

Patient, Carer and Clinician Experience of the Palliative Care for Patients in the Advanced Stages of Heart Failure

FINAL REPORT

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ABSTRACT

Introduction

Heart failure is as "malignant" as many common cancers. Those with advanced heart failure experience symptoms that have a negative impact on their daily lives. There is evidence of inequity of access to palliative care services compared to people with cancer and prognostication is a challenge. The overall aim of this study was to examine patient, carer and professional perceptions of advanced heart failure, and barriers and facilitators to improved models of care.

Methods

Semi-structured interviews and focus groups with advanced heart failure patients (n=30); carers (n=20); and professionals (n=65). Data analysed using Normalisation Process Theory (NPT) as the underpinning conceptual framework.

Results

Uncertainty is pervasive in accounts from those with advanced heart failure and their care givers. This uncertainty relates to understanding of the implications of their diagnosis; appropriate treatments and when and how to seek effective help and makes adherence more difficult. Health professionals agree that this is a major problem but feel they lack knowledge, opportunities or adequate support to improve the situation for those with advanced heart failure. Fragmented care with lack of coordination and poor communication makes life harder. Poor understanding of the condition extends to the wider circle of carers and means that requests for help may not be perceived as legitimate and those with advanced heart failure are not prioritised for social or financial support and other aids and adaptations. Patient and care giver experiences of emergency care are uniformly poor, with unsatisfactory emergency admission experiences being the norm. Managing polypharmacy and enduring concomitant side effects is a major burden and the potential for rationalisation exists.

Conclusion

Incoherence is pervasive and adversely affects individual or caregivers' ability to undertake appropriate self care strategies, to access services, and to enact treatments and has the potential to induce non adherence. Even in the terminal stages, patients and caregivers are heavily and unnecessarily burdened by health care services that are poorly coordinated and offer fragmented and discontinuous care. Services for those with advanced heart failure need to ensure patients have a clearly identified key worker or workers to help develop suitable collaborative care plans and ensure optimal communication and more integrated care. Such professionals require adequate protected time to address patient needs. Advanced heart failure patients need better access to financial support, social services and home aids and adaptations as well as clear emergency care plans and access to appropriate out of hours services to help them manage deteriorations. More counselling and support services are needed to help patients and caregivers better understand the diagnosis, implications and the benefits and limitations of the ever increasing array of pharmacological and device therapies. There is a need for a fundamental shift in the way services are configured if longstanding deficiencies in the care for those with advanced heart failure are to be improved and the goals and needs of patients and caregivers are to be met effectively.

EXECUTIVE SUMMARY

Introduction

We know that heart failure is a terminal condition and that with the notable exception of lung cancer, it is as "malignant" as many common cancers and is associated with a comparable number of expected life-years lost. Heart failure is a disease that is both an increasingly important public health problem and a devastating personal problem for growing numbers of people. The existing literature makes it clear that those with advanced heart failure experience symptoms that have a negative impact on their daily lives and that those with this condition feel unsupported. There is evidence of inequity of access to palliative services compared to people with cancer and we know that prognostication is a challenge.

The overall aim of this study was to examine patient, carer and professional perceptions of advanced heart failure, and barriers and facilitators to improved models of care, with a particular focus on issues relating to the management of crises or unexpected events as this is a particularly challenging issue for patients, carers and professionals.

The study aimed to answer the following research questions:

1. How do advanced heart failure patients and carers make sense of their condition and plan for the future, what part do health professionals play in this?
2. What services and support do patients and carers currently utilise, and how do they negotiate and mobilize these with health and welfare services?
3. What do patients, carers, and professionals perceive as the main barriers to provision of high quality, well co-ordinated care for patients with advanced heart failure and how can these be overcome?
4. What factors contribute to admission and readmission rates for patients with advanced heart failure, and what alternatives to unscheduled admissions can be identified?

Methods

The research was designed in two phases: Phase 1 was aimed at patients and carers; while Phase 2 was aimed at health professionals. Both phases employed qualitative research techniques to answer the aforementioned four research questions and drew on Normalisation Process Theory (NPT) to underpin our interview guides and data interpretation.

Phase 1. We recruited a purposive sample of 30 patients with advanced heart failure and, where possible, their associated carers (n=20). Recruitment was from the Greater Glasgow and Clyde heart failure liaison service; primary care; a palliative care clinic for advanced heart failure; and local hospital admission units. Participants in this study took part in up to two semi-structured interviews lasting between 30-90 minutes. Patients had the option of participating in either one or two interviews. Carers had the option of participating in a combined interview with the patient or a one to one interview. A total of 51 interviews took place for this study. Some patients also completed symptom and service utilisation diaries.

Phase 2. We recruited 65 health professionals from a range of disciplines including Cardiology, Medicine for the Elderly, District Nursing, General Practice, Pharmacy, the Ambulance service and the Heart Failure Liaison Nurse (HFLN) Service to take part in focus groups and interviews designed again to address the research questions. Health professionals were provided with the key findings from the phase 1 work and were asked to comment on issues raised.

Data Analysis

In both phases the interviews and focus groups were audio-taped and transcribed verbatim, with participant consent, and transcripts served as the data for analysis. Data analysis was undertaken using NPT as the underpinning conceptual framework.

Key Findings

Our key findings are described below as they relate to each of the four research questions set out in the study protocol; first relating to patient and carer perspectives and then the health professional view.

1. *How do advanced heart failure patients and carers make sense of their condition and plan for the future, what part do health professionals play in this? (Coherence)*

Patient and Carer Perspectives

Incoherence was a pervasive and key feature of participant accounts and a key element of this was around patients and caregivers' problems in *making sense of diagnosis and prognosis*. Descriptions of discussions with health professionals about diagnosis and prognosis suggested a lack of frankness and led to uncertainty amongst patients about why they were becoming progressively unwell, and therefore retarded patients and caregivers' ability to appraise symptoms and undertake help seeking behaviour. Co-morbid conditions added a further layer of complexity, as differentiating symptoms of advanced heart failure from other conditions, and from signs of normal ageing, was a challenge for participants. Both the volume and complexity of medications and treatments potentially available to advanced heart failure patients are daunting. New treatments for heart failure, such as implantable cardiac defibrillators (ICDs), posed particular challenges.

Health Professional Perspectives

Health professionals (HPs) described difficulties communicating patients' complex and poor prognosis. They felt that patients' understanding of their condition is poor; and that patients had unrealistic expectations regarding their illness and its implications. Poor understanding of diagnosis was compounded by cognitive impairment and complicated by co-morbidity. Prognostication was described as an uncertain task and HPs stated that they had to consider that patients may not want to know everything regarding their prognosis. HPs therefore faced the challenge of ascertaining from the patient the amount of information that the patient deems beneficial to them at any given point in time. In addition, current service configuration was often a barrier to good communication. HPs expressed the view that:

- Communicating a patient's prognosis requires multiple conversations taking place over multiple contacts and some indication of poor prognosis should be introduced at the outset.
- Multiple conversations allow HPs to get a feel for how much information is retained.
- Written information to back up discussions is required.
- Lack of time was a crucial issue.

HFLNs have regular contact with patients and are well placed to address patients' poor knowledge and understanding with on-going reinforcement of information but feel overstretched and short of time for this labour intensive task. Cardiologists felt constrained by pressure of time in busy hospital clinics. Generalists often felt that they would need specialist advice and support to enable them to identify when patients were entering a terminal phase. Thus, no professional group identified themselves as being fully able to fulfill this role without either additional support mechanisms being put in place or reconfiguration of services.

2. *What services and support do patients and carers currently utilise, and how do they negotiate and mobilize these with health and welfare services? (Cognitive Participation)*

Patients and Carers

Those with advanced heart failure expended a great deal of effort negotiating help with a wide range of friends, family and outside agencies. They had to work out the different roles, responsibilities and limitations of the numerous health professionals who organised their care, including General Practitioners (GPs), Heart Failure Liaison Nurses (HFLN), Cardiologists, and hospice staff. The challenge here was to make sense of their illness state and the processes of care, in an environment in which relations with healthcare providers were often fragmented and discontinuous. GPs, although viewed positively were perceived as lacking the necessary expertise. The Heart Function and Supportive Care (HF&SC) clinic and HFLN service were viewed as a real help, for the latter this was often because the nurses helped organise things for patients, but also because of the continuity they provided.

Participants' accounts convey real discomfort at having to work to distribute the burdens of their care, and an important subtext is anxiety about whether or not others would accept these burdens, e.g. help cope with medications; collect repeat medications; attend appointments; engage with specialists; function at home; and in emergency situations. Participants suggested that others sometimes failed to grasp how unwell they were, and felt that their requests for help were therefore illegitimate.

Participants described struggles to obtain aids and adaptations, social support and financial help. Adaptations such as stair lifts or walk in showers were described as key to facilitating an acceptable quality of life at home. Efforts to get appropriate support with personal care were considered frustrating. There was little evidence of patients receiving benefits advice yet clearly some patients were experiencing financial hardship.

Health Professionals

Only a minority of advanced heart failure patients access palliative services. HPs identified difficulties around the transition to/introduction of palliative care. Patients experience a cycle of admissions, then improvements, then declines, then admissions and so on. Cardiologists often focus on dealing with the immediate needs of the patient during an acute admission and fail to recognise the pattern of deterioration and the need to consider palliative care.

Prognostication, as previously described in the literature, was deemed extremely challenging. Patients who would benefit from palliative care are not identified when in-patients. Poor patient understanding of diagnosis and prognosis means the subject of palliative care is difficult to introduce.

Particular barriers around accessing hospice care were described. Professionals felt that patients perceived hospice care as synonymous with cancer and described how advanced heart failure patients struggle to see its relevance for them. Hospice staff had expected to be inundated with advanced heart failure patients when hospices extended their remit to non-malignancies, this has not occurred. There appears to be a need to promote hospices as a service that caters to patients with illnesses other than cancer and provides services beyond very end of life inpatient care.

3. *What do patients, carers, and professionals perceive as the main barriers to provision of high quality, well co-ordinated care for patients with advanced heart failure and how can these be overcome (Collective Action)*

Patient and Carers

Managing polypharmacy, figured prominently in participants' accounts. Complex mechanisms were described for obtaining, organising, remembering and taking medications. The use of generics and changes in the colour of medications proved frustrating for patients who had invested time and effort in learning the colour of particular medications. Carers often played a key role monitoring adherence. Enduring the side effects of polypharmacy was a related burden.

Continuity of care was valued by participants. Some spoke of regret that they didn't have their 'own' doctor, either GP or specialist. Patients believed that new health care systems directly compromised continuity of care. Fragmented and discontinuous care from multiple health professionals sometimes led to patients having to mediate between doctors who disagreed about their diagnosis and treatment, and who employed different medication regimes. Continuity of care did not guarantee relief of burden. Participants described professionals who seemed to lack understanding of their predicament and who made insensitive and sometimes hostile comments about their prognosis or healthcare needs. The configuration of services themselves was also an important burden, especially related to emergency admissions.

Health Professionals

Professionals felt that current service configurations acted as a barrier to the delivery of optimal care. Short appointment times and lack of continuity of care do not allow HPs to have the involved on-going conversations required to improve patients' understanding of their illness. Hospices are not equipped for active management that many advanced heart failure patients receive and require. The HF&SC Clinic model was described as ideal because of its links to community medical and social support and long appointment times. Service gaps were identified. These patients are often too complex for GPs to manage and a HFLN with an interest in palliative care would be best placed to provide care. HFLNs were clear that non LVSD patients could benefit from their input but expressed concern about resources and described a service that is already stretched.

Health care systems, as currently configured, do not promote integrated care for those with advanced heart failure and do not accommodate the communication required between disciplines and between health and social care which was found lacking at key points. GPs described their communication with HFLNs as one way; they received regular updates from HFLNs but weren't asked to provide input, which was seen as a lost opportunity. Communication between hospitals and community based care is suboptimal - patients are discharged without appropriate support. Equally, the ambulance service requires more access to patient information, especially out of hours.

A lack of 'ownership' of advanced heart failure patients was evident from the HP data. GPs, district nurses and palliative care HPs described minimal experience of advanced heart failure patients. Some HFLNs may not consider palliative care to be a part of their remit. HFLNs were thought to be the best candidate for a 'key worker' role with advanced heart failure patients but multidisciplinary team input to care was also thought important due to the complexity of the problems experienced by patients. Some GPs felt they were in the best position to be a 'key worker' because they had the best knowledge of patients' psychosocial situation but felt they would need help in identifying when individuals should be considered "end stage".

4. What factors contribute to admission and readmission rates for patients with advanced heart failure, and what alternatives to unscheduled admissions can be identified? (Reflexive Monitoring)

Patient and Carer Perspectives

Difficulty adhering to complex treatment regimens was seen as one precipitant of emergency admissions which were often underpinned by patient uncertainty about their illness. As described above, the experiences of acute admissions were uniformly described as extremely unsatisfactory, in terms of both the process of getting admitted and their in-patient stay. Consequently, they tend not to seek help, for fear they will get admitted, until their situation has become desperate. Patients and carers seemed unable to identify suitable emergency care plans, and the lack of support outside of office hours was unhelpful.

Health Professionals

Unclear pathways lead to patients' unscheduled admissions, often out of hours, via Accident and Emergency (A&E), universally deemed to be inappropriate. Patients would benefit from guidelines on where to seek appropriate help and from whom. A limitation of the HFLN service is that it is 9-5, Monday through Friday support only. If advanced heart failure patients phone a GP in an emergency it is likely they will be advised to phone an ambulance, leading to an admission via A&E. Inflexible systems prevent direct access to cardiology. Direct admissions ("back door" arrangements) were seen as the optimal way to deal with those needing admission. The ambulance service rarely has an option other than bringing a patient to A&E. Four hour A&E targets result in patients being admitted to inappropriate wards. Advance care planning can play a part in preventing unnecessary admissions by facilitating patients to be fast tracked to appropriate wards. Patients who are in contact with the hospice may have the option of hospice care rather than an unscheduled hospital admission.

Conclusions and Implications for Practice

We have demonstrated how patients must work to develop coherence, a clear understanding of their conditions and appropriate management. Incoherence, which was pervasive, adversely affects the individual or carer's ability to undertake appropriate self care strategies and to enact treatments, and has the potential to induce non adherence. Our data illustrate how even in the terminal stages of chronic but lethal illness, patients and carers are heavily, and unnecessarily burdened by health care services that are poorly co-ordinated and offer fragmented and discontinuous care. Adherence is difficult for advanced heart failure patients, so attention needs to be given to how to help with this. There is a lack of clear plans regarding what to do in an emergency, this could be addressed by developing clear pathways/plans for those with advanced heart failure so that they know what to do in an emergency and appropriate services are made available to help them action such plans. More counselling and support services are needed.

Addressing the problems highlighted in this report will not require a further guideline but rather a rethinking of our current approaches and models of care for this patient population so that they become more tailored to meeting the needs and wishes of those at the end of life rather than aimed at suiting the convenience of the health care systems serving them. We would suggest that interventions that assist patients in *integrating* understandings of their illness state with appraisals of processes of care will result in measurable improvement in capacity to perform collaborative and co-operative tasks and improve patient experience and wellbeing.

Recommendations

- *Reconfiguration of services* is necessary to facilitate good communication and promote patient and carer understanding:
 - There is a need for services to be able to accommodate the support needs for those with advanced heart failure. These needs include the opportunity to have multiple conversations taking place over multiple contacts and long appointment times.
 - Services should provide greater continuity and provide the opportunity to see the same health professional over the course of these conversations.
- *Integrated care* for advanced heart failure patients requires improved communication mechanisms between health professionals, for example cardiologists and palliative care physicians, and across sectors, for example, across the primary/secondary care interface and health and social care boundaries.
- Streamlined *admission* pathways that avoid A&E are essential to improve patient and carer experiences.
- *Key workers* need to be identified. This could be the HFLN or the GP, but someone needs to be clearly seen to have responsibility for patient care. *Such key workers* should have access to additional support/advice such as a multidisciplinary team.
- Such *key workers* should:
 - Have primary responsibility for promoting better understanding of: a) the condition and its implications; b) pharmacological and non pharmacological therapies.
 - Help patients and their caregivers to navigate and interact with health and social care services.
 - Co-ordinate care and minimize duplication and unnecessary outpatient visits.
 - Ensure regular medication reviews and rationalization of polypharmacy, where feasible.
- Advanced heart failure patients and their caregivers should have access to *emergency care plans*.
- Advanced heart failure patients and their caregivers need better access to psychological support.
- Advanced heart failure patients need better access to financial support, social services and home aids and adaptations.
- Greater attention needs to be given to providing support and advice to individuals about the *role of ICDs, and other devices* and their limitations.
- Health professionals require *high quality written information* for advanced heart failure patients:
 - to reinforce conversations around prognosis.
 - on how to access appropriate health care, particularly out of hours.
- *Hospices* should be promoted as a service that caters to patients with illnesses other than cancer and provide services beyond very end of life inpatient care.
- Health professionals require *training* on:
 - how to deliver a poor prognosis while preserving hope.
 - identifying advanced heart failure patients who would benefit from palliative care.
 - rationalisation of medications and the conversations that accompany such changes.

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FINAL REPORT

1. Introduction

We know that heart failure is a terminal condition and that with the notable exception of lung cancer, it is as "malignant" as many common cancers and is associated with a comparable number of expected life-years lost (Stewart et al. 2001). This work provides grim reading with evidence that heart failure patients, subsequent to a first hospital admission, have a median survival time of 16 months with only 25% of men and women surviving to 5 years (Stewart et al. 2001). Results from this Scottish cohort are equivalent to those of large-scale studies of hospitalised heart failure patients in both the United States (Jaagosild PM, et al. 1998) and Australia (Lowe JM et al. 1998). More recent data suggests that while outcomes are improving with median survival following a first episode of heart failure now being 2.34 years in men and 1.79 years in women, the prognosis still remains poor (Jhund et al. 2009). Such statistics provide a stark picture of a disease that is both an increasingly important public health problem and a devastating personal problem for growing numbers of people. Despite this, the poor prognosis associated with heart failure is a fact that many appear not to fully appreciate, due in part to unmet information needs (Horne et al. 2004). It is really only in the last few years that discussion of the needs of those with advanced heart failure has received any significant attention (Murray et al. 2002; Murray et al. 2005) and the implications of advanced heart failure from the patient, carer and professional perspective has been until recently relatively neglected compared to other illnesses. Those with advanced heart failure have to endure a high symptom burden, poor quality of life and emotional distress (Nordgren et al. 2003, Barnes et al. 2006; Walke et al. 2006). The research team are aware of the findings of the recent comprehensive literature review on palliative care in heart failure undertaken by the Marie Curie Palliative Care Research Unit (Low et al. 2011) which highlighted that those with advanced heart failure not only experience symptoms that have a negative impact on the daily lives of both patients and close persons but that they also feel unsupported; and that health professionals lacked confidence in diagnosing advanced heart failure and communicating a poor prognosis to patients, resulting in barriers to the provision of good quality coordinated care.

In this study we had no intention of duplicating previous work and instead we aim to produce new knowledge that will add to the existing literature. Our intention is to fill research gaps, for example in relation to what is known about caregiver perspectives, and also produce data that will help inform the development of new models of palliative care for patients in the advanced stages of heart failure. There is evidence of inequity of access to palliative services compared to people with cancer (O'Leary et al. 2009) and we know that prognostication is a challenge (Hogg & Jenkins 2012; Haga et al. 2012), so the main question is how to best move forward to improve the experience of care for this patient population.

The overall aim of this study was to examine patient, carer and professional perceptions of advanced heart failure, and barriers and facilitators to improved models of care, with a particular focus on issues relating to the management of crises or unexpected events as this is a particularly challenging issue for patients, carers and professionals.

The study aimed to answer the following research questions:

1. How do advanced heart failure patients and carers make sense of their condition and plan for the future, what part do health professionals play in this?
2. What services and support do patients and carers currently utilise, and how do they negotiate and mobilize these with health and welfare services?
3. What do patients, carers, and professionals perceive as the main barriers to provision of high quality, well co-ordinated care for patients with advanced heart failure and how can these be overcome?
4. What factors contribute to admission and readmission rates for patients with advanced heart failure, and what alternatives to unscheduled admissions can be identified?

2. Methods

The research was designed in two phases: Phase 1 was aimed at patients and carers; while Phase 2 was aimed at health professionals. Both phases employed qualitative research techniques to answer the aforementioned four research questions and drew on Normalisation Process Theory (NPT) (May & Finch 2009; May et al 2009; May et al 2007) to underpin our interview guides and data interpretation.

Ethical approval

Ethical approval (reference 10/S0701/20) from West of Scotland REC 3 was obtained for both phases of the study (Appendix 1). All participants gave informed consent before taking part. Copies of participant information sheets and consent forms are available on request.

Phase 1 Sampling

A purposeful sampling strategy was developed in order to capture the differing experiences of advanced heart failure across Greater Glasgow and Clyde (GGC). The logic and power of purposeful sampling lies in selecting information-rich cases for study in depth. Information rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, hence the term purposeful sampling (Patton 1990). The main advantage of such an approach to participant selection is that it increases the likelihood of ensuring a cross-section of the population in a small sample, which might otherwise miss certain categories of participants (Black 1993). The aim is therefore not to identify a statistically representative set of respondents but to identify respondents based on specific predetermined criteria (Pope & Mays 1995; Pope et al. 2002). We were keen to capture the experiences of different genders, to include those with diastolic dysfunction and achieve a geographical diversity among participants.

Throughout the life of the evaluation the research team made strenuous efforts to recruit from a geographically diverse area. We made contact with the GGC Heart Failure Liaison Nurse service from the very beginning of the project, explained the aims/methods of the project in detail to the Lead Nurse for the service, and attended one of their group meetings, to ensure all nurses in the service had full details of the project and all the relevant patient information leaflets. We also contacted heart failure liaison nurses individually and the appropriate hospital consultants (both cardiologists and care of the elderly physicians), attending a number of meetings with clinicians at the Glasgow Royal Infirmary, Victoria Infirmary and Southern General Hospital respectively. Primary

Care Practices were also contacted to extend our reach. Repeated approaches were made to key individuals via telephone, email and through in person meetings. Everyone we contacted was positive and helpful and promised to help with recruitment. Unfortunately, despite these efforts recruitment across the Greater Glasgow and Clyde area remained challenging, and only one centre engaged vigorously with recruitment.

Similarly recruitment of advanced heart failure patients with diastolic dysfunction proved challenging and ultimately reflects their lack of contact with health services. Two patients with diastolic dysfunction were recruited to the study, and this after intensive effort.

CHF patients were deemed study eligible if they met all of the following criteria:

- Grade 3 or 4 NYHA classification HF;
- Were symptomatic despite optimal therapy;
- Had a history of admissions/multiple health care contacts for this condition.

Exclusion criteria were:

- a history of mental impairment that would suggest that they would be unable to give informed consent to participate in the study;
- inadequate spoken English that would prevent participating in an interview undertaken in English

Phase 1 - Recruitment.

Recruitment was from the Greater Glasgow and Clyde heart failure liaison service; primary care; the Heart Function and Supportive Care Clinic; and local hospital admission units.

Clinicians were asked to identify patients according to inclusion and exclusion criteria as outlined in the section above. A total of 45 patients were identified by clinicians and 43 of these were approached and asked to take part in the study (two were not approached as one was moved to a nursing home and one developed mental illness). Of the 43 who were approached 32 consented to take part in the study. Eleven patients did not consent, this number is comprised of seven refusals, three deaths and issues with contact details for one patient. Two of the patients who did consent did not go on to participate in the study, one of these became angry about their care and withdrew and the other did not respond to repeated attempts to contact them.

Interviews

Participants in this study took part in up to two semi-structured interviews lasting between 30-90 minutes. Patients had the option of participating in either one or two interviews. Carers had the option of participating in a combined interview with the patient or a one to one interview. A total of 51 interviews took place for this study. Some patients also completed symptom and service utilisation diaries.

Methodological issues

Challenges related mostly to recruitment. Originally the study had aimed to identify only 20 patients but to undertake two interviews with each, to also get a close person to participate in an interview and to get each patient to keep a diary, capturing details of the people they made contact with on a daily basis to help them with their care and their symptoms burden. Difficulties encountered included: a) problems in identifying and recruiting patients with a recent admission; b) challenges getting close person participation; and c) problems relating to use of the patient self complete diary. These were dealt with through a series of minor changes to the study protocol which were discussed with the steering group as they occurred and were ratified via amendments sent to and confirmed by our local ethics committee. There were been 3 amendments to the methodology.

Our first amendment, in June 2010, allowed us to recruit patients who did not have a recent hospital admission (but otherwise fulfilled the eligibility criteria). We increased our proposed sample from 20 patient and carer dyads to approximately 30 patient and carer dyads in order to account for the likelihood that some patients we recruited may not have a hospital admission.

Our second amendment, in October 2010, removed the need for diary completion as a mandatory part of the protocol and allowed us to incorporate questions from the patient diary in the patient interview (as some patients had not been willing to take part because the prospect of filling in a patient diary had seemed too onerous).

Our final amendment, in March 2011, allowed us to speak to the 'close person' when a patient had not had a hospital admission. It allowed the diary interview and admission interview to be combined where this was the patient's preference and it allowed us to recruit patients who did not have a close person.

2.1 Phase 1 Data Analysis

The interviews were audio-taped and transcribed verbatim, with participant consent, and transcripts served as the data for analysis. Our original protocol stated we would use Normalisation Process Theory (NPT) as the theoretical model to help us conceptualise the data and might also use the NPT as a coding frame if deemed appropriate and we did indeed follow this approach. Normalisation process theory (NPT), focuses on the "work" or dynamic processes that take place when people are enacting complex interventions or activities and we believed it would help us conceptualise the issues of interest within the proposed project (May & Finch 2009; May et al 2009; May et al 2007), since our aim was to develop a rich picture of generic features of the "work" undertaken by advanced heart failure patients, and their carers and to use these to develop a robust conceptual model – informed by NPT – of the activities undertaken by advanced heart failure patients and their carers in coming to terms with and managing their condition. NPT has a robust theoretical basis and explains how the work of enacting an ensemble of practices (in this case the work of managing a terminal condition) is accomplished through the operation of four mechanisms: 'coherence' (sense making work); 'cognitive participation' (relationship work); 'collective action' (enacting work); and 'reflexive monitoring' (appraisal work). We had recently shown NPT to be effective in understanding treatment burden experienced by heart failure patients (Gallacher et al. 2011) and the coding frame

created during that previous study (See Table 1) was used as the starting point for our approach to analysis in the current study.

Table 1 – NPT Coding Frame for CHF Treatment Burden

COHERENCE <i>(Sense-making work)</i>	COGNITIVE PARTICIPATION <i>(Relationship work)</i>	COLLECTIVE ACTION <i>(Enacting work)</i>	REFLEXIVE MONITORING <i>(Appraisal work)</i>
Understanding the prospect of having chronic heart failure, what this means and how the condition may be managed.	Investing personal and interpersonal commitment to living with the condition and its management.	Investing effort and resources in management, carrying out tasks and experiencing the illness.	Reflecting on the effects of therapies in retrospect and determining whether to modify them.
Differentiation Understanding and differentiating between aspects of the illness, investigations, treatments and the roles of different health professionals.	Enrolment Engaging with friends, family and health professionals with regards to the illness and its management to enable them to provide support.	Skill set workability Setting a routine/strategy to cope with symptoms, exacerbations, and emergency situations i.e. therapeutic interventions and self monitoring.	Reconfiguration Altering a set routine when required such as medication regimes or appointments, to fit in with daily activities or other arrangements.
Communal specification Gaining information about the illness and its management with the help of others, for example friends, family or health professionals.	Activation Arranging help (e.g. logistical, administrative, or expert) from health professionals, social services or friends and family.	Contextual Integration Making sure you have the right financial and social resources, and integrating the illness into social circumstances.	Communal Appraisal Discussing or altering current management plans already initiated, in discussion with health professionals or friends and family.
Individual specification Achieving your own understanding of the illness and its management in personal terms, through personal research such as reading, or personal life experience.	Initiation Using organisational skills to arrange one's own contribution to management, such as arranging prescriptions, social care and transport to appointments.	Interactional workability Taking treatments, enacting lifestyle changes, attending appointments, enduring symptoms and side effects.	Individual appraisal Assessing individually whether to continue or alter current management plans.
Internalization Relating your experience to the illness and its treatment, understanding its implications, knowing when to seek help.	Legitimation Seeking reassurance about treatments from others about appropriateness of management plans.	Relational Integration Developing relationships with and confidence in health professionals and their interaction with each other. Overcoming barriers in accessing care.	Systematization Developing ways of keeping up to date with newly available treatments.

As data was analysed iteratively, Table 1 was expanded and refined to accommodate the data in a sensible way (see expanded coding frame Table 2).

Table 2 – Expanded Coding Frame

COHERENCE Learning about illness & Consequences	COGNITIVE PARTICIPATION Engaging with others	COLLECTIVE ACTION Methods for managing symptoms/ treatments.	REFLEXIVE MONITORING Monitoring illness or treatments.
CODI1 Developing an understanding of the diagnosis, and differentiating it from other illnesses TIB*	CPEN1 Engaging with friends, family or health professionals to enable them to provide support or give advice. TIB	CASW1 Developing methods for coping with therapeutic interventions (including medication regimes). TB	RMRE1 Altering treatment regime to fit in with daily activities, inc rearranging appointments. TB
CODI2 Developing an understanding of investigations, treatments or care. TB	CPEN2 Understanding the emotional distress of others due to one's own illness IB	CASW3 Developing coping strategies for symptoms, exacerbations or emergency situations. TIB	RMCA1 Discussing, altering or reviewing management plans in discussion with others (either professionals or friends and family). TB
CODI 3 Developing an understanding of the role of different health professions in the illness TB**	CPAC1 Arranging help with treatments (e.g. logistical, administrative, or expert) from health professionals, social services or friends and family and negotiating reduced help. TB (about doing)	CACI1 Installing adaptations to the home or for mobility. Moving house. TIB	RMCA2 Getting advice about or deciding on the cause of medical symptoms, and whether to seek medical attention with the help of health professionals, family or friends. IB
CODI4 Describing how a symptom feels, and attributing it to certain disease processes, or to other processes such as ageing or medication side-effects. IB***	CPAC2 Arranging help from health professionals, social services, friends or family to manage illness/symptoms, e.g. help with housework, socialising and negotiating reduced help. IB	CACI2 Integrating the illness into social circumstances. Altering social activities due to illness or its management, inc method of transport TIB	RMIA1 Making decisions about whether to follow medical advice and treatments. TB
COCS1 Making sense about illness, (including pathophysiology or explanations of symptoms) diagnosis, investigations or treatments from health professionals, friends or family, either directly or indirectly. TIB	CPIN1 Arranging appointments, investigations and treatments. TB (about initiating)	CACI3 Financial burden. TIB	RMIA2 Reflecting on care and health status. TIB
COIS1 Reaching one's own personal view of the illness and its management. TIB	CPIN2 Utilising one's own skills to contribute to managing illness, such as phoning for the results of a test, organising social care, or benefits. TIB	CAIW1 Visits and tests related to the provision of the treatment or admissions and enduring treatments. TB	RMIA3 Making one's own decisions about your illness i.e the cause of medical symptoms, or whether to seek medical attention. IB
COIS2 Researching the illness and its	CPIN2 Utilising one's own skills to contribute	CAIW2 Enacting treatments, for example	RMIA4 Reflecting on social care needed. TB

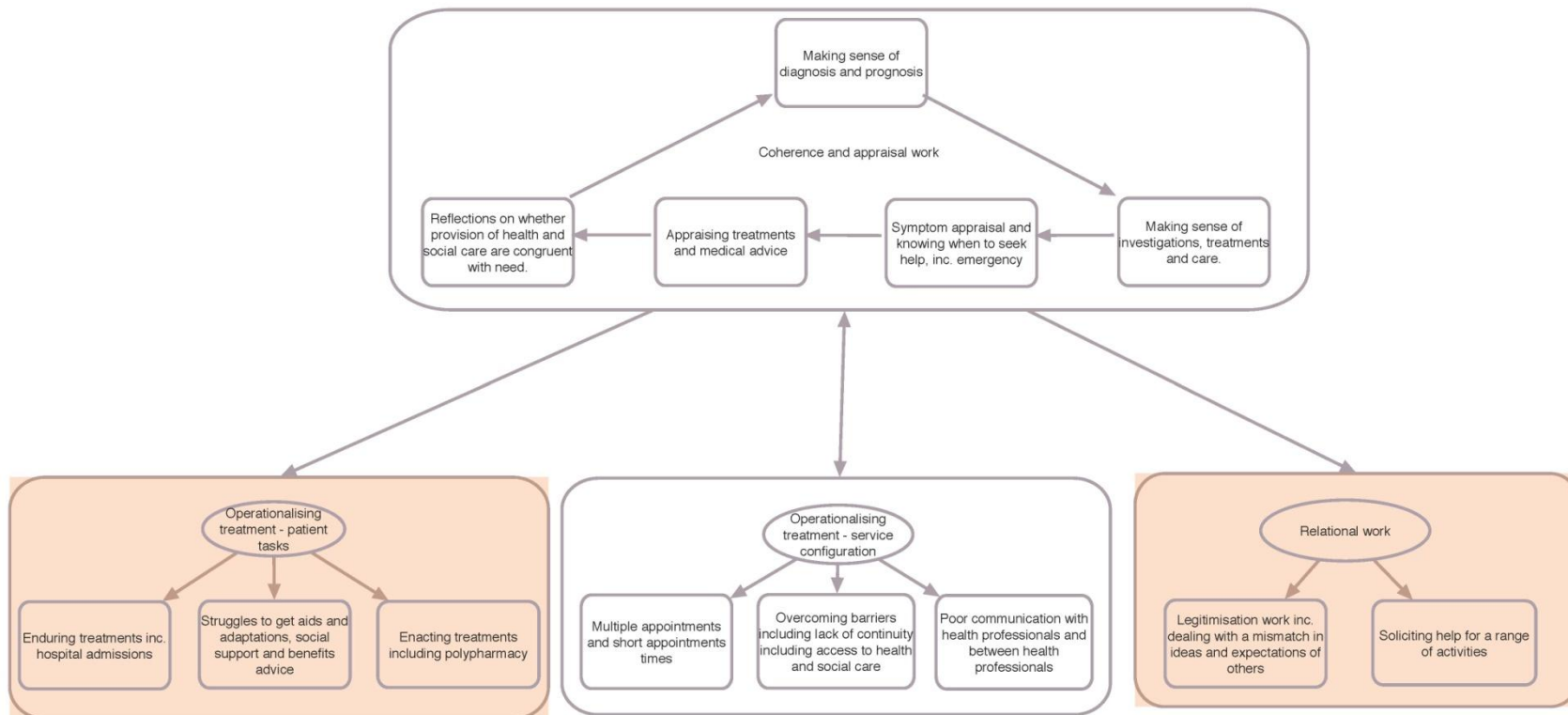
management through medical resources or other media. TIB	to managing illness, such as phoning for the results of a test, organising social care, or benefits. TIB	the work of taking multiple medications or lifestyle changes, for example, smoking or diet. TB	
COIN1 Relating how one feels (including maintaining motivation and belief systems)to the treatments. TB (inc frustration, coping, emotional work)	CPLE1 Seeking or providing reassurance about treatments from friends, family or professionals. TB	CAIW3 Enduring treatments or side effects of treatments. TB	RMSY 1 Keeping up to date with new info about the illness or new treatments. TIB
COIN2 Relating how one feels to the illness, its prognosis, and understanding the limitations imposed by it. IB	CPLE2 Discussing or comparing with others (non health professionals) about how you are coping or the seriousness of your conditions IB	CAIW4 Coping with changes in medication due to prescribing policies or pharmaceutical industry. TB	RMSY2 Developing a routine for self monitoring. TB
COIN3 Taking responsibility for your own actions. TIB	CPLE3 Dealing with stigmatisation and mismatch in ideas and expectations from others	CAIW5 Enduring symptoms of heart failure or other illness, including low mood. IB	
COIN4 Developing an understanding (oneself) of when to seek help and one's own limitations. TIB		CAIW6 Coping with incongruent interactions with health professionals	
COIN5 Relating how external factors impact on the illness, and comparing and contrasting others experiences. IB		CAIW7 Enduring family/friends interventions or intrusions. TB	
		CARI1 Describing relationships with & confidence in medical professionals. TB	
		CARI2 Coping with multiple health professionals as care givers and poor communication between them. TB	
		CARI3 Overcoming barriers to gaining access to care. TB	

*Treatment and illness burden **Treatment burden ***Illness burden

This framework provided us with a vehicle to explore the “work” surrounding acute admissions. NPT proved a useful tool to help us conceptualise the data with each construct of the theory broadly mapping onto each of our research questions. We followed the five stages of framework analysis described by Ritchie and Lewis (Ritchie & Lewis 2003): familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation. The distribution of codes was recorded, and importantly, we constantly checked to ensure important concepts or ideas were not being missed. The research team undertook “coding clinics” to ensure consistency of coding and agreement on the key concepts. In addition, all transcripts were double coded separately with the coders then discussing each transcript to ensure consistency. Refinement of the coding frame and analysis was therefore iterative.

Thereafter we examined the data carefully to look for regularities in the data and compared the data to that obtained in another CSO funded study of treatment burden in thirty heart failure patients. Analysis of qualitative data collected in two related studies helped us to characterise the nature and distribution of burden of treatment in CHF, and its relationships with experiences of symptom burdens and social context. Integrative analysis is intended to extend the context-dependent statements about data and reframe them as a context-independent conceptual model. We examined identified regularities in the data (Gladwin, 1989) to help us identify stable themes and develop a conceptual model of the work of self management undertaken by those with heart failure. We characterised the different components of treatment burden, the work patients and carers had to undertake to manage their condition and respond to the demands of health professionals and services, revealed in the qualitative data analysis and mapped them in relation to each other (see Figure 1). The figure maps the different components of treatment burden, as they were associated with each other in participants’ accounts. Second, we characterised the relationships between components of treatment burden. Our conceptual model suggests a set of contingent, but possibly consequential, relationships between elements of the model and this helped us to formulate our recommendations as provided at the end of the report.

FIGURE 1 Conceptual model



Phase 2 Sampling

Again, a purposive sample was sought in order to capture a range of views and experiences from health professionals who encounter advanced heart failure patients. We were eager to capture the perspectives of specialists in both heart failure and palliative aspects of care as well as get the view from those responsible for care in the community. The sample was examined iteratively to ensure we were capturing the opinions we required as our findings emerged. We recruited 65 health professionals from a range of disciplines including Cardiology, Medicine for the Elderly, District Nursing, General Practice, Pharmacy, the Ambulance service and the Heart Failure Liaison Nurse Service to take part in focus groups and interviews designed again to address the research questions.

Phase 2 Recruitment and Interviews

Recruitment to this phase of the study was extremely successful and considerably exceeded that which we had envisaged in our initial proposal. We conducted both focus groups and one to one interviews with participants. We chose this approach for pragmatic reasons, that is, whichever mode of data collection seemed most likely to optimise participation and reach of our study. Health professionals were provided with the key findings from the phase 1 work, in the form of short clinical vignettes, and were asked to comment specifically on the issues raised. They were additionally asked to comment on barriers they faced in their efforts to provide optimal care for advanced heart failure patients and their ideas for improvements.

Phase 2 Analysis

As with Phase 1 the interviews and focus groups were audio-taped and transcribed verbatim, with participant consent, and transcripts served as the data for analysis. We again used a framework approach to data analysis as described in Phase 1 but for this work we specifically mapped the health professional responses against the themes identified in Phase 1, in order to help us characterise health professional responses in relation to the four research questions and the issues raised by patients and their caregivers.

3. RESULTS

Table 3 provides details of the advanced heart failure patients included in the study and Table 4 information about the close persons. The age range of participants was 60-86 years, with 8 females and 22 males. The mean number of prescribed medications was 15; while the number of comorbidities ranged from two - nine with a mean of five.

Table 3

STUDY ID	AGE	GENDER	NUMBER OF COMORBID CONDITIONS	NUMBER OF REGULAR PRESCRIBED MEDICATIONS
1	73	M	8	20
2	71	M	5	17
3	67	M	5	11
4	84	M	3	5
5	69	M	9	13
6	69	M	4	18
7	72	M	2	12
8	76	M	8	18
9	70	M	7	12
10	71	M	2	16
11	60	F	7	19
12	71	M	5	21
13	81	F	4	8
14	70	M	6	13
15	76	M	6	11
16	71	F	5	19
17	61	M	3	11
18	71	M	7	15
19	72	F	7	20
20	65	M	7	15
21	78	F	7	6
22	80	M	6	15
23	86	M	7	12
24	79	M	3	24
25	79	F	4	13
26	66	M	2	12
27	71	M	6	12
28	63	F	4	19
29	68	M	6	27
30	84	F	5	10

Table 4

CARER CHARACTERISTICS	Carers (n=20)
Wife/female partner	11
Husband/partner male	5
Daughter/daughter in law/sister	3
son	1

Table 5 provides details of the health professionals (N=65) participating in interviews or focus groups.

Table 5

General Practice (inc GPs, practice nurses, DNs and practice managers)	Focus Groups x 3 (n=29)
Accident and Emergency Consultant	Interview x 1
Medicine for the Elderly Consultant	Interview x 2
Cardiology Consultant	Interview x 1
Palliative Care Consultant	Interview x 1
Cardiology trainees	Focus Groups x 2 (n=14)
Ambulance Service	Interview x 1
Heart Failure Liaison Nurse	Interview x 3
Palliative Nurse (Heart Failure interest)	Interview x 1
Marie Curie Nurse	Interview x 1
District Nurses	Focus Group x 1 (n=8)
District Nurse (Out of Hours)	Interview x 1
Palliative Care Pharmacist	Interview x 1
Pharmacist (Pharmacy Heart Failure Service)	Interview x 1

4. Findings

Our findings are detailed below as they relate to each of the four research questions set out in the study protocol.

4.1 How do advanced heart failure patients and carers make sense of their condition and plan for the future, what part do health professionals play in this? (Coherence)

4.1.1 PATIENT AND CARER PERSPECTIVES

Poor Understanding of the Implications of Heart Failure and Prognosis

Levels of knowledge, understanding and communication remain suboptimal. Incoherence was a pervasive and key feature of participant accounts and a key element of this was around patients and caregivers' problems in *making sense of the diagnosis and prognosis*.

'Heart failure'

Patients seldom described themselves as having 'heart failure'. Those who did mention the term heart failure thought that it was too extreme a term for their illness, highlighting a lack of appreciation of their poor prognosis.

When you say heart failure, you automatically think, well you know, that your heart, well, you're going to die any minute. If you know, unless you know anything more about it. A normal person will say, oh you know, you've got heart failure, in six months, how long do you think it will stop completely. ID18

I know it's what they call heart failure, its rather an unfortunate name to call it heart failure you know, you consider heart failure means that you are dead. ID 6

There were also some instances where clues were given that the patient was unaware that a heart failure diagnosis applied to them currently.

Well I assume that at some point I'm going to have heart failure, most people, I think most people when they have heart attacks it's, eh, it can be to do with some of the valves, arteries and all that sort of stuff. When I have my problem its more likely to be just the heart that just goes bang and stops because its clogged up so much that it just can't function. ID16

Heart 'problems'

Rather than talking about 'heart failure' patients described long histories of managing heart 'problems'. Multimorbidity just added a further layer of complexity, sometimes, making it difficult for patients and caregivers to distinguish what underpinned symptoms.

Her lungs doesn't work right, what the doctor says there was her lungs are totally knackered. It starts the heart off, if she takes any chest infections at all, any colds, anything, it's always the heart it attacks. ID 13 Close person

A range of descriptions of the heart 'problems' were offered:

The left ventricle isn't working properly. When I had the heart attack it damaged it a bit so that is what I was told, that is all I know. ID21

I've got fibrillation of the heart, it got damaged with all the beatings my lungs gave it and as I say it's not as if they can give me a heart operations. It's still dangerous you know, it's still, I've had a couple of wee strokes. I've never took a heart attack. ID13

My understanding of it and the only way I can describe it to you is the way I see it. You know you get a balloon and you blow it up and it's a wee bit heated and it shrivels, that's the way I picture it. They have shrivelled the wee bits of my tubes you know. ID11

A deteriorating condition

Perhaps because of their poor understanding of their diagnosis some patients had failed to recognise the deterioration of their condition. Some understood that their condition could not be 'cured' or reversed and expressed the hope that it would not deteriorate.

Well it's never going to get better. I know that I'm not dying. ID13

Where there was better understating of deterioration or the potential for deterioration this seemed to be the result of interactions with health professionals.

Her illness is only going to get worse, it's not going to get any better and we have already been told that anyway. ID 13 Close person

A terminal condition

There was little evidence patients were fully aware of the terminal nature of the condition, or if they did there was clearly an element of denial in their accounts.

It doesn't scare me, I mean if it was killing me, well it is I suppose but I just forget that bit. I don't ,I don't think I'm going to die next week I just say that's what's causing it and I know how to cope with it, if you are breathless, do the right thing and sit down. ID 6

A limiting condition

What patients were very clear about was the degree to which their illness limited their lives. Heart failure was a limiting condition and patient's capacity to live 'normal lives' was severely compromised.

My whole life is turned upside down since I've been diagnosed. You are curtailing a lot of things, you know, that you did before. ID 19

It stops me from actually doing a lot, any exercise whatsoever, you know. If I lift a bag I feel, and if I move a chair or do anything really, standing for five or six minutes, really hurts me, you know, so that's about it. ID 10

Co-morbid conditions

Co-morbid conditions added a further layer of complexity making it more challenging for individuals to understand their diagnoses and to accurately appraise the meaning of symptoms. Participant accounts made it clear that multimorbidity complicated the diagnostic process for professionals too. Differentiating symptoms of CHF from other conditions, and from signs of normal ageing, could be difficult for participants. Importantly conditions could require conflicting self management approaches complicating self care. Participants also described how they might use treatments to deal with multiple problems. Illustrative examples are provided in the following excerpts from accounts.

I'm like that with it so I think it's because of my diabetes and if I get my diabetes under control that will help my eyes so I'm not complaining about that just now I'm trying my best, doing what I'm told sticking to my diet, sticking to this water diet which I think the water diet, somebody told me, my granddaughter told me if its gout, and its serious gout not gout, cramp she says drink water and I says but I can't. I need to see the doctor because I can't go through that all the time because I think water helps. ID 29

The doctor up there, one of the top doctors, I don't know his name, he's a professor, he said one day he said I say that's the chest he said, they reckon it's the heart ... but I reckon it's the chest. ID12

We got that (referring to morphine) last Friday, she's just to take it when she's breathless or she's got osteoporosis in her back so she has taken it a couple of times when she is in a lot of pain. She says it helps right enough. ID25

The symptoms were similar to angina at the time but when I went into hospital I still had the impression that if I had I got the oxygen it would have cured whatever the effect was you know what I mean? ID04

Poor understanding of treatments and care

Uncertainty about the meaning of their diagnostic label and prognosis persisted throughout their illness careers, and this retarded patients and caregivers' ability to appraise symptoms and undertake help seeking behaviour and distorted their understanding of treatments and self care.

'I kept on saying to her, all day, 'do you want me to just phone the doctor?' and she was like 'no just leave me I'll be all right', but by, roundabout six o'clock she was just deteriorating and I could see it, she was getting worse trying to breathe. I tried, what I did was I put her oxygen up, usually I do everything before I even phone them.' ID 13 Close person

The work involved in understanding advanced heart failure extended to treatments and care. Both the volume and complexity of medications and treatments potentially available to heart failure patients are daunting.

'Off by heart and I knew the colour of the tablet but now you are going in and they are all black and white one, there's a green and white one, red and white, so you don't know if you are coming or going with them'. ID02

That's not supposed to cure acid. This is what I'm saying and it does, this is the thing that helps me, not the medication. And one of the nurses or the doctors is standing scratching her head, that's not

supposed to work, and I said well it's my body, I know what's going on in my body, I said, when I take that and the burning feeling is there it goes away in second. What would I need to come up here and tell you lies for? ID14

ICDs

New treatments for heart failure, such as implantable cardiac devices, provide many benefits and new opportunities but also pose new challenges. Patients and their caregivers rarely appreciated the functions or implications of such devices as the following comments vividly illustrate. It was clear that patients had many misconceptions about the functions of such devices and the implications of deactivation.

'And then he says the defibrillator, he didn't say he was taking it out, he says he was going to switch off the resus button off... And again I said to him and why are you doing that? And he says 'because its mainly, it can be very distressing because if X takes a heart attack and it doesn't bring him round it would keep going off and you would get into an awful state' and all that and I said 'well I'm quite willing to take that chance' I said, so just I prefer you to leave the defib as it is.' ID10 Close person

And even last time I had said to her 'why is death imminent?', talking about switching off the defibrillator and when they do that. I mean I don't think we need to even think about doing that because at the end of the day the worse thing that happens is it fires and fires and fires and you get a three minute response and somebody is here so that is not, I don't think we have to dwell on that and, you know, that sort of thing. I can understand them talking about whether you want to be resuscitated or not, I think that is quite straightforward. ID08 Close person

Communication with health professionals

Descriptions of discussions with health professionals about diagnosis and prognosis suggested a lack of frankness and led to uncertainty amongst patients about why they were becoming progressively unwell as the following examples illustrate.

'I said to him, 'am I liable to suffer a heart attack doctor?'. He said, 'not so much a heart attack but heart failure', but he did not say I had that. Then that was fourteen years ago and no-one has ever said until, in fact, the carer one morning was checking my list and I think she didn't mean to say it and she said 'heart failure'. I think her supervisor was here. Would they be frightened to tell me?' ID21

'I think it seems to me not like cancer where they say you've got five months to live or you've got a year but nobody has said that. I wonder whether that is good strategy or what, I don't know, but I really like answers but it's because we have always been in control of our lives and now we are not.' ID08

'Why was I not told that things were getting worse? I didn't expect them to get any better but I thought they would just be stabilised and he said 'because my thingy is, I don't believe in telling a patient until they need to know and now you need to know.' ID10

No they don't really tell you what the problem is they just say your heart is bad and that's it, you are getting treatment for your heart. No no, no they don't even say to you take it easy or that. When you go in there you are just a clinical case, they give you the treatment whatever it is they've decided but as far as your concerned they don't really tell you anything. ID04

Just damaged that's all I know, just damaged, they said severe damage that was all they says type of thing. ID02

Instances of health professionals delivering opaque statements such as 'you're sicker than you think' were recounted. These interactions caused patients to spend time wondering what the health professional had meant by such comments.

Well they will maybe say 'your heart is really badly scarred, you are a lot iller than you think you are' and you are saying to yourself, 'I know I am, I know I'm ill' I can see that so they are not giving you a, sometimes you are not getting the right picture to things. ID02

He came in and the way he was talking it was as if I was drawing my last breath, 'do you realise how ill you are?', I said 'oh I know, I know I'm not well'. 'But do you really, really know how serious a condition you have?, do you really realise all this?' That's what he's saying to me, so he goes away. And I thought to myself that's just what I need a wee boost, you get an idiot like that telling you how ill you are. ID6

Communicating with multiple health professionals

People with heart failure needed to work through the different roles, responsibilities and limitations of the numerous health professionals who organised their care, including General Practitioners, Heart Failure Liaison Nurses (HFLNs), Cardiologists, and hospice staff and this posed a further challenge. So for example, General Practitioners, while generally viewed positively were often described as not having the necessary expertise and thus patients, through, experience, learned when the GP could help or when it was better to seek specialist help and advice. Patients would sometimes have to interact with a number of different professionals to get the information or help they needed as is the case of this patient who was struggling to get test results.

I didn't seem to get through and that's why I went to the doctor and she took it, well the nurse said 'well I'll send it to the Royal' and that was away last Thursday, she said I'll maybe not get word until Friday when I phoned her up and told her. I said well I phoned I went down to the doctor and I got the nurse down there to do it so all right then she said I'll maybe not see it until Friday since it was late I said fair enough but I've never heard anything back from them whether it was all right or whether it wasn't all right. ID02

This could be particularly challenging outside normal working hours.

You can't get in touch with your GP at the weekend you have to go through NHS24 and you're speaking to total strangers. ID18

This time round, because they had changed the way things are now done in the national health services, it wasn't just a question of her going down to X and that being the nearest place. We had to identify the right hospitals to go to and that turned out to be a real bind because initially you had

to go to the, was it the Y first, then eventually Z. She had to go to three different hospitals. ID18
Close person

Additionally patients have to assimilate discrepancies in information provided from the range of health professional they encounter.

I remember once being in bed in hospital and the doctor said of course it's your valve that's leaking as well and at the time I only thought I had one leaking valve then I find out that I had two. So some doctors will tell you a lot and some doctors don't. ID18

4.1.2 HEALTH PROFESSIONAL PERSPECTIVES

Patients' poor understanding of prognosis

Health professionals described difficulties communicating patients' complex and poor prognosis, especially as they believed that many had little appreciation of their prognosis and unrealistic expectations regarding their illness with a general failure to recognise a downward trajectory. Poor understanding of diagnosis was thought to be compounded by cognitive impairment and complicated by co-morbidity. Consequently, the subject of palliative care is difficult for professionals to introduce as the following comments illustrate:

'They will say 'oh, at least I haven't got cancer''. HFLN 1

'It's not terminal as in cancer, you know, they still think you know if they go into hospital I will be sorted out and I'll get back out again and I'll soldier on'. HFLN 3

'Sometimes patients' perspective is that they are deteriorating or they need their medicine adjusted not that the underlying disease is actually deteriorating'. GP Focus Group 3

Why patients lack understanding

Health professionals suggested a number of explanations as to why patients fail to recognise the extent of their illness. These included:

- The fact that health professionals find it difficult to help patients grasp the complex issues in relation to their diagnosis and prognosis, especially when patients clearly have poor levels of understanding. Difficulties around prognostication for advanced heart failure generally add to the challenge.
- The lack of a 'key person' who would engage in conversations around prognostication and palliative care mean that patients lose out on communication from health professionals.
- The gradual nature of the decline experienced by those with heart failure patients.
- The fact that patients may misinterpret the purpose of alterations to medication and believe that 'something can be done' even when they are at the most advanced stage of the disease.

The following comment illustrates some of the challenges:

'They are often given the initial diagnosis at a time when they are reasonably well and the deterioration ... has been very gradual so he's actually acclimatised to it and people around him, his family, have just acclimatised to it as well so I don't know that they really see him... any differently now to ten years, even though physically he is much different now.' GP Focus Group 3

Health professionals acknowledged that patients' poor understanding is often simply associated with a lack of communication from health professionals. Health professionals were cognisant that patients were given a lot of information during consultations and were concerned about capacity to retain information in the weeks and months following consultations. They recognised too that they may be so accustomed to using medical terminology that they may fail to use language that could be easily understood by people who do not have medical training. In one instance the benefits of patients being made aware of their prognosis was queried.

'What I would like to know is what evidence is there that it's going to be beneficial for patients to be frank with them about their prognosis?' Cardiology Trainee Focus Group 2

Service configuration as a barrier to effective communication

However most health professionals were keen to improve communication with heart failure patients but described significant constraints because of the way services are configured. Short appointment times, excessively busy clinics, a lack of nursing and psychosocial support as well as an inability to provide patients with continuity of care were cited as important barriers to effective communication as the following comments highlight.

'The cardiologists, the system that they are expected to work in, the environment, the time constraints that they have, that is not conducive to having these significant conversations with patients and you can't have that conversation without actually building in some additional time or support.' HFLN 3

'I think it's currently done very badly because the current model for heart failure care is very poor so 30% of people are looked after by cardiologists and 70% by non-specialists of any sort so nobody has got any idea about the hearts, when they do see a cardiologist they are sitting in busy outpatient clinics with roughly thirteen people to be seen in three hours by a cardiologist. So you've got very little time so with the best will in the world you haven't got enough time to explore or get the patient to understand what's wrong with them.' Cardiologist

Factors that promote good communication

Communicating complex and poor prognosis is challenging and health professionals have clear ideas about factors that would promote good communication. Service configuration was often seen as a barrier to good communication. Health professionals expressed the view that:

- Communicating a patient's prognosis requires multiple conversations taking place over multiple contacts and with the same health professional, someone who has developed a good ongoing relationship with the patient.
- Some indication of poor prognosis should be introduced at the outset.
- Multiple conversations allow health professionals to get a feel for how much information is retained.
- Written information to back up discussions is required.

'The person that has those conversations needs to have a good relationship with the patient and the family but also needs to have a good understanding of how much information the patient is willing to listen to as well and are they ready to have that conversation.' HFLN 3

I'm sure that kind of patient understanding is actually, is very important but when these patients are so sick it's very difficult you know whether they have the ability to understand or whether you know their relatives might think it's an upsetting conversation so I think if you have people slightly further back in the illness or a bit weller sitting in the clinic for a long time and talk to you then maybe you can get a better understanding there but I think it's challenging with the really sick people at end stage to get them to really understand and then it's more difficult for them and their families to be really proactively invested in what's happening to them.' Cardiology Trainees Focus Group 1

This process was deemed easier to undertake if the patient is an inpatient, otherwise multiple outpatient appointments are required to give patients time to reflect on information and decide whether they want more information. HFLNs have regular contact with patients and are well placed to address patients' poor knowledge and understanding with on-going reinforcement of information but feel overstretched and short of time for this labour intensive task.

Communicating a poor prognosis

Health professionals felt it important to preserve hope while communicating a poor prognosis, and commented that this was a skilled endeavour. In order for conversations around prognosis and the introduction of palliative care to be undertaken effectively and sensitively there should be a lead up, where the patient and their carer can acknowledge that they haven't responded to treatment. Conversations should be paced so that services can be introduced at a point when they are acceptable to the patient. There needs to be recognition that the patients' priorities may not always match the professionals' expectations. Where patients have significant cognitive impairment discussions need to take place with family. As with patients, these discussions begin with trying to explore the level of understanding.

'You want to get them to begin to appreciate that ...there aren't any more things we can do physically but we are not writing patients off. We are there really to support them and to manage their symptoms, to feel as well as they can for as long, and as good quality of life as we can get. That's the kind of aim. I don't find it easy'. HFLN 2

'Initially he wasn't very comfortable about having OT or the district nurse involved. So it was all, had to be done very, at a pace that suited him'. Marie Curie Nurse

Health professionals have to consider that patients may not want to know everything regarding their prognosis which poses another interactional challenge. There was recognition that conversations about outlook were difficult for health professionals, and consequently may be avoided.

'And not many of the patients bring it up so it is a conversation that needs to be initiated by professionals and there is a lot of discomfort associated with having that discussion as is the same discomfort that professionals feel approaching any sort of any discussion around poor prognosis'. HFLN 3

'You can understand why people avoid those sorts of conversations because they don't have the confidence to have them and so they just avoid them and well hope that somebody else will have them.' Palliative Care Pharmacist

Understanding ICD deactivation

The deactivation of ICDs had emerged as an issue for patients and so health professionals were asked for their input about how these conversations could be improved. They appreciated how significant an act deactivation could be.

'They have the perception in their head that if its deactivated they may suddenly die, that as soon as its deactivated they will then die, it's like turning off the respirator.' Palliative Nurse

'The whole turning on, turning off thing which is really difficult because to say 'I want my life saving device turned off' is a big thing to say for anybody so I think that is a really difficult area and there is a lot of stress that goes into that from all sides of, everybody involved in that, particularly the patient obviously but carers and everybody else so I think it is a really difficult area'. Cardiologist

Health professionals believed that time should be built into the process early on to allow conversations with those patients with ICDs that would include the subject of eventual deactivation. The issue of ownership of this task was discussed along with the suggestion of the creation of a role which would focus on such conversations and patient education. Generalists sometimes felt they lacked the expertise to initiate such discussions.

'The patient is fitting in with the system that is in place and that we need to adopt some flexibility within that system and be able to provide accurate information at a time where the patient is consenting to that device being inserted in the first place'. HFLN 3

'It might be that there needs to be some kind of development of a post for somebody who is, that that is a key part of their role that they have these discussions pre-insertion of the device and it could be a specialist nurse.' HFLN 3

Those who had undertaken conversations about deactivation would have liked written information to give to the patient.

'I must admit I didn't feel I had an awful lot of written...I felt he wanted to read something and he wanted to know something or he just couldn't grasp it.' Medicine for the Elderly Consultant

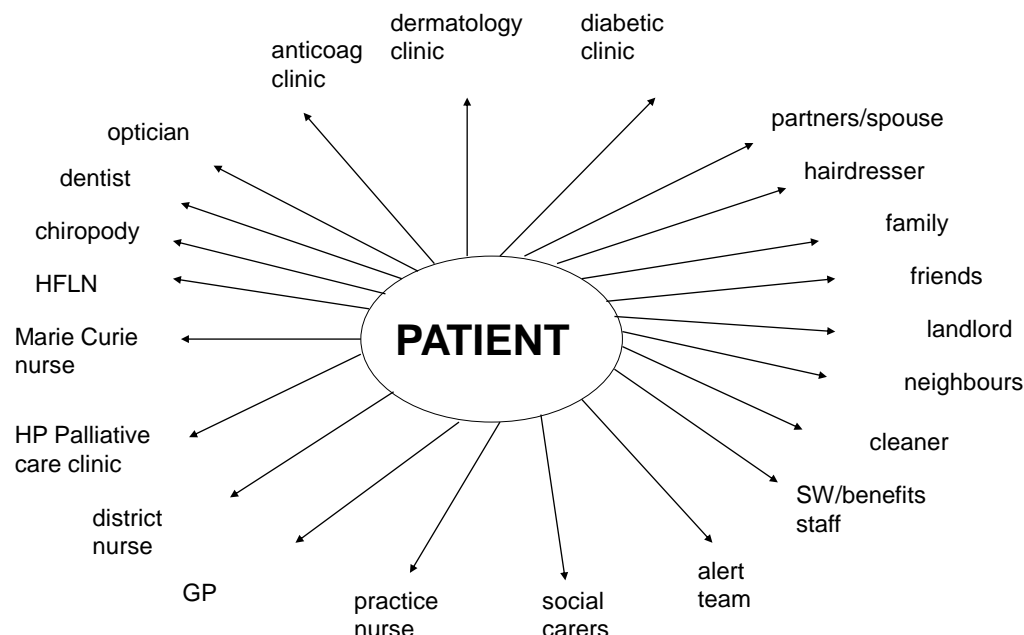
4.2 What services and support do patients and carers currently utilise, and how do they negotiate and mobilize these with health and welfare services? (Cognitive Participation)

4.2.1 PATIENT AND CARER PERSPECTIVES

Engaging with others for assistance

Those with advanced heart failure expended a great deal of effort negotiating help with a wide range of friends, family and outside agencies. They had to work out the different roles, responsibilities and limitations of the numerous health professionals who organised their care, including General Practitioners, Heart Failure Liaison Nurses (HFLN), Cardiologists, and hospice staff. Figure 2 provides an illustration of the range of contacts an advanced heart failure patient might have.

Figure 2



General Practitioners

The challenge here was to make sense of their illness state and the processes of care, in an environment in which relations with healthcare providers were often fragmented and discontinuous. General Practitioners, although viewed positively weren't seen as really being able to help greatly, because they were perceived as lacking the necessary expertise.

'I think he (GP) is simply his main contribution is to back up the suggestions of the specialists which he does very willingly and he's very helpful but we really don't see him a great deal because it's always, it's almost always specialist assistance that we need and he is the first person to say, you know, he refers us on to whoever is appropriate for the particular problem'. ID8

The Heart Function and Supportive Care Clinic (HF&SC)

The HF&SC was viewed as a real help. Patients commented on the time available to them and felt that they were listened to and their needs addressed.

'To tell you the truth I like going to see Dr X because nothing is too much for her, she is not just 'all right, okay, I'll put, right, will see you in the next three months'. She doesn't rush you out, she sits there and she listens and if she is not too sure she'll write something down and I'll get back to that question later, you know, this is the opinion, the expression she gives me and I really, really like going to see her and I told her that, 'I don't mind coming to see you doc'. ID14

However some patients were confused about the purpose of the clinic and some found end of life conversations onerous.

We are having to make decisions like no we don't want to be resuscitated and stuff like that and it's too ongoing. It would be quite good if we just did the plan, that's it, talk about the plan, where X wants to be cared for and then forget about, you know put it away and do you know what I mean? ID08

The Heart Failure Liaison Nurse service

The Heart Failure Liaison Nurse (HFLN) service was valued because the nurses helped organise things for patients, but also because of the continuity they provided.

And it's the same nurse more or less you get every time you go up. Well she has been to the house, she has spoken to us, she gets to know you. You don't feel you are just a number. ID11

She has a mobile number, not that we've used that but and she has her telephone number. If she is not there, there is an answering machine and she has always got back to us. ID08

Family and Friends

Participants' accounts convey real discomfort at having to work to distribute the burdens of their care, and an important subtext is anxiety about whether or not others would accept these burdens. Others, were most commonly called upon to help patients manage their condition; cope with their medications; collect repeat medications; attend appointments; engage with specialists; function at home; and in emergency situations.

I do all her day to day things, like making sure she gets her tablets, morning tablets, afternoon and night tablets and make her breakfast and make her dinners and go the shopping. I go and pay all the bills, do all the shopping and everything else and just generally clean up and everything. ID 13 Close person

Participants suggested that others sometimes failed to grasp how unwell they were.

In fact a friend phoned me last night, 'what's happened to you?' And I went 'I don't know Isa' she said 'could you not manage?'. I used to go to a ladies night. I says 'I can't'. ID30

They sometimes felt that their requests for help were therefore considered illegitimate by others making their situation more difficult.

The struggle to access services

Participants linked problems of operationalising specific treatments with their struggles to obtain aids and adaptations, social support and financial help. They frequently described the physical limitations imposed by their condition, for example, stairs in the home posed problems for those with breathlessness. While some had home adaptations such as stair lifts in place with evidence of great benefit, others battled to arrange such home adaptations .

She was starting to look about the place to see if I get any help with, some help with getting in and out the bath or maybe getting a shower or maybe getting a stair lift. Well, they are all in the hands of the Gods, these things, you know. She can't say 'aye'. ID24

Adaptations such as stair lifts or walk in showers were described as key to facilitating an acceptable quality of life at home yet were not easy to access.

Efforts to get appropriate support with personal care and other home services were considered frustrating. Individuals reported how such help was often delivered in ways that suited the provider organisation's needs more than the patients. Considerable effort could be expended on organising services or support at home as the following story illustrates.

'I was having difficulty getting a container for the oxygen you know the portable one. Did I tell you that already? Well that is over there. My daughter in law got one in Lloyds in East Kilbride....I was worrying about these things and also my son yesterday, my other son he rang up Scottish Gas because he came here about the situation and they said to him which had already been said that I would require a letter from a consultant before I would receive any priority. Well Susan you may be able to understand what I mean is I am not confident to ask a consultant for a letter that is going to help me. I am just not that type of person and anyway they are saying to me if it is going to make a difference of a few weeks why don't you phone the surgery, our own surgery and maybe just talk to the Practice Manager and she will put it to one of the doctors and they might do it that way. Then I thought this morning I will do it and then I thought I will need to phone Scottish Gas again to find out where they will send this letter. So after I got through and I got the story I said I take it my own GP will not be suitable. No she said a consultant or a social worker. My heart lifted then because I feel that is not as difficult as asking a consultant. Now we happen to have a personal friend who is a social worker. Would he be unable to do this for us do you think, because he knows us?' ID23

Accessing care out of hours posed particular problems and patients decided how to access care based on their experience of the speed of responses.

If you are phoning an NHS doctor you maybe wait an hour, 2 hours, before he comes out whereas an ambulance they are half an hour. ID19

Benefits advice

There was little evidence of patients' receiving benefits advice yet clearly some patients were experiencing financial hardship, either due to increased costs associated with their illness, for example taxi fares to attend appointments, or reduced income because of their inability to work

4.2.2 HEALTH PROFESSIONAL PERSPECTIVES

Palliative care

Only a minority of advanced heart failure patients access palliative services. Health professionals raised concerns about whether patients were being identified and referred appropriately. Patients who were receiving appropriate care were sometimes considered to have been fortunate. In-

patients who would benefit from palliative care are not always identified. This problem is exacerbated by the fact that these patients are dispersed across a range of wards.

'We probably don't take as good a palliative care approach to them as we should do because they are normally in an emergency medical bed and in a medical ward so they probably don't get the sort of care that they should do if they were say a cancer patient. Because quite definitely I don't think we have that sort of approach palliatively for heart failure patients in hospitals.' GP Focus Group 1

Cardiologists may be reluctant to label patients as end stage. Patients experience a cycle of admissions, then improvements, then declines, then admissions and so on. Cardiologists often focus on dealing with the immediate needs of the heart failure patient during an acute admission and fail to recognise the pattern of deterioration and the need to consider palliative care, instead focusing too much on seeking improvements in clinical status.

'I think you know from senior cardiology professionals downwards and I think that that is one of the barriers because if they are not understanding fully what is meant by palliative care then I think as well one of the other barriers that we deal with is that some of the cardiologists find it difficult to know when enough is enough for patients.' HFLN 3

Current practice, which prioritises active treatment, was described as not currently affording the opportunity to assess the patient and identify those for whom palliative care would be appropriate. The capacity to assess patients should be built in to services.

'The key there is that the cardiologist really assesses the patient and really identifies what appropriate goals of care are and then they ensure that the patient isn't losing out in any cardiological treatment that they would benefit from.' HFLN 3

Prognostication, as previously described in the literature, was deemed extremely challenging. Difficulties around prognostication add to issues of identification of palliative HF patients.

Prognostication is kind of entwined in how aggressive you decide to treat them and having an understanding that there comes a point where actually the right thing to do is not to put them back on the IV diuretics but it is to say that you know this is the third time we've been here. This is not going to get better, what is it that you want us to do now? Medicine for the Elderly Consultant 1

Indeed, a desire for clear criteria for the identification of advanced heart failure patients was expressed. Such criteria were thought to be especially required in a climate of limited resources.

'Who should get it? And I believe that people in most need should get it so the thrust in the palliative care community with the palliative care doctors just to give to everybody with heart failure I think that is that laudable ambition but certainly given the funding problems we have at the moment we can't do very much for people so we have be really thoughtful about what we do and I think we should target towards people who need it the most.' Cardiologist

Given the desirability of continuity of care for heart failure patients there was a wish, from those providing palliative care in the community, for the identification of advanced heart failure patients to take place early so that relationships can be developed.

Hospice care

Particular barriers around accessing hospice care were described. Professionals felt that heart failure patients perceived hospice care as synonymous with cancer and with in-patient care in the last days of life. As such advanced heart failure patients, who may have a poor sense of their own prognosis, may struggle to see the relevance of hospice care for them.

‘I’ll be the only patient there who has heart failure’, and he felt quite, other people have a cancer diagnosis and he just wasn’t very keen, very comfortable. ‘Marie Curie Nurse

‘There is resistance because they associate hospices still with death and certainly with the Marie Curie, the Marie Curie name as well, that might be the connection with cancer.’ Palliative Care Pharmacist

‘Some have greatly benefited from going to the hospice day units. I think at first some of the patients are a bit surprised that they are being referred to a hospice day unit quite a lot of them have got the view that it’s a hospice. That’s where people go to die, it’s only for cancer patients.’ Palliative Care Nurse

GPs and HFLNs described a very mixed picture regarding advanced heart failure patients accessing hospice care. Some described good links and had frequently admitted advanced heart failure patients for both day care and in patient stays. Elsewhere there was little contact and no experience of advanced heart failure patients accessing hospice services. Some struggles to obtain hospice care for patients were described and difficulties accessing care quickly were mentioned.

‘By the time you’ve tried to get palliative care involved they end up dying in hospital because it has literally taken weeks to try and get the transfer to the hospice.’ Cardiology Trainees 2

Hospice staff had expected to be inundated with advanced heart failure patients when hospices extended their remit to non-malignancies, this has not occurred. There appears to be a need to promote hospices as a service that caters to patients with illnesses other than cancer and provides services beyond very end of life inpatient care.

The benefits of hospice care were extolled and health professionals were clear that advanced heart failure patients would benefit from the services on offer particularly the expertise of hospice staff in conducting end of life conversations and the opportunity for respite for carers that day services offered.

‘It’s just more the personal care is so much more individualised and I think patients can really benefit from that. I think they really would benefit from it and also I think the nursing staff here are much more experienced in probing and having deeper, and having a bit more time to have deeper conversations about what you are thinking about how do you think you are doing, those sort of conversations. ‘Palliative Care Pharmacist

However it was noted that hospices are not equipped for active management that many advanced heart failure patients receive and require. Some advanced heart failure patients benefit from attending day services at the hospice but patients who are not well enough to leave home cannot benefit from these services.

Barriers to Care in the Community

The fact that carers, the patients' wider circle of friends and family, and some professionals often do not grasp the gravity of the patient's condition makes life even more difficult for those with ESHF as they can feel that their requests for assistance are not seen as "legitimate" as the following comments illustrate.

' They look well they don't look as unwell as that person with lung cancer, they I suppose they don't get the help, I think even their relatives you know some of heart patients have come up and said oh the relatives don't understand, they think there is nothing wrong with you, because they look physically okay.' Palliative Nurse

'As soon as you attach the label cancer anyone you meet in any aspect of your life feels sorry for you and wants to, and feels they can understand that. I'm not sure that a home help or a pharmacist or a social worker, they see the diagnosis in heart failure, would necessarily interpret that the same way that we or a cardiologist or a heart failure nurse would.' GP Focus Group 3

Thus patients may struggle to get much needed help and wait long periods to get aids and help from a range of services due to the fact the seriousness of their condition is not generally appreciated by caregivers, both lay and professional. Health professionals often made the point that cancer patients with a comparable prognosis and symptom burden could access community care more readily. The inability to access appropriate support in the community was cited as one precipitant to potentially avoidable admissions. The following illustrate the difficulties heart failure patients encountered.

'One lady that was up today, apparently she would crawl up the stairs, she would get so far then she would have to crawl up. She was a right sided patient and I think they have, you know I think her and her daughter have basically just recently tried to kind of access, you know get a stair lift and I think they have had to do that privately'. Palliative Care Nurse

Cancer patients have access to psycho social support from charity funded services and health professionals noted that there are no equivalent services for HF patients.

'I mean even things like financial support and things like that because for cancer patients you've got Maggie's and things like that it's a lot easier to access a lot of services for cancer patients as opposed to non-cancer patients'. District Nurse Focus Group

Heart failure care

Many heart failure patients are not cared for by cardiologists, partly because ESHF patients are dispersed across many wards making it impossible for them to see the cardiologists.

'You want to do their best for people with heart failure but the reality is they generally get scattered around the hospital'. Cardiologist

The lack of access to specialist care is most acutely experienced by non Left Ventricular Systolic Dysfunction (LVSD) patients who do not have access to HFLNs and were thought to receive minimal care with regard to their heart failure. These patients are often too complex for GPs to manage and a HFLN with an interest in palliative care would be best placed to provide care. HFLNs were clear

that non LVSD patients could benefit from their input but expressed concern about resources and described a service that is already stretched.

If they have right sided heart problems we don't have access to these, these specialist nurses, and they don't have the contact and you know from the clinic I generally find that these people with right sided heart failure they come up to the clinic, they see their GP very infrequently, they have no contact with the district nurse so with regards to their heart failure they have minimum contact with a health care professional. Palliative Nurse

HF patients who live in care homes were also thought to be missing out on the specialist care of HFLNs.

'Well I've been in this post I think four years and to my knowledge I've never known any of the heart failure specialist nurses to be in care homes.' District Nurse Focus Group

4.3 What do patients, carers, and professionals perceive as the main barriers to provision of high quality, well co-ordinated care for patients with ESHF and how can these be overcome (Collective Action)

4.3.1 PATIENT AND CARER PERSPECTIVES

Polypharmacy

Managing polypharmacy, figured prominently in participants' accounts of treatment burden. Complex mechanisms were described for obtaining, organising, remembering and taking medications.

'I'm on Wednesday that'll be empty and I'll use Thursdays and then I'll take the Friday ones out I'll fill those two boxes up again and that will do me Monday, Tuesday, Wednesday and Thursday instead of trying to wait and leave them all until the end of the week. If I sat and tried to make that box up so now I work it in a three and four days, once there are three days empty I'll go and fill it and then the next three days and I'm onto the Sunday so that's me filled the Thursday, Friday and Saturday up and I've got the six in my box and I'm onto the Sunday and when I take the Monday out I just fill the Sunday one up itself.' ID2

The use of generics and changes in the colour of medications proved frustrating for patients who had invested time and effort in learning the colour of particular medications only to find everything changed on a monthly basis adding to their difficulties.

Off by heart and I knew the colour of the tablet but now you are going in and they are all black and white one, there's a green and white one, red and white, so you don't know if you are coming or going with them. I think that's what's keeping me the time. ID02

Carers often played a key role in promoting and monitoring patient adherence .

'And he leaves the lid open so that's when I know he has taken his pills and I don't care I go in and waken him up. He'll say 'you are like a sergeant major' but I'll say 'you are supposed to'. ID7

Enduring the side effects of polypharmacy was a related burden for those with ESHF.

If they give me or take any tablets off me or give me more tablets they just really knock me out. I'm quite happy steadily with these tablets that I'm on. ID10

Misconceptions and poor understanding about the purpose of prescribed medications and their risks and benefits could adversely affect adherence. For example, one man was reluctant to take the morphine he had been prescribed because he remembered watching a film about someone who had developed an addiction. He had not discussed his fears with health professionals.

It was a craving, he had suffered that much pain been in hospital so long he was fed it (morphine) morning, noon and night to ease the pain it became part of his nature, he had to have it, he became a criminal to get it, no fault of his own, just a victim of circumstances but as I say I would be wary of it but under proper guidance or necessity I would take it. ID 04

Enacting life style changes and self monitoring was another important feature with many reporting how they developed strategies and routines to carefully monitor fluid intake.

I keep an idea, it would drive me nuts if I had to try and measure it up because you can't measure it, because the milk in your cornflakes counts, the soup counts, you know, it's not all fluid I just couldn't measure all that. ID1

Multiple appointments

Multiple appointments at different clinics (for both cardiac and non cardiac problems) on different days pose major difficulties for patients, both from the logistical perspective (e.g. organising transportation) but also physically as attendance at these appointments can be exhausting and a major effort. Multimorbidity thus served to increase further the demands upon patients.

'X is going to the health centre to see one nurse on a Monday for talking sake, he's having to go back to see another nurse on the Wednesday and then he has got to go back and see somebody else on another day, she says he is down at the same department three times in a week and he could be done in one day. Each of them that, the Sister, the Nurse and the anti-coagulant clinic. She says it's the same building and yet he has got to go three times daily, he's got to go three times a week, different days'. ID12 close person

They will probably say to me right we will need to send you for further tests. Which is more hassle of going downstairs and coming back up these 40 stairs. Oh, I've got to up ten, stand on the landing for maybe, stop on the landing for two or three minutes just to I get my breath and then go up another ten and stand on the second landing so on and so on until I get to the top and I need oxygen, but I haven't got oxygen because I smoke. They will not give me oxygen in the house. ID14

...nearly a week recovering from the journey (to attend clinic) of it, weren't you, five days and you would say you were wiped out. ID16 Close person

You know that's what I'm trying to get at, he's not getting the time to relax and enjoy the telly because his minds on 'oh I need to mind', once or twice he has missed an appointment because there have been that many at the one time. ID02

Continuity of care

Continuity of care was valued by participants. Some spoke of regret that they didn't have their 'own' doctor, either GP or specialist. Patients believed that new health care systems directly compromised continuity of care.

'These days it's not so easy as that, because the consultants have got the X and the consultants are not allowed to have special patients anymore you know they've got to take anyone, because my other consultant has pointed out to me recently, you're the people I see, they're not allowed to have their own patients anymore, you know they have to take what's there I would think. So it's like the GPs, you no longer have your own GP, which I think is a really bad thing in the health service, because I think in general people like to see the same doctor and they like to know the doctors knows what's wrong with them and I think that's really advisable.' ID2

A lack of continuity of care meant participants having to explain their, often complex, medical history multiple times.

'You have got to explain all your illnesses, over and over again to a new doctor.' ID15

Fragmented and discontinuous care from multiple health professionals sometimes led to patients having to mediate between doctors who disagreed about their diagnosis and treatment, and who employed different medication regimes.

'I mean if you are seeing different doctors and they might change something here and then another doctor will say well no we are going to put this one on to that one and your medication is changing a lot'. ID 20

Such disagreements could also extend to fundamental disagreements regarding issues such as prognostication.

Communication difficulties

Continuity of care did not guarantee relief of burden. Participants described professionals who seemed to lack understanding of their predicament and who made insensitive and sometimes hostile comments about their prognosis or healthcare needs.

'It was a Professor from there, when they realised that he wasn't a malingerer, he put us onto the heart people because it showed that there was something wrong with the one side of his heart.' ID 11 Carer

Poor communication between professionals and professionals and patients also presented difficulties for patients, for example, participants gave accounts of struggles to obtain test results, where they might pursue a number of people to get results and still have their questions unanswered and there could be a feeling that professionals were less than forthcoming about the results of investigations.

'Each time you go into hospital, at least in my case, you are kept in the reception and in the course of that you are through for an x-ray you don't get the results of the x-ray they don't really tell you. ID 04

Sometimes patients mentioned the difficulties they had understanding medical terms.

I am totally non technical medically, if you use a word of two syllables and its medical I don't follow you. ID08

Out of hours admissions

Out of hours admissions were deemed extremely problematic. Patients had no opportunity of either continuity of care or heart failure expertise. Ultimately patients believed that they were only able to access useful care within routine working hours. Attempts to access care out of hours were characterised by confusion and frustration.

But when I was admitted last time in fact I was taken in as an emergency at the weekend, which is the worst possible time to be taken into hospital and you're taken into whichever hospital is receiving, which is likely to be the X and you're shoved in this ward and wait to be looked at by various doctors on duty at the weekend. There's no specialists there really. And you're sort of stuck in these wards and if you go on a Friday night, you're stuck there for two days until Monday, you know until things can be sorted out, but nothing is actually being done. ID18

Where plans had been set up, at the Heart Function and Supportive Care (HF&SC) clinic, to access care out of hours without having to negotiate Accident and Emergency, patients were relieved.

I think because she has a plan sort of arranged, you know, you would just be admitted straight to the Royal without this furore of going through Accident and Emergency and hanging in there feeling terrible for hours. You would just go straight to, I think that is what part of the plan is about to relieve a lot of that. A lot of that yuk. Close person ID08

4.3.2 HEALTH PROFESSIONAL PERSPECTIVES

Polypharmacy

This was recognised as an issue by health professionals but often they felt there was little they could do to help as the following comment indicates.

'I mean it must be dreadful but you know you have the option to take your water tablets and run to the toilet, don't take them retain fluid and be breathless, go back into hospital you know'. GP Focus group 3

Prescribing guidelines mean that the colour of medications change and this can result in additional frustration for ESHF patients. Pharmacists were keen that ESHF patients were encouraged to phone their pharmacists with any queries regarding changes in colour and they felt pharmacists had a role in warning patients about changes to colour.

'I would love to see chemists being more pro active and actually warn patients in advance.' Palliative Care Pharmacist

'It's a huge problem (changes to colour of medication) but that's the prescribing advisor you need to speak to because they tell us what we have to prescribe and we have to'. GP Focus Group 2

Pharmacists were keen that ESHF patients should use the same pharmacist each time so that they could establish a relationship with them and bring queries about medication to them. They acknowledged that housebound patients often lost out on the opportunity to discuss their medication with a pharmacist. Regular medication reviews were deemed important but were not provided to all.

'I think that's where palliative care really comes into its own because we will critically look at those tablets and cut as many as we can out with, in agreement with the patient though.' Palliative Care Pharmacist

'Yeah certainly from my perspective I can see patients..... who have not had their medication reviewed for a long time.' District Nurse Focus Group

Some health professionals felt conversations around rationalisation of medication could be difficult and interpreted as 'we're giving up you'. Other health professionals thought it was not difficult to say 'these medications are not indicated for you'.

'It's about having an appropriate conversation then basically to reassure that I'm not giving up but because their next question would go well why have I been on it for so long if you are saying that's not really going to work for me anymore and they are very hard conversation, very had questions to answer. 'Palliative Care Pharmacist

The single biggest challenge for HFLNs in caring for ESHF patients is ensuring adherence to medication regimes. HFLNs talked about continually having conversations with patients to reinforce the need for adherence. This challenge is made more complicated when patients claim strict adherence.

'There has been lots of work done looking at dossette boxes and what people take and what they don't take and roughly you know at least 30% of people don't take what you give them. Cardiologist

I think most of them will still just say they are going to do what the doctors says and I would say there is still, if the doctor says that, they are nodding in front of the doctor but then maybe not actually quite follow the instructions as they are supposed to. 'Palliative Care Pharmacist

Another difficulty around medication that emerged was the lack of capacity to make rapid changes to regimes.

'It's been slightly difficult to co-ordinate any rapid changes to his medication, because he has all his medication in a dossette box and I do notice that the heart failure nurse is saying well I'll come back and review him in a week but actually it takes a week to get the change of medication into the dossette box.' GP Focus group 3

'You are discharged or a letter you then have to take that letter to your doctor, your doctor has to generate a script, the script has to go to the pharmacy, the pharmacy then has to then you know make it up and then send it to you, so you probably, it is a slow process so when you get the palliative stage symptoms can change quickly but its sometimes you know getting the medicines to change, its sometimes a bit slower. 'Heart Failure Pharmacist

Service configuration

The configuration of health care systems emerged as the most significant barrier to delivering optimum care.

'You are up against it because the system doesn't work like that, short appointments when people come, don't see the same doctors or nurses, admissions to sort out, you know, the presenting issue, presenting complaint, but not getting to grips with the reasons for repeated admissions. Quick discharges because you need the beds so you are trying to sort out this one area in a system that's actually working against you, so I think that is hugely challenging'. Palliative Care Consultant

A range of aspects of current health care systems frustrated health professional efforts to care for ESHF patients:

- Inadequate communication systems, between disciplines and with other agencies.
- A clinic system defined by a short appointment times, a requirement for symptomatic patients to attend hospital based clinics and for co morbid patients to attend multiple clinics.
- A 'lack of ownership' of ESHF patients and associated lack of continuity of care prevents health professionals having the involved on-going conversations required to improve patients' understanding of their illness.

Service configuration - communication

Communication emerged as a key barrier. Health care systems do not accommodate the communication required between disciplines and between health and social care.

ESHF patients are likely to suffer from co morbidities that complicate their treatment and require effective communication between the different specialities.

'Very few of these patients have just one chronic disease don't they and this is regularly debated at lots of meetings that we go to. You know you will have pathways for each disease.' Medicine for the Elderly Consultant 2

Communication between health professionals was absent at key points. Different disciplines can contribute to the care of ESHF patients but are currently unaccustomed to working together, for example, cardiology and palliative care. A 'cultural clash' between cardiology and palliative care was described along with a desire for improved communication between the two disciplines.

'Heart failure, the way we have treated it for many, many years its quite structured, there are lots of flow charts, you know lots of measurements and its I think palliative care is maybe seen as being very fluffy and you know whereas its quite holistic and maybe more listening to the patients needs.' Palliative Care Pharmacist

'Everybody needs to talk to each other to understand that we are just the bad guys and they are good guys and we need to talk and try and find some common ground.' Cardiologist

Communication difficulties were experienced between other secondary care disciplines.

'I think there are a certain population are more appropriate to be followed by us but it would be nice to have a slightly closer link with all these other services including palliative care.' Medicine for the Elderly Consultant 2

Communication between primary and secondary care was also suboptimal.

'There is lack of communication, we just don't quite know what's going on there (hospital) and what new services there are, what services have been taken away so it would be very useful to know a bit more.' GP Focus Group 1

GPs described HFLNs as being very competent at keeping them abreast of heart failure patients' care but their communication with HFLNs was one way; they received regular updates from HFLNs but weren't asked to provide input, which was seen as a lost opportunity. District nurses had no contact with HFLNs.

'Many of the heart failure patients are actually liaise directly with the heart failure nurses in the hospital so we are cut out of the loop at that stage so it's quite difficult then to come back in right at the end.' GP Focus Group 2

'I've never met a heart failure nurse'. District Nurses Focus Group

Communication between hospitals and community based care is suboptimal - patients are discharged without appropriate support.

'The patient is home from hospital, they (GPs) don't always know what's happened and what changes have been made to their medication and things. They don't get the letter until later.' District Nurses Focus Group

Equally, the ambulance service requires more access to patient information, especially out of hours and pharmacists felt excluded from communication between health professionals and had little access to patient information.

'I certainly think that you could share you know, anticipatory care plans and stuff better with pharmacists, ... all the community pharmacist will know about a patient is what is on their prescriptions if you walk through the door... it would just make it easier for the community pharmacist to adapt their medicines to pick up the phone to be more willing to, you know, solve a problem because they know more about the patient.' HF Pharmacist

Where communication was described as effective, for example between GPs and district nurses or cardiologists and HFLNs, it involved regular face to face contact.

'We all work well with the GPs. We are all really close in the GPs surgeries.' District Nurses Focus Group

Communicating using telephones was also favoured.

'I think it's easier because they are a complicated patient because of the sensitivities and stuff to pick up the phone and speak to the GP or the consultant and say do you know what I'm thinking about

this, what do you think rather than sending a letter which is a) going to take some time and b) can be misunderstood, misconstrued.' HF Pharmacist

The electronic Palliative Care Summary (ePCS) was mentioned in relation to an occasion when out of hours care had been unable to access the information. However, in principle, health professionals were very keen on the ePCS.

'The information will be assessed by the GP as well and that will be documented with an electronic palliative care summary as well which out of hours, so when the patient makes that out of hours call, that electronic palliative care summary comes up and they know.' HFLN 3

There were no examples of paper or electronic systems of communication being described as effective. Pharmacies faced particular challenges communicating outside the NHS system.

'And the problem with community pharmacists as well they are independent contractors, obviously you've Boots, Lloyds, you know family shops these people all have different computer systems, different operating procedures. So even from a very simple point of view if you were trying to share electronic information with a community pharmacist you know it might be difficult from an IT point of view because they essentially all use different IT so you know again there is problems with all these things.' HF Pharmacist

Recognition that communication is lacking was widespread. Improved communication between disciplines could contribute to improved signposting, earlier referrals and rationalising patient treatment, for example, rationalising appointments across disciplines and the potential of electronic communication was recognised.

Service configuration - clinics and appointments

Health care systems, as currently configured, do not promote integrated care for ESHF patients. Short appointments prohibit ongoing in-depth conversations that improve patient understanding of their condition. Additionally, there was acute awareness that elderly, symptomatic, co morbid patients had onerous appointment schedules at a range of clinics and that the potential benefit to the patient from attending appointments was not commensurate with the effort involved. Efforts had been made in both primary and secondary care to rationalise appointments and there was recognition that computing systems could support further rationalisation.

'A lot of the people they are breathless, they can't walk very far but they still have to come to their hospital appointments or even to go to the clinics to get their blood checked.' Palliative Nurse HF clinic

'We have made great efforts so that they come once and the practice nurses do at the one clinic appointment deal with all their chronic conditions so they don't need to keep attending'. GP Focus Group 3

The idea of very ill patients attending clinic appointments was queried along with the suggestion that they might be more appropriately cared for at home. Those who are housebound stand to lose out on hospital based care.

'This model of dragging people up to the clinic you know and dragging them back again is absolutely wrong. 'Cardiologist

Service configuration - a lack of ownership of ESHF patients

A lack of 'ownership' of ESHF patients was evident from the health professional data. GPs, district nurses and palliative care health professionals described minimal experience of ESHF patients.

'I'm a district nurse in the surgery. I must admit we don't have a lot of experience of palliative care with heart failure patients.' GP Focus Group 3

'I thought about it, when did I last see a patient with heart failure. And that would be I would estimate when I was a McMillan nurse I was involved in the heart failure patients roundabout 2005.' Marie Curie Nurse

There was widespread uncertainty around who was responsible for provision of the various components of palliative care for heart failure patients.

'I don't think we have worked out well enough between the heart failure nurses and ourselves who is going to do what'. Palliative Care Consultant

'Defining roles, as to who does what, like that, like are Marie Curie able to go and stuff with a heart failure patient? And I think there is confusion over all of that. 'District Nurses Focus Group

HFLNs provided care for ESHF patients but felt stretched and wondered about their capacity for providing adequate palliative care. Some HFLNs may not consider palliative care to be a part of their remit.

'The heart failure nurses, they maybe think they are there to care for like you know, to monitor the fluids, balance the, all the aspects of being a heart failure nurse and the palliative care aspect, is it necessarily their role? And I do think this varies greatly and there are some heart failure nurses that do provide the holistic care.' Palliative Nurse HF clinic

Service configuration - a better model

How a better model of care for ESHF might look was discussed with particular attention to improving clarity of roles and 'ownership' of HF patients.

A multidisciplinary team input to care was thought important due to the complexity of the problems experienced by patients. However this approach would ideally be combined with a 'key worker' approach to ensure 'ownership' of heart failure patients. HFLNs were thought to be the best candidate for a 'key worker' role with ESHF patients but it was noted that if palliative care was added to their remit extra resources would be required. Some GPs felt they were in the best position to be a 'key worker' because they had the best knowledge of patients' psychosocial situation but felt they would need help in identifying when individuals should be considered 'end stage'. GPs potential for being effective 'key workers' was questioned on the grounds that they lack expertise in heart failure.

'I mean I think that the key worker ... is absolutely essential in making sure that that care happens and I think that that role is essential in being able to communicate to the key people what's going on'. HFLN 3

'I mean we really would be co-ordinating it and its good to have her for advice but she can't physically organise the prescriptions or organise support for the family. 'GP Focus Group 3

'I think those patients could be very well looked after in general practice with our district nurses.'GP Focus Group 2

'X feels that GPs should be the coordinators for palliative care for heart failure. I think that is unrealistic and naive because they don't have the experience. You want your patient to be cared for within a heart failure team, who have got different things to offer, you know the nurses, the doctors, the physiotherapist, maybe the palliative care doctor and the GP, if he has got an interest, can get involved at that point but we see thousands of people with heart failure and we should look after them'. Cardiologist

Health professionals were cognisant that often heart failure patients may not have access to a specialist. They were keen that services be organised to facilitate access to cardiologists for more heart failure patients. Specialist nurses should also be available to ESHF patients to provide expert input and psychosocial support.

'In breast care the consultant's there, but they have also got the specialist nurse ,so why should it be any different for these patients? That someone has time to sit with them'. District Nurses Focus Group

Defining palliative care

Health professionals talked about what was meant by the term 'palliative care'. Traditionally palliative care is understood to refer to very end of life care; the last few days before death. However those more involved in the provision of palliative care espoused a wider definition with a holistic approach compatible with continuing care from cardiology.

In the same way that the meaning attached to 'hospice' can act as a barrier when health professionals attempt to introduce hospice care, 'palliative care' can be an off putting proposition for patients. Changing the name to 'supportive care' to reflect a more current meaning was a notion that split opinion.

'Maybe it should be more 'supportive care' than 'palliative care'. I tend to see people have a knee jerk reaction just to describe what the word palliate means.' Medicine for the Elderly Consultant 1

'I think probably if you change the language then it's going to lead to more confusion'. GP Focus Group 2

However, for the purposes of thinking about improving care for ESHF patients, the definition of what is meant by palliative care, if indeed that is the term to be used, requires consideration and agreement. Such a definition would differentiate palliative care from heart failure care.

'We have lots of things we can do for patients so we need to decide what we are going to do for patients clearly and thoughtfully so we need to define what we are doing so, palliative care for heart failure I think what that is and we can't just you know talk in vague woolly terms about it. So we need to identify and specify you know to find what we mean by palliative care heart failure so I think that's important and I don't think people are doing that. 'Cardiologist

Prognostication

Prognostication could be an obstacle to the introduction of palliative care. Prognostication with ESHF patients was considered an uncertain task. The uncertainty, in some cases, had to do with the infrequency of contact with HF patients.

'We are more familiar with the pattern of how long it takes people to die from various cancers.' GP Focus Group 3

'The problem is identifying these patients that you would term as palliative'. Cardiology Trainees Focus Group 2

Because health professionals felt uncertain about prognostication the heart failure patients' prognosis becomes a topic that is never broached making it almost impossible to introduce support from which the ESHF patient might benefit.

Difficulties around prognostication are illustrated with examples of failure patients who survive longer than they were expected to. The existence of anomalies are used to support the notion that prognostication is an almost impossible task. These unusual cases, however, may be better remembered than those who follow a more predictable trajectory.

'I mean the number of times you have thought that people you know were going to perhaps die, they go into hospital and they are stabilised and they come out and they live for goodness knows how longer'. GP Focus Group 3

Primary care based health professionals, keen to contribute to palliative care but lacking prognostication skills, would appreciate an indication from cardiology of the patients place along the illness trajectory.

'I mean that is something that would be educational from a cardiologist could tell us that if you get to stage 4 and you are on maximum tolerated drugs your life expectancy is whatever'. GP Focus Group 3

4.4 What factors contribute to admission and readmission rates for patients with ESHF, and what alternatives to unscheduled admissions can be identified? (Reflexive Monitoring)

4.4.1 PATIENT AND CARER PERSPECTIVES

Emergency admissions were often underpinned by patient uncertainty about their illness state and processes of care. The unpredictable trajectory of CHF, compounded further by the presence of multiple co-morbidities, meant that unscheduled admissions were common. Often patients lives were defined by an unending pattern of admissions and readmissions.

I've been in, I don't know how many admissions I've had this year, I must have had about at least thirty, at least...In and out constantly. ID30

Before I went to my bed I felt it coming on me, starting to get breathless, but I fell asleep and it woke me up and I persevered through the night and phoned my GP in the morning and she just sent me an ambulance and they took me up to X (hospital) and I was in again for another week. ID 6

Adherence to medication

Difficulty adhering to complex treatment regimens was seen as one precipitant of admissions.

'It's my ain fault, well, I'm not taking my bloody tablets in time and just disregarding them and I wouldn't take my water tablets because I was going to the toilet all the time and couldn't be bothered with this carry on and every time I went out I had to take these tablets with me when I came back in I can't be bothered taking them so the consequence of that was I'd fluid in my arms my legs and my hands and whatever else. ' ID 1

Importantly, the experiences of acute admissions were uniformly described as extremely unsatisfactory, in terms of both the process of getting admitted and in-patient stays. Discharge planning was not always well co-ordinated.

Poor admission experiences

Admission through A+E was often described as unpleasant because it involved long uncomfortable waits and required patients to describe their history to multiple health professionals.

To lie there roughly, and this is only a rough guess, from the back of 11 to the back of 4. As I say there could be reasons for that but I thought it was an awful long time to lie before being admitted. ID 04

They have no beds so you are lying down there on a trolley... I've seen me lying down there one night eighteen hours I lay down there and eventually I got put to a ward. ID30

When I saw the registrar on Monday he looked at me and he said 'I think you should be in hospital' and I said 'yes I do'. He said 'can I admit you today?' and I said 'yes'. So I was admitted after 1 o'clock, no, coming up to 2 and I got my bed and the chair beside the bed and I sat in the chair for six solid hours before the doctor came to take any notes or admit me and when he came I didn't know what to do with myself.' ID23

Poor in patient stays

Ward environments were described as unacceptable.

What you are thinking about was that dreadful admission in December where you were in A+E forever and then we were admitted to this ward where it really seemed to be for drug addicts and it, you were in almost a month and I was all for bringing you home and signing you out it was just awful. ID08 close person

The hospital, no no, like when I've been before conditions were terrible, when you go to the toilet there was excrement in the toilet and urine and it would make you sick. I couldn't face it... I wouldn't go because it's hell in the wards, y'know the conditions, it's a shame, people shouting and bawling, the television on and you can't sleep or nothing you know. I mean I was there with a heart condition and I didn't want this y'know. I wanted peace and I couldn't get peace. ID19

You get all these daft folk in the wards who are screaming and shouting, calling the nurses all the swear words under the sun, it is unbelievable. ID01

Inappropriate wards

Participants spent time in wards where their symptoms could not be treated before finally reaching a cardiology ward.

A ward that didn't deal with the heart and I'm having to tell the doctor down there what to do to get rid of my fluid. This is what they do in ward x, I need to be at ward x, that's where they deal with this and that doctor did everything I said but one of the times I got put in I lay down there nearly two days before I got up to a ward where they could treat me. ID 30

Poor discharge planning

Discharges were sometimes poorly planned and left patients wondering what the admission had achieved and feeling that they had been sent home in order to vacate a bed.

The nurse came up and tapped me on the shoulder, are you ready to go home? Eight o'clock in the morning. I said I would like to see a doctor before I can get home. No, you are going home. They are desperate for the bed, desperate. So I went down to another wee place and I waited seven hours on them sorting out the medication. ID01

I went into hospital then and they let me out. I was only in a couple of days, they let me out and I said there is something wrong here because I'm not fit to be out. So I was out a couple of days and I was in again worse than ever. You know so and they gave me no medication or nothing to take, the hospital, the first time which is very unusual. ID12

Admissions are feared

These poor experiences mean that participants are fearful of admissions and will do everything they can to delay admission whenever possible. Participants dreaded exacerbations that might lead to future admissions. They tend not to seek help, for fear they will get admitted, until their situation has become desperate.

No the thing is the hospital is the last resort you know what I mean and I wouldn't do it, I wouldn't phone for a doctor or a medic unless I thought there was something seriously wrong. ID04

These patients are caught in a revolving door because they will delay seeking help which then means the likelihood of being able to stay at home is reduced and the length of their stay is likely to be increased.

Back door arrangements

Back door arrangements, whereby participants could negotiate direct admissions to cardiology services, were described by a few and these improved experiences greatly. These backdoor arrangements, having direct access to cardiology, improved participants' hospital experiences and their feelings about the prospect of future admissions. Thus, it was clear that having a clear management plan, in terms of how to deal with emergencies, which bypassed the accident and emergency (A+E) department, was greatly appreciated and made an immense difference to those few individuals who had been provided with such an option.

So rather than going through the accident and emergency and all that rigmarole I come straight to the ward. ID 6

I lay down there nearly two days before I got up to a ward where they could treat me so Dr X and the ward sister here came up with a system that she would phone me... on the Monday and I would tell her what my weight was and if I didn't feel right or that I could phone her. And instead of going to the doctors and A & E and all this I would phone up and I would say my weight is up to such and such and I'm awful breathless and I'm starting to get sick ... So I'll phone her and she'll say right fine, just get a wee bag and just come in and I come straight into the ward and there is a bed. Might need to wait until three in the afternoon for a bed, doesn't matter, but whether I'm sitting they are getting the intravenous drip in you know and I'm getting rid of that as soon as I come into here and that's the care plan they have got for me here. ID30

4.4.2 HEALTH PROFESSIONAL PERSPECTIVES

Advanced heart failure patients' experiences of multiple unscheduled admissions were universally deemed to be completely inappropriate. The current system fails patients at various junctures. Those with advanced heart failure who need to access care out of hours, when GPs or HFLNs are not available, are compelled to present to A&E departments from where they are admitted. They are rarely admitted to cardiology wards and consequently may not receive optimum care. Hospital stays are likely to involve unnecessary investigations and last longer than is necessary.

'The whole admission process is quite daunting and I think that some of the things that, particularly for patients who have repeated admissions...something that can be avoided particularly the length of stay and also the need to attend for inappropriate investigations that they have each time they are admitted to hospital and having to repeat their history.' HFLN 3

Admissions via accident and emergency

If HF patients phone a GP in an emergency it is likely they will be advised to phone an ambulance, leading to an admission via A&E. Out of hours GPs feel that they have no option other than an admission via A&E. The ambulance service also has no option other than bringing a patient to A&E.

'The quality out of hours is not the same as in hours. It's not. Palliative Care Pharmacist

I think as an out of hours GP if you go to someone who has acute heart failure and you know you just, you don't know that patient there is not much more you can do. 'GP Focus Group 2

Accident and Emergency departments were deemed entirely inappropriate environments for advanced heart failure patients.

'You really don't need to have them lying around an emergency department. It provides no safety for these people because some other individuals in there have very challenging behaviour. It provides absolutely no privacy and no dignity at all so these people are coming in who are in their last days or weeks of life and we are throwing them into the mix of undifferentiated presentations and it is unacceptable, and frankly appalling 'A&E Consultant

Inappropriate wards

Because of four hour waiting targets and a reduction in hospital bed capacity patients are dispensed to any ward with capacity which means that they are likely to end up in an inappropriate ward.

'And it's all to do with the beds being cut and they've not the capacity'. GP Focus Group 3

'Going to a general medical or bouncing to three different wards and never ending in a cardiology ward or in a ward that someone has got an interest in whatever the problem is, never seeing anyone who knows what's going on, being extremely unwell. 'Medicine for the Elderly Consultant 2

Changes to out of hours admission procedures mean that patients may not end up in the hospital most local to them posing problems for both the patients and their families.

'I mean there is not always space at your local hospital that, so therefore you are going to somewhere where they don't have your notes and they don't know you and the family doesn't know even how to get there.' GP Focus Group 3

Direct access to cardiology or other appropriate wards would mean that patients could avoid the unpleasantness of being admitted via Accident and Emergency and receive effective treatment sooner. GPs found arranging access to specific wards increasingly difficult because of changes to management systems.

'The consultants have lost control of their beds... I tried to speak to the consultant geriatrician ... who could admit.... You can't! The consultant actually said he has no control over his beds, you have to phone the bed manager who is a non-clinician and then they are shutting the beds anyway so I mean the consultant surgeons have all lost control of their beds'. GP Focus Group A

Health professionals uniformly would like to be able to admit advanced heart failure patients directly to cardiology wards. Where direct access had been achieved health professionals were satisfied with the experience.

'We would be delighted if that happened and you could get direct admissions to these wards, you could get the enthusiastic heart failure nurses engaging in the ward instead of having to chase around the place to try and find who is where and a guy in the orthopaedic ward or the PI ward or the respiratory ward and whatever else it is so we just try and make admissions easier to come about and to arrange, to organise and more pleasant to happen.' Cardiologist

'Palliative end stage should have access to direct admission to cardiology ward.' Cardiology Trainees 2

'That admission was planned and was a phone call to the cardiologist to take him directly to the cardiology ward and that was a much smoother path.' Medicine for the Elderly Consultant 2

Additional precipitants to hospital admissions

Hospital admissions also occur because the support to keep people at home is not available or cannot be put in place rapidly enough. Some GPs may prefer to let the hospital take responsibility and some families may not feel confident caring for someone suffering from distressing symptoms.

'Heart failure tends to be fine and then suddenly take a very marked dip which is very distressing and that often prompts admission because there is this sudden change, even though there is a chronic background of heart failure so I think that is one of the barriers is just trying to get services in quick enough when things are you know when things deteriorate rapidly like that and trying to help kind of other relatives etc at home and the service is also trying to get medication in quickly, perhaps oxygen in quickly, getting things that would help palliate this situation so unfortunately I think that is often why hospital admissions are precipitated it's just because you can't get these things quick enough.' GP Focus Group 3

'I have spoken to people who think their GPs are frightened to take responsibility and say well stay at home.' District Nurses Focus Group

'One of the difficulties is that its often that patients with heart failure, particularly when they deteriorate their symptoms are very, very distressing and sometimes it can be difficult for other family members involved in the house. I can think of one case that I had where his wife was very elderly, she didn't feel that she was able to really care for him, even when he was at a very end stage she just didn't feel confident looking after him at home.' GP Focus Group 3

Guidance and support for advanced heart failure patients

A limitation of the HFLN service is that it only provides support 9-5, Monday through Friday. There is a need for access to 24/7 help and support. HF patients also required appropriate guidance and pathways for help seeking, especially out of hours. Such support and guidance may result in patients getting help in a timelier manner and could reduce the number of patients experiencing emergency admissions at the end of life.

'So is it about talking to family or who, the closest carer and giving them the confidence or and with the patients themselves sort of giving them the confidence to get in touch with somebody earlier at an earlier point.' Palliative Care Pharmacist

'I think there needs to that if there is that clearer path it keeps everybody right from primary care providers through secondary and through palliative services.' Cardiology Trainees 2

Planning care

Health Professionals feel more competent to support people at home if there is a plan in place.

'I mean a just in case box is just, you know, this is for pain, this is for agitation, this is for sickness, give them this...if you just had that sort of set out, then I'm sure I would be much comfortable at dealing with these patients and keeping them at home'. Out of Hours District Nurse.

HF patients are more likely to have their needs identified if a holistic assessment is carried out.

'Within specialities that we tend to focus on the speciality that we work with and sometimes we miss all the other things that is going on outside the box and that's why I think the holistic assessment is absolutely crucial.' HFLN 3

Anticipatory care plans

Anticipatory care plans (ACPs) can play a part in preventing unnecessary admissions and when admissions are unavoidable can facilitate patients to be fast tracked to appropriate wards. Patients who are in contact with the hospice may have the option of hospice care rather than an unscheduled hospital admission. An anticipatory care plan is a formal document whereby patients' preferences for end of life care are stated and communicated to health professionals.

Although ACPs were view very favourably there were some issues attached to their use. The paperwork involved was considered time consuming by health professionals who already feel stretched. ACPs may create unrealistic expectations and then disappointment when implementing the patients' preferences proves impossible. Part of the process of completing an ACP with an advanced heart failure patient should therefore involve managing expectations.

'I'm not entirely convinced that we either have the resources or the knowhow as to make that happen realistically'. HFLN 3

'I think whoever is sitting with that patient doing the anticipatory care plan with them or allowing them to fill the bit in themselves have to make it clear that you know, you can't guarantee that all your wishes will be able to be met.' District Nurses Focus Group

Introducing the prospect of completing an ACP to patients who do not appreciate their prognosis is challenging.

'While they are here at the clinic they are well enough to make decisions, to make the decisions now so that they will be in place for the future when they aren't as well and I think for some people it's like 'oh but that's going to be a long, login time away'.' Palliative Nurse HF clinic

4.5 ADDITIONAL FINDINGS: TRAINING NEEDS OF HEALTH PROFESSIONALS

Training and education emerged as key requirements to improve health professionals' ability to care for advanced heart failure patients. Broadly, those who were more accustomed to providing palliative care, GPs, district nurses and palliative specialists, were keen to improve their knowledge around heart failure and those with heart failure expertise were keen to develop skills around palliative care. There was recognition that, as the population ages, there will be an increased requirement to care for advanced heart failure patients.

'It's going to become such a big part of all our working careers though, the ageing population so it's something that we are all going to have to deal with'. Cardiology Trainees 2

Heart failure education

Primary care practitioners and palliative specialists felt they had much to offer patients (and indeed colleagues interested to learn about palliative care) but a range of knowledge gaps around heart failure were identified. They wanted to learn about the medication used with advanced heart failure patients and how to recognise the transition to the progressive phase of illness.

'Yeah if I was going to see more of these patients or more people coping with end stage heart failure I would welcome more education about heart failure'. Marie Curie Nurse

'I think (we can care) from a palliative point of view but not necessarily from a cardiac point of view. I think we all lack that ability if we are honest because we are not specialist in heart failure.' District Nurse Focus Group

End of life conversations with advanced heart failure patients pose particular challenges due to patients' poor understanding of their prognosis so even health professionals accustomed to having end of life conversations expressed a need for training in End of Life conversations specifically for advanced heart failure .

'I personally feel uncomfortable when it gets to the end section where we have to ask patients where they would prefer to die because probably because of lack of training and but like you not knowing what to ask them and is it appropriate whether they maybe do feel quite well. GP Focus Group B

But with heart disease they don't know its bad news. In fact they think the stent has pretty much sorted them out and it's difficult to break bad news to someone who really doesn't suspect bad news'. Cardiology Trainees 2

Palliative care education

Health care professionals were clear that cardiologists would benefit from improved knowledge of palliative care although some queried whether or not there was an interest from cardiology.

'I think you know from senior cardiology professionals downwards and I think that that is one of the barriers because if they are not understanding fully what is meant by palliative care then I think as well one of the other barriers that we deal with is that some of the cardiologists find it difficult to know when enough is enough for patients.' HFLN 3

'One of the problems is that most cardiologists aren't very interested in heart failure patients, it's not a glamorous thing to do because it doesn't involve doing things to people, operations, procedures, it involves difficult long admissions with people with lots of problems, lots of co-morbidity. Cardiologist

I'm not sure if they, the palliative care was necessarily something they regarded as in their remit to do and I think it possibly stems from the fact that cardiologists, you know I think some of the doctors they are all about cure, keep treating and treating and treating until the person dies'. Palliative Nurse

Some cardiology trainees suggested palliative care and cardiology spend time working in each other's disciplines to develop skills. Others disagreed as they would be dealing with patients that they wouldn't see later in their careers.

'I don't see the benefit of us spending time in hospices unless it is geared up for heart failure patients because these are patients that we are not going to see you know.' Cardiology Trainees 2

As described earlier there appears to be a split amongst HFLNs as to whether palliative care for heart failure patients should be incorporated into their role. However there was acceptance that if HFLNs were to be expected to provide palliative care they would require training as their expertise lies very much with managing HF in terms of monitoring and medication management.

'If you are expecting them to provide holistic care then that's not what they do but if you are expecting them to manage the heart failure and medication then that's what they do very well.' GP Focus Group 3

'If traditionally they have never had to deal with that aspect (palliative care) of it then its maybe unfair to say to them well that's what you should be doing. It may require a lot of education and training for that to happen when their case load is so great.' Palliative Nurse

5. Conclusions and Implications for Practice

We have demonstrated how patients must work to develop coherence, a clear understanding of their conditions and appropriate management. Previous research has highlighted this as a problem (Barnes et al 2006; Rogers et al. 2000). Incoherence, which was pervasive, adversely affects the individual or caregiver's ability to undertake appropriate self care strategies and to enact treatments, and has the potential to induce non adherence. Our data illustrate how even in the terminal stages of chronic but lethal illness, patients and carers are heavily and unnecessarily burdened by health care services that are poorly co-ordinated and offer fragmented and discontinuous care. This resonates with a recent systematic review which stated that the existing literature demonstrates the need to improve care coordination and communication between patients, their families, and health care professionals (Low et al. 2011).

Importantly, we know that 97% of heart failure patients are multimorbid (Barnett et al 2012) and our data shows how this adds a further layer of complexity for those with advanced heart failure. Multimorbidity in advanced heart failure matters as those suffering from additional chronic conditions must undertake further self management work while at the same time enduring conditions that adversely affect their capacity to adhere and perform self management. The burden of illness therefore interferes with the foundations of successful self management. Different combinations of illness multiply the tasks of self care and add layers of disability that threaten not only personal capacity and coping, but also make the wider patterns of work that sickness requires – co-ordinating visits and tests, organizing support and mobilizing resources, navigating the healthcare system – steadily more difficult to accomplish (Shippee et al. 2012). Contemporary healthcare is built on a specialized division of labour, focuses on specific problems, and disciplines activity by reference to protocols and guidelines. These rarely consider co-morbidity, but as they continue to multiply in number so does the burden of treatment grow. Clinical guidelines are intended to structure care and also to imply the accountability of practitioners to improve quality of care and outcomes. Importantly, the extent to which existing guidelines and corresponding quality and performance programmes account for the concomitant existence of multiple chronic conditions in the same patient is limited (Boyd et al. 2005, Guthrie et al. 2012). It has been posited that this has important consequences in that increasing treatment burden will negatively impact adherence and consequently outcomes. (May et al. 2009). Our research confirms that patients with advanced heart failure are indeed burdened by the work of co-ordinating their care, mobilizing support and navigating health and social care systems.

Health professionals agree that the way health services are currently configured acts as a barrier to effective communication. This clearly exacerbates the problems of incoherence which makes appropriate self care more difficult. Busy clinics with lack of continuity and few opportunities for access to psychological or other supportive services is a problem. Adherence is difficult for advanced heart failure patients, so attention needs to be given to how to help address this problem. There is a lack of clear plans available regarding what to do in an emergency, this could be addressed by developing clear pathways/plans collaboratively with advanced heart failure patients so that they know what to do in an emergency. However, it is crucial that appropriate services are made available to help them action such plans. Each advanced heart failure patient needs a key worker or at least a key individual identified who agrees to assume responsibility for their care and to help

them understand how best to navigate the health and social care systems. More counselling and support services are needed to help those with advanced heart failure come to terms with information they will receive. The lack of adequate support to help patients and caregivers cope after a difficult discussion is seen as a problem.

The heart function and supportive care clinic model currently operating at Glasgow Royal Infirmary and the clinic at the Jubilee were both described as ideal because they offered continuity of care, ease of access, links to community medical and social support and long appointment times.

'They have direct number to our nurses so if they go home and they don't feel very well they just have to ring us and we will admit them very quickly and our clinic set up is different as well. I think like you guys see patients five, ten minutes. We have half an hour to forty five minutes to see a patient and we see our patients every week, every two weeks so we pick up little, little signs that they are not going so well a little more oedema you know, and when we're concerned we can very, very quickly get patients to wards and do all our assessment again. And its done very aggressively so I think our setting is completely you know surreal compared to general hospitals.' Cardiology Trainees Focus Group 2

To conclude, the issues raised here highlight how care for those with advanced heart failure remains suboptimal from a patient perspective. Even though clinical guidelines and health policies have strongly encouraged discussions and planning in end of life care, the literature is clear that poor understanding of the implications of advanced heart failure amongst patients is endemic (Momen NC & Barclay SIG, 2011) and the current study highlights that little progress is being made and that these problems are persistent and to a large extent, structurally induced by the health care systems as they currently operate.

Our work has a number of strengths and limitations. First our research was limited to a single geographical location, Greater Glasgow and Clyde. Patients in this area have access to a well developed heart failure liaison nurse service, and therefore may be better served than patients in some parts of the UK, particularly rural areas where there is less access to such support services. However, our findings resonate strongly with the existing literature in this field (Dev et al. 2012; Low et al. 2011; Barclay et al. 2011). Secondly, we used a framework approach, underpinned by Normalisation Process theory, and therefore there could be a concern that data was "shoehorned" into an existing theoretical framework. However, we sceptically sought evidence for the adequacy of the Normalisation Process Theory framework, by looking for data that did not fit within our framework and therefore practically tested it as an analytic tool. Our work also has a number of important strengths. First, we used a highly regarded theoretical framework to underpin our work. Secondly, we took a robust approach to analysis, with all the patient and carer data being double coded by two parties independently with comparison of results and discussion to ensure consistency of coding. We also held "data clinics" to further ensure consistency and validity of our findings. Finally, we were able to compare our findings with other related research being undertaken by our research group and also asked health professionals to respond directly to the findings from the patient and caregiver interview data. Consequently, we were able to move beyond the existing descriptive work in this sphere and undertake *explanatory work* to increase understanding of barriers to optimal care and the actions that must be taken for us to improve the experiences of those with advanced heart failure.

Addressing the problems highlighted in this report will not require a further guideline but rather a rethinking of our current approaches and models of care for this patient population so that they become more tailored to meeting the needs and wishes of those at the end of life rather than aimed at suiting the convenience of the health care systems serving them. We would suggest that interventions that assist patients in *integrating* understandings of their illness state with appraisals of processes of care will result in measurable improvement in capacity to perform collaborative and co-operative tasks and improve patient experience and wellbeing. Our findings strongly suggest the need to pursue integrative solutions that give priority to patient and carer needs, especially in such heavily multimorbid populations, and move away from disease centred approaches.

6. Recommendations

The recommendations outlined below reflect conclusions based on the research findings from our commissioned research with individuals with advanced heart failure, their caregivers, and a range of health professionals who provide care for such individuals. The recommendations were also informed by related work with more stable heart failure patients and an ongoing systematic review of the patient experience of heart failure. Our findings were shared with the steering group prior to submission and it is noteworthy that our lay representative on the group expressed the view that the findings reflected well her experiences as a caregiver for someone with advanced heart failure and her view that our recommendations, if implemented, had the potential to improve care for those with advanced heart failure.

- *Reconfiguration of services* is necessary to facilitate good communication and promote patient and carer understanding:
 - There is a need for services to be able to accommodate the support needs for those with advanced heart failure. These needs include the opportunity to have multiple conversations taking place over multiple contacts and long appointment times.
 - Services should provide greater continuity and provide patients with the opportunity to see the same health professional over the course of these conversations.
- *Integrated care* for advanced heart failure patients requires improved communication mechanisms between health professionals, for example cardiologists and palliative care physicians, and across sectors, for example, across the primary/secondary care interface and health and social care boundaries.
- Streamlined *admission* pathways that avoid A&E are essential to improve patient and carer experiences.
- *Key workers* need to be identified for those with advanced heart failure. This could be the HFLN or the GP, but someone needs to be clearly seen to have responsibility for patient care. *Such key workers* should have access to additional support/advice such as a multidisciplinary team.
- *Key workers* should:
 - Have primary responsibility for promoting better understanding of: a) the condition and its implications; b) pharmacological and non pharmacological therapies.
 - Help advanced patients and their caregivers to navigate and interact with health and social care services.
 - Co-ordinate care and minimize duplication and unnecessary outpatient visits.
 - Ensure regular medication reviews and rationalization of polypharmacy, where feasible.
- Advanced heart failure patients and their caregivers should have access to *emergency care plans*.

- Advanced heart failure patients and their caregivers need better access to psychological support.
- Advanced heart failure patients need better access to financial support, social services and home aids and adaptations.
- Greater attention needs to be given to providing support and advice to individuals about the *role of ICDs, and other devices* and their limitations.
- Health professionals require *high quality written information* for advanced heart failure patients:
 - to reinforce conversations around prognosis.
 - on how to access appropriate health care, particularly out of hours.
- *Hospices* should be promoted as a service that caters to patients with illnesses other than cancer and provide services beyond very end of life inpatient care.
- Health professionals require *training* on:
 - how to deliver a poor prognosis while preserving hope.
 - identifying advanced heart failure patients who would benefit from palliative care.
 - rationalisation of medications and the conversations that accompany such changes.

7. A list of publications/abstracts/conferences/papers

Published Abstracts and Papers (see Appendix 2)

1. Jani B, Blane D, Browne S, May Cr, Montori VM, Shippee N, Mair FS. *Identifying Treatment Burden as an Important Concept for End of Life Care in those with Advanced Heart Failure*. Current Opinion in Supportive and Palliative Care. 2013 In press
2. Pettit, S., Browne, S. , Hogg, K.J., Connelly, D.T., Gardner, R.S. , May, C.R., Macleod, U., and Mair, F.S. (2012) *ICDs in end-stage heart failure*. BMJ Supportive and Palliative Care, 2 . pp. 94-97.
3. Browne S, May C, Macleod U, Mair F. *“Mind the gap”: Patient Knowledge and Understanding of Their Condition, Treatments and Prognosis Remains an Issue For Those With End Stage Heart Failure (ESHF)*. BMJ Support Palliat Care 2012;2:5.
4. Mair F, Browne S, Morrison D, Macleod U, May C. *Barriers to provision of high quality care for patients with end stage heart failure*. BMJ Support Palliat Care 2012;2:Suppl 1 A17-18.
5. F S Mair, S Browne, D Morrison, K Gallacher, U Macleod, C R May. *Treatment burden in end stage heart failure (ESHF): a qualitative study*.BMJ Support Palliat Care 2011;1:A8 doi:10.1136/bmjspcare-2011-000020.21
6. F S Mair, S Browne, D Morrison, U Macleod, C R May. *‘You’re sicker than you think’: continuing communication problems in end stage heart failure*. BMJ Support Palliat Care 2011;1:A17 doi:10.1136/bmjspcare-2011-000020.50

Findings have been disseminated at a range of national and international meetings as outlined below:

1. Frances Mair was invited by the Center for the Science of Healthcare Delivery’s Healthcare Delivery Research Program and of the Center for Translational Sciences Activities at Mayo Clinic, and spoke at the Mayo Clinic Grand Rounds on October 12 2012 at Mayo Clinic in Rochester, Minnesota on the subject of, “Treatment Burden – A New Target For Quality Improvement” using the End-stage congestive heart failure research as the exemplar and describing the importance of the patient experience of treatment burden set forth by the way healthcare is organized and delivered. Grand Rounds at the Mayo captures the attention of the staff at Mayo Clinic in Rochester and thru its broadcasting to colleagues in Arizona, Florida, and across the Midwest of the USA.
2. Invited talk Marie Curie Cancer Care, London September 2012. Topic: Treatment burden in ESHF: what is it, why does it matter and what can be done about it? (F Mair)

3. Invited Talk: Patient Perspectives of Advanced Heart Failure. An Update on the Management of Advanced Heart Failure With A Focus on Palliative Care. Royal College of Physicians and Surgeons of Glasgow 22 November 2012. (F Mair)
4. Invited talk Scottish Heart Failure Nurse Forum : Patient, carer and Clinician perspectives on end of life care. Campanile Hotel November 2012, Glasgow.(F Mair)
5. Browne S, Macleod U, May C R, Mair F S. Patient and Carer Experiences of End Stage Heart Failure - North American Primary Care Research Group, New Orleans, December 2012 –oral presentation.
6. Browne S, May C R, Macleod U, Mair F S. High Quality Care For Patients With End Stage Heart Failure (ESHF) – Barriers and Facilitators. Society for Academic Primary Care, Glasgow, October 2012 - oral presentation.
7. Browne S, May C R, Macleod U, Mair F S. Hospital Experience and Attitude to Hospital Admissions in Heart Failure Patients: Findings from a Qualitative Study – Scottish School of Primary Care Annual Conference, Glasgow, April 2012 – oral presentation.
8. Browne S, May C R, Macleod U, Mair F S. ‘Mind the Gap’: Patient Knowledge and Understanding of Their Condition, Treatments and Prognosis Remains an Issue For Those With End Stage Heart Failure (ESHF) – Marie Curie Annual Palliative Care Research Conference, March 2012 – poster presentation.
9. Mair FS. Illness and Treatment Burden in Advanced Heart Failure. Marie Curie Annual Palliative Care Research Conference, March 2012. Invited oral presentation.
10. Mair F S, Browne S, Macleod U, May C R. Barriers To Provision Of High Quality Care For Patients With End Stage Heart Failure (ESHF) - The 9th Palliative Care Congress, Gateshead, March 2012 – poster presentation
11. Browne S, Morrison D, Macleod U, May C R, Mair F S. Making Sense of End Stage Heart Failure. Qualitative Health Research Conference – Vancouver – October 2011. Oral Presentation.
12. Mair F S, Browne S, Gallacher K, Morrison D, Smith F, Macleod U, Montori V, May C R. Treatment Burden and Chronic Heart Failure: Why We Need More Person Centred Care. Qualitative Health Research Conference – Vancouver – October 2011. Oral Presentation.
13. Browne S, Morrison D, Macleod U, May C R, Mair F S. Making Sense of End Stage Heart Failure – Society Academic Primary Care Annual Meeting – Bristol - July 2011. Oral Presentation.
14. F S Mair, K Gallacher, D Morrison, S Browne, S Macdonald, V Montori, U Macleod, Carl May. Treatment Burden and Fractured Care: Findings from a Qualitative Study – Society Academic Primary Care Annual Meeting – Bristol - July 2011. Oral Presentation.
15. S Browne. Making Sense of End Stage Heart Failure. NEYNL CLRN Palliative Care Specialty Group Conference - York - May 2011. Oral Presentation.
16. F S Mair, S Browne, D Morrison, , K Gallacher, U Macleod and C R May Treatment Burden In End Stage Heart Failure (ESHF): A Qualitative Study. - COMPASS Collaborative Annual Scientific Meeting – Edinburgh - April 2011. Oral Presentation.

17. F S Mair, S Browne, D Morrison, U Macleod and C R May. 'You're sicker than you think': Continuing Communication Problems in ESHF - COMPASS Collaborative Annual Scientific Meeting – Edinburgh - April 2011. Poster Presentation.

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