of ACP and processes need to be implemented using existing tools and operational guidance documentation.

Psychoeducational intervention development:

Caregivers need accessible information related to the patient's diagnosis and HF symptoms to enable the caregiver to support the patient manage their condition. Caregivers need to recognise signs of deterioration and know who to contact in these situation. Improved knowledge could lead to improved self-care capabilities, better management of the patients' condition and a sense of empowerment for the patients and caregivers.

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Appendix I Supporting quotes from phase 2

Additional quotes to support the description of caregivers' QoL and support needs when caring for a patient with advanced HF.

Context	Quotes
Its 24-7	*"You know but it's like a 24 7, well it is a 24 7, you know." (ID 1049)* *"It worries me at times, if I am going out for a while...I worry. I usually ring to see how she is getting on" (ID 1102)* *"ack everything I do for him is [satisfying] you know, but when somebody's not well you know what I mean cos as well, I'd like somebody to do it for me." (ID 1049)* *"well I mean I love her, I do it because she is my sister" (ID 1088)* *"If it was me he would be doing exactly the same." (ID 1106)*
My life is ruled by the condition	*"Even when doing physiotherapy with [son], I am supposed to do that every day. I don't have time to do that every day with all the rest that goes on." (ID 1096)* *"I don't meet friends for lunch very much like I did before; lady friends because I don't like leaving him too long." (ID 1093)* *"A lot of the activities have been knocked out of me because I feel that I can't go out for too long at a time. All those things, they impact me and make me cross." (ID 1114)* *"But I said I couldn't look after the two of them as I would end up dead as well... I just think it has taken an awful lot out my health." (ID 1034)* *"Then I am basically disabled by something; it is very hard because the expectation is still there and I find that hard to.... emotionally distraught... I have found the last 7 weeks very tough. The expectation is still there, it doesn't change. I am here for whatever is needed." (ID 1114)*
It's an emotional rollercoaster	*"sometimes it gets me down. There might be a few weeks or months before it happens again, when I cry my eyes out and then you get over it." (ID 1093)* *"it's just when it all builds up and then I get a bit depressed cos I just worry for him" (ID 1049)* *"There are days that it really gets you down because you are just so exhausted... you could burst into tears at the drop of a hat because you are on your own and you don't have anybody..." (ID 1138)* *"They were really, really good to him and they kept me really well informed as to what was happening. There was never time when they couldn't talk to you. If they were in the middle of doing something they would say could they come round to me in maybe 5/10 minutes." (ID 1138)* *"Fantastic because [consultant] is such a good communicator. He sits down and tells it how it is. He doesn't mince words but you get a very good feeling from him, that you can trust him and that he is making good calls." (ID 1097)* *"it is just knowing that they are they, is the support. I mean [name] my son, if there is anything that needs doing, or they can help. They would say, "We will do that", they will always step in..." (ID 1106)* *"we have good friends, good neighbours, and good family. We are very lucky in that way... It is just nice to know that I have friends and family around if I*

Context	Quotes
	needed to do something or help or whatever and people will say, if I have to cancel, is there anything they can do or would I like them to drive and there are people who would do that, they say they would take [patient] to his appointment if I can do it..." (ID 1106) *"It does help me, they are great in the heart failure clinic. Absolutely, the nurses are wonderful." (ID 1093)*

Improved service provision

Subtheme	Quotes
Planning for the future	*"You get gradual things; we have the stair lift in obviously. We have a garage door that lifts up and down itself. We are lucky to be able to make changes like that so that he can get his scooter without any problem." (ID 1106)* *"No nobody has told us what to expect If anything happens to him, what are we supposed to do?" (ID 1034)* *"The first few times it happened and her being close to death and being asked by the doctors about resuscitation is very nerve wrecking."(ID 1113)* *"I just think if anything is going to happen that it would be better in his own house. I don't think he would like to die in the hospital with crocodile tears around his side."* *(ID 1034)* *"It can't be done, the sort of treatment he gets isn't available [at home], the sort of treatment he gets at hospital isn't available at home...He has to go in, there's no way of keeping him out." (ID 1122)* *"but there's an awful lot of things we weren't prepared for...it wasn't until much later your sitting and you go what happens next, where do you go from here?" (ID 1122)* *"I know that when my brother had it [palliative care], it was great, especially the last week of his life. The Marie Curie nurses came and stayed overnight." (ID 1088)* *"My Mum was in the hospice and they were absolutely brilliant. We always thought the hospice was going to be doom and gloom, people do die there but the atmosphere is completely different. We used to just go there for a cup of tea and just breathe as well and a relaxed atmosphere." (ID 1096)* *"I ask for strength and that I can cope. Just talk to God." (ID 1093)* *"praying, I've got a strong faith, we both have and knowing that I had that sort of group of friends around me was really, really helpful." (ID 1136)*
Continuity and co-ordination of care	*"The last visit we did was October or November before Christmas and I had her brought down in a wheelchair because she wouldn't walk because she was too depressed. I brought her in and they asked what had happened to her. She didn't want to talk about it. They did the blood pressure, told the doctor, the blood pressure is fine and then they say "see you in a year". Whether she had broken her hip or broken her ankle or was going to jump out a window.... Do you care, you are just a number?" (ID 1113)* *"I got in touch with the heart failure nurse Monday, she said we have a bed for*

	Quotes
	him in Ward X, they will ring you this afternoon. We sat here all day on the Monday, I phoned at a quarter to 6 and they hadn't heard of me so that was another night we didn't get any sleep." (ID 1136) *"I would like somebody to look at [patient] in the overall. I feel that, when I take [patient] to the heart people, they made it quite clear they were only interested in her heart and nothing else and when I take her to the Rheumatoid people, they just put her back on the methotrexate." (ID 1034)* *"I think my mother has a lot of unmet needs, she feels she is being passed from Billy to Jack and nobody really cares and if I had have stayed in London, I presume she would be in a nursing home by now." (ID 1113)*
Transitions of care	*"getting him out of the hospital was a nightmare. I took the car over, I had the car at the door, he was in the Ward, they were getting a chair for hime at the door, he was in the Ward, they were getting a chair for him but the chair didn't turn up and didn't he walk down and carry the bag which was a nightmare and that was a bit worrying." (ID 1136)* *"He came home and we said we would see how we go. If I can't cope we will get help from somewhere, I don't know where but we will." (ID 1096)* *"I was told she was going home. I could have taken her there and then but I hadn't anything ready. I had a panic attack...We have got no information. I was told she was going home and that was that." (ID 1153)* *"Having a social worker to do an evaluation when he is being discharged. I know [patient] would just say I'm ok the wife will look after me, it should be a joint conversation." (ID 1141)* *"Oh I need more information. I'm always anxious when he comes out of hospital. They never give you anything... You got a discharge letter from the hospital but it didn't have all the facts in it" (ID 1122)* *"we found it difficult because you were going up to the hospital twice a day and this went on, he was in for I think it was 8 – 10 weeks originally and I think in total now he was 18 weeks in altogether on and off." (ID 1122)*
Information needs to empower the caregiver to make decisions	*"We have been told that there are three forms of each, mild, moderate and severe. So hers is moderate, so they won't do anything about the valve until the leakage would be severe. So I asked how you would know if it was it was severe. The answer I got was "you would know". In other words you would probably be flaking out or whatever." (ID 1038)* *"I would love to know more about his diet, what he should and shouldn't eat... It would be good to have the information. You would be nearly better off sending it to the carers rather than the patients to be perfectly honest" (ID 1096)* *"I think sometimes those refresher courses are always good." (ID 1097)* *"Fantastic because [Consultant] is such a good communicator. He sits down and tells it how it is. He doesn't mince words but you get a very good feeling from him, that you can trust him and that he is making good calls." (ID 1097)* *"the consultant this week was the first really to set us down and detail but only because we had asked for a sit down with her as a group." (ID 1122)* *"Once she [niece] was there she was listening to what the Doctors were saying*

	Quotes
	and then she was translating it into my language which was a great help." (ID 1136) *"Yes, I would like any information I can get." (ID 1093)* *"If there was any kind of list that was made up of various support services I wouldn't mind having something of that nature." (ID 1102)* *"one of the doctors pulled me aside and said to me that my wife is like a car ... now I was basically on my knees, emotionally ... he said to me that my wife is like a car and her engine has to be rebooted. I didn't know what to think of that." (ID 1153)* *"They probably couldn't without his say-so, but I would like an update even, someone saying this is the way he is. I know it's probably confidentiality stuff but if you're sick and living in our house I do think I should know if there's something not right." (ID 1096)* *"...the last time we were in, one of the Registrars I think said they wanted to hang on to her and see with a colleague later on that day. In the meantime, somebody else said they needed the bed and she was discharged." (ID 1102)*

Emotional support

Subtheme Knowing when to get help	*"I was worried that I wouldn't be reacting properly. I didn't quite know what I was to do at that stage. He was meant to have a bed. Again I rang the Heart Failure Clinic. Having them there is a great help. So I rang them and they listened to me because they had seen him and they said to get an ambulance. If you get an ambulance, he will get in that way and if he doesn't get in now he would be in very serious trouble. That was grand. I called the ambulance and got him in that way" (ID 1106)* *"We were also given a phone number to contact heart failure nurses, which again we didn't understand, when do you contact them, why do you contact them?" (ID 1122)* *"Yes, but when do I take him to hospital? Is it when he's coughing, is it when he's breathless?" (ID 1122)* *"During the night, when he was ill, whatever is wrong with him, it was always the night time that was the worse...Making the decision is very difficult. You don't want to appear to be stupid, not stupid, doing things on the spur of the moment. And maybe it's not necessary. What's the word? You don't want to make a fuss over nothing." (ID 1136)*
Someone to talk to who has journey	*"She says "mum, don't you be worrying about dad. Dad is great. Look at dad" She talks to me like this sometimes but I don't tell her my problems. Why give them, pass on your worries to your children. What's the point? They can't do anything. You would only upset them." (ID 1093)* *"a lot of group things can be very beneficial if you had someone there, even if something happens and you have this core group who have been on the same journey with you." (ID 1097)*

	Quotes
	"I would like to know if there is anyone else out there who has the same problems we have" (ID 1122) *"[patient] can ring the heart failure clinic but there isn't anybody there I suppose who would say, if I am unhappy I could ring." (ID 1106)* *"you want somebody to talk to but it has to be the right person. It has to be the person that you're not going to upset more" (ID 1136)* *"maybe somebody in the same position as you could say "yes, that has happened to me and this is how I coped with it" (ID 1138)* *"If they have one [support group] I would certainly give it a go." (ID 1138)*
Communication challenges at all levels	*"we would worry about her because she wouldn't say exactly how badly she was feeling... We were kind of cross with her because she wouldn't say and we could have lost her that weekend" (ID 1178)* *"You try to hide it from them too I suppose because you don't want them to worry." (ID 1138)* *"there are other members of the family who are our age and have washed their hands of us sort of thing" (ID 1153)*