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**Experiences and perceptions of the role  
of palliative and end of life care in heart  
failure: A modified grounded theory  
study.**

**Volume 1 (of 2)**

**Rachel Stocker**

**Thesis submitted for the degree of Doctor of Philosophy, School of  
Medicine, Pharmacy and Health, Durham University.**

**2014**

## Abstract

Heart failure (HF) is a progressive, life-limiting illness affecting around 750,000 people in the UK, with a mortality rate of 50% within four years. A large body of qualitative research demonstrates variable quality of HF care at the end of life, difficulties in identifying the dying phase, poor communication, and a failure to achieve a 'good' death. However little is known about the assessment of the need for palliative care, the recognition of the last days of life, or the extent to which these considerations are communicated to patients and carers and to the wider multi-disciplinary team. Greater understanding of the transition points from HF diagnosis to death may inform future service planning, including the most appropriate model of palliative care to apply to this patient group. Thus, the aim of this study was to explore experiences of giving or receiving a prognosis and managing the transition point from diagnosis to palliative and end of life care for those with HF.

The study involved two stages. The first was a systematic review of the uptake of the Liverpool Care Pathway (LCP) in order to assess current utilisation of end of life care pathways. The second utilised a modified constructivist grounded theory methodology to assess experiences of giving and receiving a prognosis, combining semi-structured interviews with clinicians, observations of clinic and home visit appointments, followed by a series of longitudinal semi-structured interviews with thirteen patients with HF and nine carers.

The systematic review demonstrated that the LCP was utilised for less than half of all dying patients. Interviews with clinicians revealed frustration and uncertainty about the contested nature of HF diagnosis and prognosis. Most clinicians rejected the concept of HF as a terminal illness in their everyday practice, and expressed uncertainty about roles and responsibilities for end of life care, alongside a reluctance to actively plan for end of life for individual patients. In contrast, some clinicians demonstrated the ability to deliver problem-based, individualised care but sometimes felt constrained by the perceived lack of multi-disciplinary advanced care planning. Most patients and carers talked about death and dying in general terms but felt that HF specific end of life considerations did not apply to them. They placed much more importance on understanding the emergence of their symptoms and negotiating everyday restrictions. Most patients had not made any decisions about advance care directives, and reported no prognostic discussions with clinicians. Overall, the majority of participants rejected notions of HF as a terminal illness in favour of day to day management and maintenance, despite obvious deteriorations in disease stage and needs over time.

This is the first known study exploring the experiences of prognostic communication at all stages of the HF disease trajectory. Findings raise questions regarding the pragmatic utility of the concept of HF as a terminal illness and have implications for future HF care pathway development. A key recommendation emerging from this study is that notions of prognosis should be ultimately rejected for HF care, and be replaced with a problem-based approach to care which combines elements of active and palliative care from diagnosis onwards, alongside regular assessments of communication preferences.

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## List of Terms

ACEIs: Angiotensin-Converting Enzyme Inhibitors

ARBs: Angiotensin Receptor Blockers

BMA: British Medical Association

BNP: B-type Natriuretic Peptides

CDDFT: County Durham and Darlington NHS Foundation Trust

COPD: Chronic Obstructive Pulmonary Disease

CPR: Cardiopulmonary Resuscitation

DNAR: Do Not Attempt Resuscitation

DoH: Department of Health

EF: Ejection Fraction

End of Life: Specialised care delivered in the final week of life.

GP: General Practitioner

HF: Heart Failure

HF-LVSD: Heart Failure with Left Ventricular Systolic Dysfunction

HF-PEF: Heart Failure with Preserved Ejection Fraction

H-IDSN: Hydralazine and Isosorbide Dinitrate

ICD: Implantable Cardioverter Defibrillator

IRAS: Integrated Research Application System

LCP: Liverpool Care Pathway

LVAD: Left Ventricular Assist Device

NCHSPCS: National Council for Hospice and Specialist Palliative Care Services

NHS REC: National Health Service Research Ethics Committee

NICE: National Institute for Health and Care Excellence

NT-proBNP: N-terminal pro B type Natriuretic Peptides

NYHA: New York Heart Association

Palliative Care: Specialised care delivered in the final year of life.

PCT: Primary Care Trust

RCN: Royal College of Nursing

WHO: World Health Organisation

## **Statement of Copyright**

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### Journal papers

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**Stocker, R.** & Close, H. (2013). Assessing the uptake of the Liverpool Care Pathway for the dying patient: a systematic review. *BMJ Supportive & Palliative Care*, **3**(4): 399-404.

### Journal papers in preparation

**Stocker, R.**, Close, H., & Hungin, A Pali S. (2014). Discussing prognosis and end of life care in heart failure: differences between clinician groups. In preparation.

**Stocker, R.**, Close, H., & Hungin, A Pali S. (2014). Coming to know, tell, and act upon a prognosis: Clinical prognostic liminality in unpredictable progressive illness. In preparation.

**Stocker, R.**, Close, H., & Hungin, A Pali S. (2014). Heart failure prognosis: a cloak of ignorance or a comfort blanket? In preparation.

### Book chapters

**Stocker, R.**, Close, H., & Hungin, A Pali S. (2013). End of Life Care in Heart Failure: Is it Time to Reinvent The Wheel? In Rose Richards and Jennifer Creek (Eds.), *Chronicity, Care and Complexity*. Oxford: The Inter-Disciplinary Press, pp. 169-179. ISBN: 978-1-84888-190-7 - EBSCO index.

### Peer-reviewed conference abstracts

**Stocker, R**, Close, H, & Hungin, A Pali S. (2013). Experiences of prognostication and the transition point from active to palliative and end of life care in heart failure: A grounded theory study, *BSA Medical Sociology Group 45<sup>th</sup> Annual Conference, 11-13 September 2013*. York, England.

**Stocker, R**, Close, H, & Hungin, A Pali S. (2013). Experiences of prognostication and the transition point from active to palliative and end of life care in heart failure: A grounded theory study, *42nd Society for Academic Primary Care (SAPC) Annual Scientific Meeting, 3-5 July 2013*. Nottingham, England.

**Stocker, R**, Close, H, & Hungin, A Pali S. (2013). Experiences of prognostication and the transition point from active to palliative and end of life care in heart failure: A grounded theory

study, *Wolfson Research Institute for Health and Wellbeing Research Colloquium, Durham University, 17-18 April 2013*. Stockton, England.

**Stocker, R & Close, H (2013)**. Experiences of prognostication and the transition point from active to palliative and end of life care in heart failure: A grounded theory study, *Midlands Health Psychology Network 2013 Conference, 14 February 2013*. University of Birmingham, England.

**Stocker, R & Close, H (2012)**. Assessing the uptake of the Liverpool Care Pathway for dying patients: a systematic review, *41st Society for Academic Primary Care (SAPC) Annual Scientific Meeting, 3-4 October 2012*. Glasgow SECC, Scotland.

**Stocker, R, Close, H & Hungin, A Pali S (2012)**. End of Life Care in Heart Failure: Is it time to reinvent the wheel?, *Making Sense of: Chronicity: A Health, Illness and Disease Project, 30 August – 1 September 2012*. Oxford University, England.

**Stocker, R, Close, H & Hungin, A Pali S (2012)**. Perceptions, attitudes and experiences of end of life care for heart failure: Are current end of life paradigms appropriate and applicable for heart failure?, *Psychology Postgraduate Affairs Group Annual Conference, 18-20 July 2012*. Northumbria University, England.

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**Stocker, R. & Close, H (2012)**. Perceptions, attitudes and experiences of end of life care for heart failure: Are current end of life paradigms appropriate and applicable for heart failure? Invited speaker, *School of Medicine, Pharmacy and Health Seminar Series, Durham University*. 1<sup>st</sup> May 2012

# Chapter 1 Literature Review

The purpose of this chapter is to review the literature surrounding the burden of heart failure on the NHS, patients, and carers. The complex, contested diagnosis of heart failure will be described with reference to the burden on patients and carers. Relevant issues are presented concerning the delivery of care from diagnosis, periods of stability, advanced heart failure, and towards the end of life phase. This includes the recognition of the patient who would benefit from a palliative care approach to their care, the recognition of the last few days of life, challenges associated with communication, and the most appropriate model of palliative care to apply to this patient group.



## **1.1 The Scale of the Problem: The Epidemiology of Heart Failure and Patient and Carer Burden**

This section outlines the epidemiology of heart failure, including incidence, diagnosis, treatments, and prognosis. Patient and carer burden is also discussed.

### **1.1.1 The Epidemiology of Heart Failure**

#### **1.1.1.1 Incidence**

Heart failure (HF) is one of the leading causes of death in the Western world[1], with estimates putting the prevalence in the British population at 1-2% and the cause of 120,000 hospitalisations every year[2]. The prevalence of HF rises sharply at around 75 years of age to around 10 to 20% in 70 to 80 year olds[3]. In the elderly, HF prevalence is equal between genders; however it is more common in younger men. The prevalence of HF is rising with an increasingly aging population – with 750,000 adults in the UK currently living with HF compared to 100,000 in 1961[4] – alongside the increase in cardiac pharmaceutical treatments which prolong survival and prevent second cardiac events[3]. Around 10% of patients in hospital beds suffer from heart failure and this accounts for around 2% of the national expenditure on health[3]. Even so, it is suggested that clinicians substantially under-report HF due to a preference for an aetiological diagnosis or a diagnosis of a co-morbidity. The mortality rate of patients with HF is 50% within four years[3], with 30-40% of patients dying within a year of diagnosis and thereafter a mortality rate of less than 10% per year[5, 6]. Prior to 1990, 60-70% of patients died within five years of diagnosis[7]. Significant improvements in the six month mortality rate have been seen since the 1990s, decreasing from 26% in 1995 to 14% in 2005[8]. This improvement appears to be as a result of improvements in drug treatments and surgical options, as well as service configuration improvements such as specialist heart failure clinics.

#### **1.1.1.2 Health service workload and economics (cost to NHS)**

HF costs the NHS a significant amount of money. One UK study[9] evaluated the cost of both direct components of HF-related healthcare (such as hospitalisations, consultations, and drug therapy), and service use attributed to a secondary diagnosis of HF such as nursing home care. The authors estimated that the direct cost of HF was £716 million in 1995 (1.83% of total NHS expenditure), of which 69% was attributed to hospitalisations, with the additional costs associated with long term nursing home care and secondary HF admissions accounting for a further £751 million (2.0% of total NHS expenditure). Current costs to the NHS are unknown

but are likely to be hugely increased due to the increase in the ageing population and the cost of associated care.

### 1.1.1.3 Definition

HF can be defined as an abnormality of the heart function or structure, leading to a failure of the heart as a pump to deliver sufficient oxygen to support physiological circulation[7]. HF is characterised by symptoms, primarily: “shortness of breath at rest or during exertion, and/or fatigue; signs of fluid retention such as pulmonary congestion or ankle swelling; and objective evidence of an abnormality of the structure or function of the heart at rest”[3]. Recently more emphasis has been placed on the need for both the presence of HF symptoms and a physical presentation of fluid retention for diagnosis[10].

Many different descriptive words are used by clinicians to describe the particular type of HF a patient has, such as ‘acute’, ‘advanced’ and ‘decompensated’, and the classification system of the New York Heart Association (NYHA) described in detail in page 9 – although their definitions are not precise. Recent guidelines state that the classification of HF should use the following distinctions; ‘new-onset’ (first presentation), ‘transient’ (recurrent or episodic HF over a limited time period), and ‘chronic’ (persistent, either stable or worsening)[3]. Chronic, worsening HF is the most common form of HF leading to hospital admission, comprising 80% of cases[7].

#### 1.1.1.3.1 Heart failure due to left ventricular systolic dysfunction (HF-LVSD)

HF with left ventricular systolic dysfunction (HF-LVSD), also known as ‘systolic HF’ or ‘HF with reduced ejection fraction (HF-REF), is the best understood type of HF in terms of pathophysiology and treatment[7]. HF-LVSD is characterised clinically by the left ventricle becoming weakened and consequently unable to pump blood with the force required to sustain normal bodily circulation. The capacity of the left ventricle to pump blood is measured by its ejection fraction (EF), which is stroke volume divided by the end-diastolic volume. A reduced EF is indicative of systolic dysfunction. Major trials involving patients with HF have mainly specified an EF of  $\leq 35\%$ .

#### 1.1.1.3.2 Heart failure with preserved ejection fraction (HF-PEF)

Half of all patients with HF have a preserved left ventricular ejection fraction (HF-PEF)[11], also known as ‘diastolic HF’ or ‘HF with normal left ventricular ejection fraction’. It is thought that the left ventricle becomes stiff, rather than weakened, in HF-PEF which results in difficulty filling with blood to pump. It is uncertain whether or not HF-LVSD and HF-PEF represent distinct forms of HF or exist as part of one HF spectrum. The pathophysiological mechanisms

underlying HF-PEF are still uncertain[12]. Patients with HF-PEF are more often female, obese, and more likely to have hypertension and atrial fibrillation compared to those with HF-LVSD[7]. Treatment options for HF-PEF are poorly understood and patients with HF-PEF are often excluded from heart failure clinical drug trials which weakens the evidence base for treatment.

#### **1.1.1.4 Aetiology**

HF occurs as a result of deterioration in heart function, specifically damage or loss of heart muscle; ischaemia (restriction of blood supply), increased vascular resistance with hypertension, or a tachyarrhythmia (abnormally rapid and irregular heart beat). Coronary heart disease is the most common cause of heart disease, initiating HF in 70% of patients[3]. Other causes include myocardial infarction, smoking, hypertension, disease of the heart muscle, congenital heart disease, arrhythmia, damaged heart valves, and other causes of damage to the heart muscle such as from a viral infection, long-term heavy drinking, and some cancer treatments[13, 14].

#### **1.1.2 Patient and Carer Burden**

##### **1.1.2.1 Symptom Burden**

The burden of symptoms on the HF patient is significant and enduring, especially in advanced HF. In a large retrospective study[1], the primary symptoms identified in advanced HF were breathlessness (88%), pain (75%), fatigue (69%), and anxiety (49%), alongside a wide range of other symptoms. Currently little data exists of the symptom burden over time, hence the need for the current study which illustrates experiences of the burden of heart failure over time, and between categories (newly diagnosed, stable, advanced).

##### **1.1.2.2 Depression and Quality of Life**

The difficulties that patients experience when managing their condition all negatively influence their quality of life. Many patients experience depression (18%-47% self-reported[15]) and anxiety (25%-50% self-reported[16]), especially when the patient has a greater number of physical symptoms[17]. Depression in particular is independently associated with an increase in one-year mortality and hospitalisation in heart failure[18, 19], and the strongest predictor of short-term decline in patient health status[20]. Negative experiences of symptoms predict quality of life levels, with peaks in symptoms precipitating hospital admission[17]. Mood is also an independent predictor of both mortality and quality of life in HF[21], and patients who report negative mood states are more likely to report a poorer quality of life than non-depressed patients even when compared with patients of a

higher NYHA class – suggesting that personal interpretation of functional ability, rather than clinical status, predicts quality of life[21]. Ascertaining quality of life levels and tailoring treatment to benefit different domains is time critical, with community based surveys recording mortality rates of 30-40% within one year of diagnosis[22]. However, relatively little is known about the burden of symptoms for the patient with HF. Potential correlates of quality of life in patients with HF have been identified as overall symptom burden, including global symptom distress, psychological state, functional status, spirituality, and co-morbid conditions[17]. Furthermore, specific symptoms such as lack of energy, feeling irritable, and feeling drowsy can independently predict quality of life in patients with HF[23]. Consequently, having an impaired quality of life can impact severely on the individual's life, in domains such as physical symptoms, psychological problems, adverse effects of treatments, social consequences, and negative sexual experiences[17].

Recent research into the patient with HF's perceptions of definitions of quality of life, and what actually constitutes their quality of life level has identified that patients view domains such as having the ability to perform physical and social activities, feeling happy in daily life, and having fulfilling relationships with their family and significant others to be the most significant elements in the measurement of quality of life[24]. Furthermore, the factors most affecting quality of life identified by patients were their physical symptoms and condition, mood, positive outlook, economic status, social support, social activities, spirituality, and performance of health related behaviours[24].

#### **1.1.2.2.1 Quality of life and psychosocial difficulties towards the end of life**

Negative experiences of heart failure symptoms predict poor quality of life levels, with peaks in symptoms precipitating hospital admission[25]. Relatively little is known about the burden of symptoms on the HF patient over time. Research has focused on symptoms associated with hospital admission but little is known about experiences of symptoms of quality of life over time. Having an impaired quality of life can impact on elements such as physical symptoms, psychological problems, adverse effects of treatments, social consequences, and negative sexual experiences[25]. Depression also predicts quality of life, and can lead to over-reporting of symptoms which makes it even more difficult for clinicians to accurately identify a course to death[17]. It should be noted that depression can manifest itself as physical symptoms in elderly patients. Measuring quality of life as a routine part of assessment can also provide additional information about disease course and outcome that cannot be measured using traditional indicators[17]. The majority of patients with HF attach more weight to quality of

life over longevity, with no differences between groups found with respect to patient estimated life expectancy, particularly when more functionally impaired[26].

Researchers have increasingly moved towards a holistic model of care for patients with HF, taking into consideration a multidimensional assessment including physical, social, and psychological domains of measurement and treatment. However non-pharmacological literature evaluating holistic interventions is sparse, with much of the existing literature encompassing “one size fits all” interventions not necessarily based on rigorous development, implementation, or evaluation. This may be due to the difficulties in accessing a functionally restricted population, coordinating the involvement of several different staff groups, lack of time and resources to conduct such tasks, and a lack of named central point of access for patients. Nonetheless, evidence suggests that any successful intervention must incorporate both individually tailored strategies to encompass holistic considerations of care in addition to systemic frameworks – including elements of coping styles, sense of meaning, self-efficacy/perceived control, social support, family dynamics, and religiosity/spirituality[27].

#### **1.1.2.3 Carer Burden**

Quality of life in those who care for someone with HF is also significantly impaired, in concordance with other chronic conditions[28]. The largest burden for carers seems to be related to the emotional component within the relationship between carer and patient, which can be altered when dealing with the disease[29]. High levels of psychological distress, including low mood, depression and anxiety have been found in carers as well as patients with HF themselves[30], and lower levels of quality of life in carers compared to the HF patient when the patient is admitted to hospital, even after controlling for age and gender[31]. Qualitative research reveals that carers often worry about upsetting the patient, and when death is recognised as a possibility, worrying about whether they would know what to do when it occurred[32]. Carers also feel particularly burdened coping with the patient’s increasing disability and the concurrent gradual loss of independence both for the patient and themselves, often resulting in social isolation[32].

#### **1.1.3 Making a diagnosis of heart failure**

Diagnosing HF involves the combination of clinical investigations into the underlying abnormality of the heart, assessment of patient reported symptoms, aetiology, and precipitating and exacerbating factors. Patients and their carers often experience poor levels of diagnosis communication, and many clinicians feel under skilled in communicating a diagnosis.

### ***1.1.3.1 Diagnostic pathway***

The diagnosis of heart failure may occur at the start, middle, or advanced stages of the disease - often several months or years after the disease has developed. Patients may present to their general practitioner in primary care with symptoms such as breathlessness, fatigue, and fluid retention; or they may be diagnosed after an acute admission to secondary care with similar, more acute symptoms. The 'gold standard' for diagnosing heart failure is with an echocardiogram[33], usually conducted in a specialist cardiology clinic in secondary care. General practitioners are encouraged to arrange an echocardiogram for their patients with suspected heart failure to fully confirm the diagnosis. Specialist cardiology clinics may also arrange magnetic resonance imaging (MRI) scans of the heart, chest x-rays, or an electrocardiogram (ECG).

Formal diagnostic pathways may be used to diagnose suspected heart failure. The National Institute for Health and Care Excellence provide a HF diagnostic pathway for clinicians[34], which includes a detailed history, clinical examination, echocardiography, and natriuretic peptides. This pathway is intended to provide a comprehensive system for diagnosing suspected heart failure, however many of those with heart failure live without a formal diagnosis due to variable access to echocardiography and clinical reluctance to diagnose HF and therefore intervene aggressively (in line with the diagnostic pathway) in certain groups, including older people[35].

At the time of diagnosis patients are usually referred to a specialist heart failure clinic in secondary care in order to achieve disease stability. This is achieved with a combination of medication, disease management advice and lifestyle advice, which includes advice on exercise, smoking cessation, alcohol consumption, sexual activity, and other considerations such as air travel and driving regulations. Medication often takes several months to titrate successfully, whilst patients become familiar with their new drug regimen. As such, a patient may be categorised as 'newly diagnosed' for many months. Equally, a diagnosis may only occur when the patient is in advanced heart failure but still categorised concurrently as newly diagnosed.

### ***1.1.3.2 Symptoms***

Patients with HF may experience a number of symptoms, the most common being breathlessness, pain, fatigue, and anxiety[1]. The origins of these symptoms are not fully understood at present. New York Heart Association (NYHA) criteria are primarily used to classify the severity of HF based on common symptoms, from Class I (no symptoms) to Class

IV (symptoms of cardiac insufficiency even at rest[36]). The definition of each NYHA class is given in Table 1.

**Table 1 New York Heart Association Classification**

NYHA Class	Patient Symptoms
<b>Class I (Mild)</b>	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, or dyspnea (shortness of breath).
<b>Class II (Mild)</b>	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitation, or dyspnea.
<b>Class III (Moderate)</b>	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitation, or dyspnea.
<b>Class IV (Severe)</b>	Unable to carry out any physical activity without discomfort. Symptoms of cardiac insufficiency at rest. If any physical activity is undertaken, discomfort is increased.

Table reproduced from the European Society of Cardiology, ESC Guidelines for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2012[7].

The severity of symptoms may fluctuate regularly and as such, a patient’s NYHA class may change from month to month or even week to week, even in the absence of medication changes[37]. However the functional class tends to deteriorate – unevenly – over time. Moreover, symptoms do not necessarily predict the NYHA class or severity of a patient’s HF, with mild symptoms often being found in patients with severe damage to the heart and vice versa. Consequently, clinical guidance recommends that symptoms alone should not be used as a sole basis for diagnosis. Instead, clinicians are recommended to combine symptoms with patient history, physical examination, and tests.

### **1.1.3.3 Cardiac assessment**

#### **1.1.3.4 Biomarkers**

The use of biomarkers for identifying HF in individuals is considered by many to be one of the first ports of call when making a diagnosis in primary care. It has been identified that measuring cardiac natriuretic hormones such as B-type natriuretic peptides (BNP) and N-terminal pro B-type natriuretic peptides (NT-proBNP) can provide information in screening for various types of heart disease, heart failure, and can inform a differentiation between HF-LVSD/HF-PEF[38]. Some evidence suggests that these biomarkers may be more sensitive and accurate than the traditional method of ECG and echocardiogram[38]. However, each of these biomarkers has relatively low sensitivity and specificity, which in practice makes it difficult for a GP to be 100% certain of a diagnosis without a definitive echocardiogram assessment.



Despite this, anecdotal evidence suggests patients are often given a heart failure diagnosis in primary care on the basis of (unconfirmed) biomarker tests.

#### 1.1.3.4.1 Echocardiography

GPs (general practitioners) are encouraged to refer a patient with suspected HF to secondary care where HF can be confirmed using an echocardiogram, a test which uses sound waves that echo against structures in the heart to build a detailed picture of the heart. Echocardiography represents the “gold standard” of the assessment of systolic and diastolic function for HF[39]. Echocardiography is often seen as the most useful and consequently the most utilised method of cardiac assessment[3]. However echocardiography is not always available to all patients due to variable access in rural and urban areas, variable patterns of referral, and reluctance to diagnose and intervene aggressively in older people[35, 40].

In practice there are four groups of patients with HF with regards to their method and status of diagnosis: (i) those with a diagnosis of left ventricular systolic dysfunction (HF-LVSD) have been confirmed with an echocardiogram, (ii) those with HF preserved ejection fraction (HF-PEF) who do not have lower levels of left ventricular systolic function, and in whom diagnostic findings are often less pronounced, (iii) those who are diagnosed with HF by their GP without an echocardiogram to confirm their diagnosis (which may actually be chronic obstructive pulmonary disease (COPD) or a related condition), (iv) finally, those community patients suffering from undiagnosed HF. This study seeks to understand the diagnostic and prognostic experience of patients in whom a diagnosis is uncontested and thus its starting point is group (i). (See 3.4.3 for a full description of the sampling methodology and its rationale).

#### 1.1.3.5 Diagnosis communication

Diagnosis communication can often be poor in HF. Suggested reasons for this are highlighted in earlier sections and include a lack of consensus on a single definition of heart failure, difficulty in explaining a complex pathophysiological process into language appropriate for the individual patient and their carer, and general reluctance to use the term[41].

Many primary care clinicians find it difficult to communicate information about the nature of HF to their patients. Many GPs resort to using euphemisms such as “your heart is not pumping hard enough” rather than use the emotive term of “heart failure”. A 2005 study[42] in this area found that not only were GPs more likely to, and prefer to use euphemisms, but also patients who had their condition described to them in this way were less likely to view it as serious compared to those who heard the term heart failure. The authors point out that even though guidance suggests being open with the patient about their condition, this may

precipitate a more negative response from the patient. GPs may choose to compromise patient openness for the sake of minimising distress, the fear of which is well founded according to the study results. However, again this study used quantitative methodologies which may not help to identify possible areas of improvement or the finer details of the communication process which could satisfy the requirement to be open but still minimise patient distress.

The standard model of treatment for HF is an active, curative approach, and as part of this, conversations surrounding the diagnosis primarily include treatment options and exclude talk about the disease trajectory and the suggestion of eventual palliative care. Many clinicians feel uncomfortable speaking about a prognosis in HF and do not wish to destroy hope for the patient and their family[43].

## 1.2 The Management of Heart Failure

This section outlines the various aspects of NHS health and social care individuals with heart failure receive over the course of the disease, after diagnosis until death. It includes treatments, the difficulties of making and communicating a prognosis in heart failure, care pathways for the primary stages of the disease, and the benefits of a palliative approach when necessary.

### 1.2.1 Treatments

Treatments for HF are split into three groups; non-pharmacological, pharmacological, and devices/surgery.

#### 1.2.1.1 Pharmacological

There are many different evidence-based pharmacological therapies used for the treatment of HF. Pharmacological objectives include reducing mortality, relieve morbidity, and aid prevention. One major challenge in prescribing for HF is the assessment of the patient's ejection fraction (EF), i.e. the fraction of blood pumped out of the right and left ventricles with each heartbeat. This is a key indicator of prognosis in HF, however there is no accepted cut off point for an EF level which would indicate a problem. Likewise, there is no generally accepted EF level for a healthy patient – figures vary between 50% - 75%. Many RCTs in HF have used patients with an EF level of <35-40%, however there is evidence of a large body of symptomatic patients with HF with an EF of 40-50%[3]. There is no consensus about the level at which to treat heart failure. Similarly, the pharmacological evidence base has been developed in relatively young, mobile populations and its true utility in the range of patients with HF is unknown. This explains some of the prescribing variability for HF whereby many patients do not receive guideline-recommended drugs for various reasons[40, 44].

Pharmacological therapies for those with a reduced EF consist of angiotensin-converting enzyme inhibitors (ACEIs), beta-blockers, aldosterone antagonists, angiotensin receptor blockers (ARBs), hydralazine and isosorbide dinitrate (H-ISDN), digoxin, diuretics, and other drugs used to treat cardiovascular co-morbidity such as anticoagulants, antiplatelet agents, and statins. It should be noted that there is a paucity of research on HF-PEF and thus no treatment has been shown to reduce morbidity and mortality with patients who have HF-PEF (i.e. a preserved EF)[3].

#### 1.2.1.2 Non-pharmacological

Non-pharmacological treatments for heart failure consist primarily of patient educational programmes for self-care management, most often delivered by specialist heart failure

nurses. The aim of patient education in heart failure is to empower patients with an understanding of their condition and to prevent and manage symptoms, including the definition and aetiology of HF, symptoms and signs of HF, exercise and diet recommendations, understanding of the importance of adherence, immunisation, risk factor modification and pharmacological treatment, and information regarding sexual activity, sleep/breathing disorders, and the psychosocial aspects of the condition[3]. Educating patients about their heart failure has been shown to improve the number of hospitalisations attributed to heart failure, and reduce mortality[45]. Most patient education is delivered one-to-one rather than in a group format[46].

Weight monitoring is another aspect of non-pharmacological treatments for heart failure and clinical guidance[7] recommends daily weight monitoring. Daily electronic home weight monitoring has been shown to reduce mortality in advanced heart failure patients[47].

### **1.2.1.3 Devices**

Surgeries are available for HF which involve inserting a device into a part of the heart to either pace the heartbeat, shock the heart if it enters an abnormal rhythm, or assist the heart to pump blood more effectively. Devices include valvular, aortic valve, mitral valve, pacemakers, cardiac resynchronisation therapy, implantable cardioverter defibrillator, and left ventricular assist devices (LVAD). Heart transplantation is also an option in a minority of cases, with either an in vivo heart or an artificial heart[3]. Implantable cardioverter defibrillators (ICDs) in particular reduce the incidence of sudden death by up to 50%[48].

## **1.2.2 Prognosis**

Prognostication – in the sense of making a judgement of length of life – is extremely difficult in HF due to the unpredictable nature of organ failure, with peaks and troughs in function and often sudden deterioration due to decompensation of cardiac function. Identifying a prognosis is often linked pragmatically and in policy terms with the recognition of the patient who would benefit from a palliative approach to care, as well as the recognition of the last few days of life.

### **1.2.2.1 Prognostic clinical indicators**

Other clinical indicators for prognostication in HF include advanced age, ischaemic aetiology, resuscitated sudden death, hypotension, NYHA functional class III-IV, prior HF hospitalisation, tachycardia Q waves, wide QRS, LV hypertrophy, reduced work exertion, elevation of BNP/NT pro-BNP, hyponatremia, elevated troponin, biomarkers and neurohumoral activation, and low LVEF[3]. All patients with HF will experience a progressive decline in function. For 50% of

patients death will occur after a long period of chronic decline, punctuated by acute episodes and hospitalisations. The other 50% will die suddenly, particularly in the earlier stages of the disease[7, 49]. The proportion of those with HF dying suddenly has reduced compared to statistics published in the 'historic era' (around the 1990s), with a concomitant increase in those dying from either progressive heart failure, or non-cardiovascular causes[50]. At the time of writing the mortality rate for patients with HF is reported as 50% within 4 years of diagnosis, and 40% of patients admitted to hospital with HF have either died, or have been readmitted within one year[3]. However, prognostication is not an exact science and there is no consensus nationally or internationally on the optimum combination of prognostic factors.

### 1.2.2.2 Comparisons with cancer

Predicting a dying trajectory in terminal illnesses (i.e. “an advanced stage of a disease with an unfavourable prognosis and no known cure” as defined in Mosby’s Medical Dictionary[51]), introduced by Glaser and Strauss in 1968[52], provides important information not only for the patient and clinician to manage the condition, but also to plan and deliver health care services at the appropriate time. The disease trajectory for cancer is well established and fairly straightforward to estimate for most cancers categorised as terminal. However the inherent difficulties in prognostication for HF have a follow on impact on the ability to accurately identify a dying trajectory in this particular patient group. This is illustrated further in Figure 1, showing a comparison of the disease trajectory of terminal cancer and HF. Research has identified no typical functional decline trajectory in HF[53].

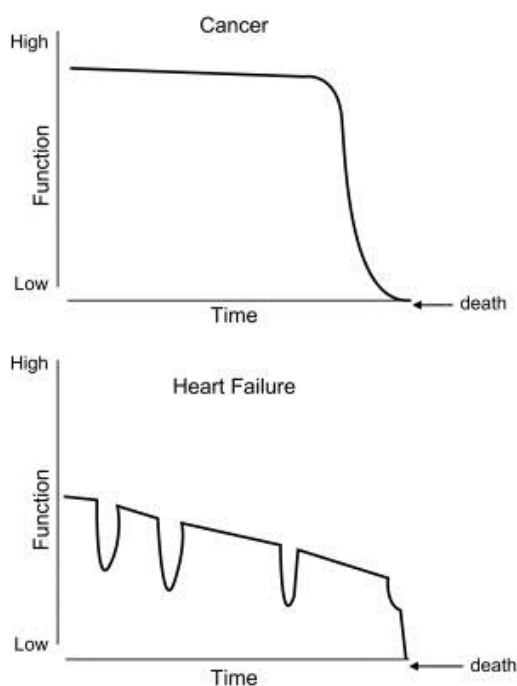


Figure 1 Disease trajectory in cancer and heart failure

Reproduced with permission from Goldstein, N. E. & Lynn, J. (2006)[54].

### 1.2.2.3 The Surprise Question

A tool used to 'prompt' prognostication is the surprise question, "Would I be surprised if this patient was to die in the next 6-12 months?". As such, this is a simple clinical prognostic screening tool used to identify patients with progressive illnesses, including heart failure, for a discussion about end of life care needs and preferences. A "not surprised" response has been shown, in cancer, to successfully identify patients at risk of dying in the following year[55]. The surprise question has been integrated in the Gold Standards Framework Prognostic Indicator Guidance[56], and used as a starting point for needs-based coding which requires regular assessment of prognosis in order to deliver the most appropriate care at each stage (see Figure 2).



Figure 2 Prognostic Indicator Guidance: Needs-Based Coding

Reproduced from the Gold Standards Framework Centre in End of Life Care: GSF Prognostic Indicator Guide (2011)[56].

Whilst the surprise question has been helpful in clinical practice, the literature suggests that it should not be used as a single tool to identify patients who require access to palliative care, particularly for patients with advanced heart failure or chronic obstructive pulmonary disease, as it may "enshrine a narrow concept of palliative care[57] (p 740)" which focuses on active and palliative care being two distinct modes of care rather than palliative care being a life-long, continuous component of care[58]. Furthermore it is argued that many clinicians would not be 'surprised' if *any* 80 year old patient died within the next year regardless of whether or not they had heart failure[57], and in a recent study 87% of specialist heart failure nurses surveyed reported 'no' to the surprise question for their cohort of NYHA III-IV patients[59], of which only 31% had died within the following 12 months.

### 1.2.2.4 The Seattle Heart Failure Model

The Seattle Heart Failure Model (SHF) is a multivariate risk tool designed to predict 1-, 2-, and 3-year mortality in heart failure by using clinical characteristics such as age, gender, aetiology, cholesterol, NYHA class, amount of diuretic prescribed, and others[60]. Whilst the model has been shown to predict mortality in some cases, it is predominantly derived from clinical trial

data or restricted cohorts, especially younger patients with fewer comorbidities, and consequently it lacks generalizability (spectrum bias)[59, 61] and has limited utility in older patients. Furthermore, tools such as the SHF can easily become out of date as new therapies are introduced[62]. A Scottish study published in 2012 comparing the Gold Standards Framework Prognostic Indicator Guide and the SHF reported that whilst 86% of patients with NYHA III-IV grade heart failure met the criteria for entry onto the Gold Standards Framework using the Surprise Question, only 4% of the same cohort were deemed to be within the last year of life using the SHF. Overall mortality for this cohort was in fact 31% at 12 months[59] which shows the SHF underestimating mortality risk, a finding reported in other studies[63].

### 1.2.3 Multidisciplinary care

Multidisciplinary care is an integrated, collaborative team approach to health care involving clinicians from a range of disciplines and a range of skills, knowledge and experience. Working together in this manner is purported to benefit patients and carers by virtue of improved team communication and support, care coordination, improved treatment, and reduced service duplication. In the context of heart failure, a multidisciplinary team may include a specialist cardiologist, specialist heart failure nurse, palliative care specialist, physiotherapist, dietician, and a psychologist amongst others[64]. This approach has been widely endorsed in clinical guidelines, especially for confirmation of the initial diagnosis, management of advanced or unstable heart failure, and for those unable to be managed at home[10]. A recent study of the impact of care at a multidisciplinary heart failure clinic[65] illustrates the potential importance of treating patients with HF in this manner, with those in the study who were in the intervention (multidisciplinary care) group showing fewer repeat hospital admissions compared to the control group (39% vs 57% respectively, crude hazard ratio 0.59, 95% confidence interval 0.38-0.92) and improved self-reported quality of life at six month follow-up ( $p < 0.001$ ). Furthermore when the data were added to a previous systematic review and meta-analysis conducted in 2004[66], the combined results attain statistical significance for the reduction of all-cause hospital admission rates and death rate compared to the control group who had 'regular' HF care. This clinic used many different multidisciplinary elements to their intervention, including rapid access to expert health care professionals, regular telephone contact from a nurse, individualised treatment plans from a cardiologist, one-on-one health education with patients and family including a patient-kept diary, dietary assessments from a dietician, analysis of current medications and possible interactions, and monthly follow-up visits. Other European and international research shows similar improved care (compared to routine care) for those receiving multidisciplinary care shows this mode of

care to be cost-effective, with hospitalisations significantly reduced in the multidisciplinary care group which produced a net cost saving[67].

It remains unclear which elements of multidisciplinary care are most strongly associated with positive outcomes. Another recent study[68] suggests that frameworks for multidisciplinary care already exist and are being utilised for care of patients with HF concordant with care received by cancer patients. In a mixed-methods comparison made between HF and cancer patients both receiving multidisciplinary care[68], the authors found no real significant differences in the experiences of these two types of patients, including on measures for symptom burden, emotional distress, quality of life, and satisfaction with service. Conversely those with HF were found to be more functionally independent and had more hospital admissions in this sample, possibly due to the inherent differences in the two conditions. It is suggested that this up-to-date Irish study using patients who are actually receiving reference-standard MD care (as is strongly recommended in the literature) do not require specialist palliative care compared to cancer patients, and they also purport it is possible that the palliative care needs of patients with HF have been over estimated. Consequently the authors recommend that the research focus needs to shift from the suggested failings of palliative care for patients with HF and instead draw attention to identifying and evaluating the transition point from care that intends to maximise function, to palliative care. Experiences of this transition point and the specific elements of MDT care most strongly associated with positive patient outcomes remain under-researched and poorly understood. Thus the current study aims to elucidate experiences and perceptions of palliative and end of life care in heart failure, in particular the transition from active to palliative and end of life care.

#### **1.2.4 Coordination of care for heart failure**

Many patients with heart failure, and their carers, describe frustrations and issues negotiating care tiers and coordination of care. A lack of care coordination has been identified as promoting communication related barriers, especially surrounding the transition point from active to palliative care. Some of these issues are attributed to the primary-secondary care gap, where processes, resources and skills for palliative care can be lacking in primary care, and the different locations of cardiology care and palliative care within the NHS primary/secondary care system[69]. A Scottish qualitative study[32] using semi structured interviews with patients with HF identified a lack of continuity and coordination between hospital and community care teams, as well as a lack of planned community support apart from visiting their GP. Issues of poor coordination have also been identified by health professionals who often feel frustrated that this often results in inappropriate hospital



admissions[70]. Most patients said that they did not have access to a specialist cardiac nurse[32], and an adequate care plan was not always drawn up for the patient after discharge. These issues become particularly prominent when the patient is near the end of life and may require input from several clinical groups and care tiers, especially during out of hours.

Further difficulties with coordination and systemisation of care lie within patients at the end of their life who are placed on the Liverpool Care Pathway (LCP), endorsed by the Department of Health End of Life Strategy[71]. The LCP has been shown to facilitate holistic care and appropriate standards of record keeping in end of life care. It is used when the clinical team expect death to occur within the next 1-2 days, based on specific criteria including: an agreement within the clinical team that the patient is dying and that two of the following four criteria apply: the patient is (i) bed bound, (ii) semi-comatose, (iii) only able to take sips of fluids, and (iv) is no longer able to take tablets. A recent audit of LCP use within a hospital in the North East found that 49% of non-cancer patients did not qualify for LCP use[72]. The uptake and utility of the LCP in HF is unknown and is the subject of a systematic review as part of the current study (see Chapter 2 for further details).

### **1.2.5 Care pathway for stabilised heart failure**

Once a patient is deemed to be on the most effective pharmacological treatment and is showing little to no signs of change in their cardiac function, they may be categorised as stable. Stable patients are seen much less often than newly diagnosed or advanced patients – every six months is common, or they may even be discharged from secondary care with advice to return if their health worsens.

Monitoring (clinical review) is recommended during treatment for heart failure including during periods of stability, conducted during specialist heart failure clinic appointments or by the patient's general practitioner. This includes clinical assessment of functional capacity, fluid status, cardiac rhythm (examining the pulse), cognitive status and nutritional status. Drug treatments are reviewed at this time and changed if necessary, and blood is taken and tested. If the patient's condition or drug treatment has changed, a follow-up would usually be conducted within two weeks.

Patients may remain stable for several years – or they may not achieve stability at all, particularly if formal diagnosis occurred late in the disease trajectory.

### **1.2.6 Care pathway for advanced heart failure**

As heart failure is a progressive disease, eventually routine drug therapy and symptom management strategies which worked sufficiently during periods of stability no longer provide adequate symptom relief for the patient, despite efforts made by the clinical team to change medications, provide lifestyle advice, etc. Patients experience a worsening of their symptoms, particularly breathlessness, fatigue and fluid retention. At this point the heart failure is classed as advanced. This can be a very difficult time for patients and their families, with the patient's – and carer's – quality of life deteriorating in line with an increase in symptoms and functional restriction[25, 73].

At this stage patients are often unable to attend clinic appointments due to their ill health, and home visits are arranged by the specialist heart failure nurse. This may be as frequent as once a week, and often patients receive unrelated visits from other nursing staff (such as district nurses) for comorbidities – meaning individuals may see clinicians several times a week at this point.

Palliative care can often relieve symptoms in advanced heart failure. However, communication between patient, carer, and clinician can suffer at this time which may then present difficulties in making a referral to palliative care. A discussion of communication difficulties in HF and the role of palliative care in HF is presented below.

#### **1.2.6.1 Communication**

Experiencing a chronic, life limiting illness especially at the end-stage can be a frightening and confusing time for individuals and their families[74]. The Department of Health End of Life Strategy (2008) indicates that the need for good standards of communication between patient, carer, and clinician is paramount at the end of life. However, communication difficulties are one of the most prevalent and enduring issues experienced by both patients with HF and clinicians today, and frequently a source of patient dissatisfaction[70]. It has been identified that cancer patients tend to have a 'better' experience of communication[75]. This is in addition to an on-going disagreement amongst professionals about a single definition of HF, precipitating a reluctance of clinicians to use the term "heart failure" and explain the finer points of the illness[41]. It seems that standards of communication for palliative care in HF have been out of everyday clinical focus for quite some time.

Many health care professionals struggle to communicate with patients about their prognosis and the future, particularly in unpredictable diseases such as HF, due to a lack of training. Further, the mere presence of a dying person can be perceived to be highly threatening on

both social and individual levels[76], stemming from a fear for their own and/or loved one's mortality, fear of inadequacy, or a fear of not being accepted. The combination of a lack of training and the phenomenon of feeling threatened when in the presence of a severely unwell person can result in communication apprehension.

#### **1.2.6.1.1 Patient understanding**

Issues with patient understanding of the disease play a major contribution to experiences of communication. Qualitative research[77] revealed that many patients with HF have an ambivalent attitude towards gathering more individually tailored information about their condition, whilst others felt that their doctor did not give them enough information about their illness, possibly to avoid overloading them with too much or irrelevant detail, or a wish not to cause unnecessary alarm[78]. This may be further compounded by some patients' view that "doctors know best", and 'stepping away' from the finer details of the decision making process[79]. In general, patients with heart failure and their carers would like more information than professionals estimate in order to understand their illness, with studies showing roughly the same proportions (64% in Fomiga et al[80]., and 55% in Fried et al.[81]). One European-based population study revealed an international preference to always be informed in the scenario of having a serious illness with less than a year to live[82], with those younger than 70, having experience of illness, and with more education being more likely to want to know their limited life expectancy.

Disease specific barriers can also prevent patients with HF from communicating effectively with clinicians; such as memory loss, fatigue, confusion[79], and impaired psychosocial functioning especially with a high incidence of depression amongst HF sufferers[17]. Depression in particular can negatively impact upon communication, with the symptomology of depression including difficulties in the ability to think clearly, maintain hope, and social interaction. The end result being that only 19% of patients with HF are aware of their prognosis (compared to 68.5% in cancer) in one study[83].

#### **1.2.6.2 Prognosis communication**

Recent research inquiry has focussed specifically on communication between clinician and patient at the point of diagnosis and giving a prognosis in HF, and the impact this has on patient knowledge. Many seriously ill patients are overly optimistic about their prognosis, possibly due to issues with clinician communication, prognostication skill, and/or the receptivity of the patient[81]. One large US-based cross-sectional survey with patients, carers, and clinicians found that in 46% of patient/clinician pairs studied, the clinician reported

discussing the possibility of death from HF whereas the patient reported no discussion of this nature. Also in 23% of patient/clinician pairs, the clinician reported the discussion of approximate life expectancy, whereas the patient again reported no such discussion. Such results are the effect of ineffective communication between clinician and patient. The authors also found that many patients do not wish to talk about prognosis – with percentages rising in line with patient’s belief of a longer life[81]. Whilst this study involved patients, carers and clinicians, due to the quantitative nature of the investigation there was no further exploration of issues raised. Furthermore no information was included about the length of time between prognosis communication and the study – exacerbating possible difficulties in recall bias in patients and carers, and clinician social desirability response bias (where the clinician may inflate their reporting of good prognosis communication). Other lines of inquiry in cancer have found that patients with advanced solid tumours overestimate their life expectancy[84]. Earlier discussion of end of life preferences between patient and clinician are also associated with less aggressive treatment towards the end of life in cancer patients[85]. However, end of life conversations were only initiated by the clinician a median of 33 days before death in the cancer-based CanCORS study[85], when the end of life period is typically underway, with most conversations occurring in the outpatient setting. Earlier end of life conversations also significantly increase the odds of the patient receiving hospice care[85]. However as described earlier, many end of life discussions may not be recognised by the patient or their carer, and Mack et al found that only patient or patient surrogate *recognised* end of life discussions were associated with less aggressive care. Furthermore, patients who held more inaccurate beliefs about their prognosis were more likely to rate their clinician’s communication with them positively, suggesting that they perceive their clinicians as better communicators when they convey a more optimistic view of treatment (in this case, palliative chemotherapy). In this particular study, 81% of colorectal cancer patients gave answers which were not consistent with understanding that chemotherapy was very unlikely to cure their cancer. This underlines the importance of effective palliative and end of life communication with patients and their carers as it seems their understanding of the discussion, and not the discussion occurrence itself, contributes towards mode of care near the end of life. However, patients may not accept medical facts when presented to them, particularly surrounding prognosis and end of life care. Factors which have been found to contribute towards patient acceptance include lack of trust in clinicians, alternative belief systems, and use of ambiguous language by clinicians[86, 87]. In particular, one cancer-based ethnographic study found elements of ‘collusion’ between doctor and patient, where conversations during consultations would

quickly transition from discussion of prognosis, to a discussion of treatment options and schedule, refocusing attention and leading to false optimism[86]. It can be argued that patients who do not fully understand the nature of their non-curative treatment, such as palliative chemotherapy and various treatments and interventions for HF, have not met the standard for true on-going informed consent to their treatment.

Qualitative study in the UK using older adults suffering from HF and primary care professionals[78] corroborated previous findings of a lack of understanding of the nature of HF amongst patients. The barriers surrounding this were indicated by some patients as a simple desire not to know their prognosis as it would cause them to worry. Anxiety and fear were experienced by patients who were aware of their prognosis, possibly due to difficulties in communication with their clinician and a resulting limited understanding of HF. Even so, the number of patients who were aware of their prognosis were in the minority in this particular study. Others felt anxiety as they were all too aware of the impact of HF. Many patients also reported being shocked at being given a clear diagnosis of HF by secondary care clinicians even when visiting their GP previously for the same symptoms. GPs reported facing difficulties in explaining HF to their patients, commonly using more complicated terms such as “ventricular dysfunction” rather than “heart failure” - resulting in unclear advice and explanation and bringing about confusion and resentment for the patient. A similar qualitative study conducted in 2000[77] corroborated findings of unclear communication and prognosis in general. A qualitative Swedish study conducted in 2010[88] with physicians in a medical geriatric clinic expanded on the difficulties clinicians face with patients with HF, with themes including issues with unpredictable disease trajectory and confronting the anxiety and frustration of close relatives, making difficult decisions about the continuance or withdrawal of active care including ICDs and resuscitation, and acknowledging the need for better follow-up, cooperative, and continuing care.

Finally, two Canadian studies (2007 and 2013) used grounded theory to ascertain HF patient and cardiologist preferences for what they would like to talk about at the point of prognosis communication[89, 90]. It was found that patients wanted to hear about their level of wellness, have the opportunity to be informed by their clinician, to hear truthful statements from their clinician about their prognosis and related treatments and outcomes, and for the clinician to maintain hope throughout. Cardiologists wanted patients to understand their particular role in the patient’s HF care, particularly in order to foster a mutual trust and respect for each other. Controlling prognosis communication was important from both the

cardiologist and patient perspective, with some patients preferring to wait until they could 'handle it' and others leaving it up to their clinician to control the decision of when the most appropriate time to breach the topic of prognosis would be. Patients in particular hoped for quality of life and symptom control throughout, with end of life decisions being under their control also. Both cardiologists and patients viewed prognosis communication as a cardiologist's duty to initiate and deliver in a manner which the patient would understand. This was often dependent on the clinical setting, and outpatient clinics were deemed to be less appropriate (due to the time limited nature) than the hospital ward for prognostic discussions. However it has also been suggested alternatively in some studies that avoidance of prognostic communication can increase patient's distress [43], while denial of prognostic information may actually have a positive effect on coping[91] and health status[92] in other studies.

### *1.2.6.3 Other barriers to effective communication*

Additional barriers to effective communication have been recognised as stemming from the speciality of the clinician. For example, it has been argued that specialist cardiologists tend to place too much concentration on providing care within their speciality when the best treatment for the patient may actually be to hand over to specialist palliative care[93] – possibly due to feeling ill equipped to recognise palliative needs in their patients[70]. Another reason identified by healthcare professionals is a sense that the 'other side' (cardiac vs. palliative) has a different care philosophy which makes it difficult for clinicians to communicate and coordinate effectively[94]. In one piece of qualitative research, cardiologists described a 'sense of failure' when considering this handover as they could not prevent the condition from being a cause of death[70].

Further clinician based barriers include possible influences of personal attitudes towards end of life, and clinician ethnic background[95]. Patients belonging to an ethnic minority tend to use health services less and have poorer outcomes compared to white patients[96]. American inquiries indicate that African Americans are more likely to prefer aggressive life-sustaining treatment compared to European Americans, even after controlling for socioeconomic status[96]. Other researchers have found differences in the way in which patients from different cultures view end of life, with some cultures such as Korean and Mexican Americans being more likely to believe that prognosis should only be disclosed to the family and not the patient – something which flies in the face of anti-paternalistic care that has been championed over the last thirty years[96]. Other American studies have shown a significant disparity in levels of medication management, patient-centred communication, and beliefs about

patient's risk behaviours and adherence with medical advice, when clinicians and patients do not share the same ethnic background[97]. Clinicians who show a lack of awareness or sensitivity towards these cultural differences may be compromising the high standards of patient care required.

#### **1.2.6.3.1 Communication strategies**

In light of reported communication difficulties, recent research has focussed on the application of different communication approaches/strategies when giving a diagnosis or a prognosis to a patient. Lawrie and Kite suggest that many clinicians fall into the trap of such strategies as the 'velvet covered hand grenade' approach[41] (pg 101), with jargon being used to disguise bad news and confuse patients. The 'hit and run' approach[41] (pg 101) is also ill advised, with information given but no real opportunity for the patient to discuss and negotiate. Finally, the 'give it straight' approach[41] (pg 101) in response to a direct question is also not recommended, with the authors suggesting that it would be better to explore why the patient wants to know the information and to what amount of detail[41]. The authors conclude by suggesting that if the key aspects of physical care in HF are balancing and monitoring, then the key aspects of effective communication in HF should surround pacing and tailoring of communication at transition points.

#### **1.2.6.4 Summary of barriers to communication**

Several barriers to communication have been identified in the preceding sections, including factors stemming from the patient, the disease itself, professional related factors, and system related factors. These barriers are summarised in Table 2.

## Barriers to communication

Patient and disease-related factors	Difficulty in attending and participating in clinic appointments due to symptoms
	Co-morbidities such as dementia, poor eyesight and hearing
	Depression
	Lack of 'common language'
	Tacit acceptance of professional agenda
	Cognitive impairment
	Relapsing-remitting nature of disease
Professional-related factors	No agreed single definition of the disease
	Perception that patients want prognostic certainty
	See role solely as monitoring medical treatment
	Don't want to upset patients
	Feeling of powerlessness
System-related factors	Poorly coordinated care especially between primary and secondary care
	Lack of planning and continuity of care
	Time constraints

Table 2 Barriers to communication in heart failure

Reproduced with permission from Radcliffe Publishing Ltd, from Lawrie I., & Kite, S. (2006) Communication in Heart Failure. In: Johnson M, Lehman R (eds). Heart Failure and Palliative Care: A Team Approach.

### 1.2.7 Palliative care

#### 1.2.7.1 Definition of Palliative Care

Defining the term 'palliative care' is problematic, with considerable debate on the interpretation of existing definitions. Generically, palliative medicine has been defined as "the appropriate medical care of patients with active and advanced disease for whom the prognosis is limited and the focus of care is the quality of life[98]". Palliative care as a speciality



was recognised in 1987 by the Royal College of Physicians. It is an approach to treatment which aims to:

- *'Improve the quality of life of patients and their families facing the problem of life-threatening illness*
- *Prevent and relieve suffering*
- *Identify, assess and treat pain and other problems, physical, psychosocial and spiritual*
- *Affirm life and regard dying as a normal process*
- *Offer a support system to help patients live as actively as possible until death[99].'*

By definition, palliative care is an active approach, providing care for those suffering from an illness which will not respond to curative treatment. Palliative care is not intended to hasten or postpone death, rather, palliative care encompasses physical, psychological, social, and spiritual problems in order to achieve the best quality of life possible for both the dying person and their carers. It is considered important to maintain the underlying notion that death is a natural, normal process.

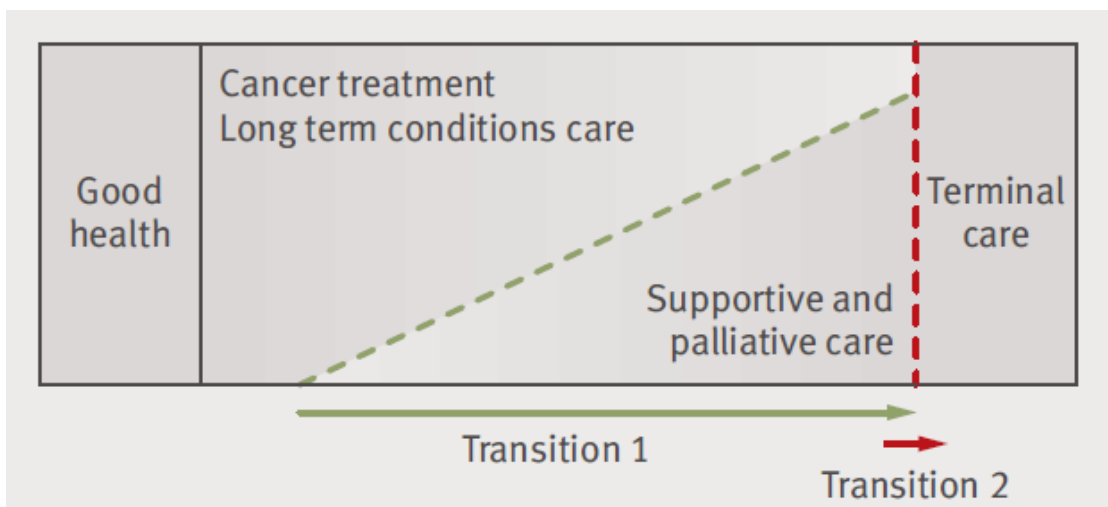
The World Health Organisation (WHO) has defined palliative care as:

*"...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:*

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patients illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications[100]."*

As such, palliative care includes both medical therapies such as opioids for symptom relief, and holistic care including psychological and spiritual needs of the patient. Palliative care also involves consideration of the wellbeing of family/carers, and extends beyond the patient's death to acknowledge the need for support and care for those who have been bereaved.

Despite the WHO stating palliative care is applicable early in the course of illness, clinicians may not integrate palliative care into their treatment until they feel life prolonging treatment has become futile. Fisher suggests that it should begin “the moment the cancer is diagnosed, or even before[101]”, with palliative care running concurrently with curative treatment so that the question of a transition point from solely active care to solely palliative care does not become an unwieldy concept or decision to make by the patient and the clinician – rather, the principles of each form of treatment are combined. However other researchers such as Doyle argue that palliative care should not be from the point of diagnosis, as it may confuse patients and antagonise health care colleagues, making the role of palliative care more baffling which would merely serve to give the impression of professional grandeur[102]. This segregation and sequencing of curative followed by palliative care has been criticised, and a concurrent approach to care has been suggested by several health care professionals and researchers in conjunction with the WHO[103] who recognise that issues at the end of life have their origins at an earlier time in the trajectory of the disease[104]. This earlier introduction of palliative and subsequent end of life care is depicted below in Figure 3.



**Figure 3 Key phases in palliative and end of life care**

Reproduced with permission from BMJ Publishing Group Ltd., from Boyd, K & Murray, S. (2010) Recognising and managing key transitions in end of life care[105].

For the purpose of this study, palliative care is defined as both generalist and specialist palliative care, involving clinical, psychological, social and spiritual supportive care. Due to the variability and unpredictability of the disease trajectory it is difficult to define a timescale for palliative care.

### *1.2.7.2 Palliative care in heart failure*

Palliative care is recommended in heart failure to help the patient and their family cope with distressing symptoms, including psychological and spiritual support. Whilst guidance recommends that some form of palliative care should be commenced at diagnosis, more often than not it is started in the last few months of life, if at all – only 6% of those dying of heart failure are referred to palliative care[106], as the need for palliative care is more clearly ‘demonstrated’ with poor symptom control. In the context of heart failure, patients may be prescribed palliative drugs (such as oral morphine) for symptom control, and referred to local hospices to socialise and rest, perhaps one day a week. Hospices usually offer in-patient care for very ill patients, for respite for their carers, and/or to give them as much comfort as possible in their final days – however some hospices do not care for those dying of heart failure, possibly due to a lack of clinicians skilled in the particular challenges of the disease or an arbitrary restriction stemming from a lack of beds.

Alongside definitions of palliative care, professional care bodies such as the National Council for Palliative Care (NCPC) outline some of the fundamental underlying principles for palliative care[98]. Importance is placed on quality of life including good symptom management, patient autonomy and choice, open and sensitive communication with patients, their carers, and professional colleagues, and finally a recognition that a ‘unit of care’ within this specialist service includes not only the dying person but also those who matter to that person.

Adaption to a diagnosis of dying and the requirement for palliative care demands a significant, radical reorganisation of both individual and family life. When confronted with a terminal diagnosis, each family member must redefine their expectations of themselves and their relationships with one another. As a consequence of the inception of the modern hospice movement, coupled with the wishes of a significant number of terminally ill patients to die at home, palliative care models place a strong emphasis on support for the family. Whilst most wish to spend the final hours of their life at home, the majority of the final year before death for those with heart failure tends to be spent at home, with exacerbations immediately preceding death precipitating the last hospital stay. Furthermore, the carers can be seen as holding a unique position of need in palliative care, both providing and requiring support. As such, it is also vital to support and value the contribution made by carers to palliative care[107].

Research evidence suggests that, partially due to the difficulties in prognostication for HF, accurate identification of patients with HF requiring palliative care is challenging in the first

instance. Inquiry continues into the identification of new biomarkers to predict poor prognosis, however there is increasing interest in the importance of psychosocial factors for heart health. Evidence suggests that measures of personal and psychological circumstances are indeed associated with incident cardiovascular disease, and individual differences in the capacity to successfully control negative emotions and perceive a mastery over their illness could be protective of CVD[108].

The Department of Health have acknowledged that certain services and levels of training need to be improved to deal with systematic prognostic identification issues. To that end, the Quality Outcomes Framework programme includes a Palliative Care Register specifically for GPs to identify which of their patients are in need of end of life care. Once these patients are identified, the intention of the Register is to prompt a reassessment of the priority of care and measures of quality, with a change from routine and preventative care to elements such as care planning, symptom relief, and home support if appropriate. The Supportive Care Register, as part of the Quality Outcomes Framework, comes with an incentive scheme whereby GP surgeries who maintain Palliative Care Registers score points, which in turn convert to financial incentives. However there is a risk that whilst patients may be named on the register, this might not convert to an adequate or appropriate package of care[109]. The Gold Standards Framework for Palliative Care also contains guidance for GPs on how to accurately identify patients who need palliative care, including prognostic scoring information. It is recognised in Department of Health direction[71] that the definition of the beginning of end of life care is variable, and can be initially recognised by different individuals or teams such as the patient, their health and social care team, or their primary or secondary care clinician. Implementation of the Gold Standards Framework has been shown as facilitating a significant improvement in end of life care in GP practices[110].

### ***1.2.7.3 Specialist Palliative Care services***

Specialist palliative care encompasses hospice care (including inpatient hospice, day hospice, and hospice at home) in addition to other specialist advice, support and care provided by hospital palliative care teams. As such, people who may benefit from specialist palliative care are those whose symptoms cannot be managed effectively and quickly by their usual care team[111].

Despite NICE guidelines stipulating that specialist palliative care services should be accessed on the basis of need and not diagnosis, use of these services amongst those with non-cancerous illness, including HF, is low, despite the burden of HF being similar, and around the

same number of individuals dying of HF every year as those dying of cancer[112]. 2010-11 data show only 17% of service users across all specialist palliative care settings have a primary diagnosis other than cancer. This has improved from recent years, 5% in 2000 and 12% in 2008, depicted further in Figure 4.



Figure 4 Proportional uptake of palliative care of cancer and non-cancerous conditions by palliative care setting (2010-11 data)

Reproduced from the National Survey of Patient Activity Data for Specialist Palliative Care Services: MDS Full report for the year 2010-11. National Council for Palliative Care[113]. (pg 18)

#### 1.2.7.4 *Transition point*

Clinician based communication with those suffering from HF can be viewed as one of the fundamental aspects of care provision. This is especially apparent when considering the transition from active to palliative care[70]. The ‘transition point’ is recognised as a major turning point for patients with HF, just as for those suffering from cancer[68]. One overriding issue when dealing with HF is the difficulty in prognostication due to its unpredictable disease trajectory[114]. Clinicians often find it difficult to predict the end of life stage and ultimately, course to death and appropriate transitory point[53]. In addition, the difficulties in defining palliative care also contribute to if and when a decision is made by a clinician to classify a patient as palliative or non-palliative[69]. Some clinicians, patients, and their families may not recognise that death is near for the patient and consequently step away from considering a transition to palliative care. These transitions may include place of care, goals of care, and/or the care giver[115]. As HF is characterised by a steady decline punctuated by acute exacerbations, some clinicians may be reluctant to terminate ‘active’ care in due to the possibility that the patient may recover again. This may result in a delayed or absent recognition that the patient would benefit more from palliative care than active care, and

therefore that the transition to palliative care is necessitated. It has been suggested that the notion of a patient 'crossing the line' from active to palliative care should be discarded in favour of concurrent care, comprising active management and symptom control[69]. When a transition from active to inpatient palliative care is achieved, some patients feel 'caught off-guard' by the initial consultation, possibly due to lack of awareness of their prognosis and the appropriateness of palliative care for their current condition[116]. One recent American retrospective case note audit found only 10% of patients with HF received a referral to palliative care, the majority of whom were referred when seriously ill and in the later stages of dying[117].

Relatively little research has been conducted specifically on the communication surrounding the transition point from active to palliative care, and a recent review[118] identified that papers are predominantly qualitative with no mixed methodology papers (apart from basic quantitative demographic data), and strongly indicate that further research is required in this area in order to establish an information base surrounding effective communication comparable to that of oncology.

## **1.2.8 End of life care**

### **1.2.8.1 Definition of End of Life Care**

End of life care has been separated from palliative care as a distinct model of care. The term, however, is quite ambiguous and has been used to describe the total care of an individual with an advanced, incurable illness who is in the last year, months, weeks, days, or hours of life. As such, the definition includes palliative care modes of care, with the addition of specific models of care for the last few days and hours of life. End of life care pathways such as the Liverpool Care Pathway are mostly concerned with the last few days of life, whereas other definitions of care given at the end of life specify the final year of life. The World Health Organisation define end of life care as;

*“the active, total care of patients whose disease is not responsive to curative treatment [intended] to attain maximal quality of life through control of the myriad physical, psychological, social, and spiritual distress of the patient and family[119].”*

Whilst end of life care has been separated from palliative care, the link between the two is evident and other definitions such as the European Society of Medical Oncology *“palliative care when death is imminent”* recognise this relationship.

For the purpose of this study, end of life care is defined as the last year of life, in line with the NICE quality standard of end of life care[120]. There is overlap with the definition of palliative care, and it should be recognised that end of life care may, in reality, last several years or indeed a matter of hours. The confounding nature of a lack of concrete definition of the end of life period may precipitate problems in planning for the end of life, and the role of palliative care as a model of care. The current study is focused on how end of life care – broadly within the last year of life but including elements of palliative care earlier in the disease trajectory – is planned for and communicated with patients with heart failure.

#### ***1.2.8.2 End of life care in heart failure***

The need for end of life care in oncology is very well historically established, with NICE guidelines and defined frameworks constructed specifically[121]. Forty years ago, the term ‘end of life care’ was synonymous with ‘end of life care for cancer patients’. However recent research inquiry has strongly suggested that those who suffer from chronic diseases such as HF have a similar need for end of life care, as their health steadily declines and the symptoms of their disease worsen. End of life care is currently recommended for all patients with heart failure, whether they die suddenly or progress slowly towards death. NICE guidance on end of life care specifically states the end of life definition includes those dying of a sudden, acute crisis in their condition as well as those progressing slowly towards death. Sudden death is often caused by sudden arrhythmic cardiac death, more common in earlier phases of heart failure, whereas multi-organ failure is the usual cause of death if patients have a slow, prolonged journey towards death[122]. Once an individual with heart failure enters the last days of life the situation often progresses rapidly, and the severity of symptoms at this time often mean that an admission to hospital cannot be avoided, particularly out of hours.

Yet, palliative care and end of life care guidelines which have been written for cancer patients are still being used as an overall framework for those with HF, despite the disease nature and trajectory being entirely different. All of the difficulties in prognostication described previously can lead to what has been termed “prognostic paralysis[123]”, where both the discussion of end of life care and the actual implementation of end of life care is not initiated, or initiated too late to be effective. Very few patients with HF are seen by palliative care providers, often due to lack of resources or staff specialist training, or simply the opinion that cardiology can provide palliative care input[124]. However all patients irrespective of diagnosis have a right to good end of life care[71] and palliative care providers have been strongly encouraged to widen their remit to all diagnoses, not just cancer. Patients with HF in particular have comparable levels of overall need such as symptom burden, and more pressing

needs for the treatment of breathlessness[68]. Despite this encouragement from the Department of Health and NICE, the numbers of non-cancer patients referred to specialist palliative care remain low. Some authors suggest that specialist palliative care services are simply not equipped to deal with the specific challenges of palliative care for HF and may arbitrarily refuse HF patient access due to this – indeed in 2004 one survey polled English specialist palliative care services (59% response rate), of which 10% did not accept patients with HF at all[124]. Only 5% of services had specific treatment guidance or pathways for HF, despite 95% of respondents advocating the role of palliative care in HF. It seems that these current issues for patients with HF may have historical baggage based on the past exclusion of these patients in palliative care.

Recent end of life care strategies for cancer advocate the extension of treatment and communication directives to other disciplines[71], however these existing oncological models may not be useful for patients with HF, and indeed for their clinicians to implement, due to the unpredictability of the disease[118]. It is argued that as patients with HF require certain types of symptom management, e.g. for breathlessness, that reproducing a cancer model of palliative care for patients with HF is not appropriate[68]. Research indicates that patients with HF tend to receive less information about their condition compared with oncology patients[75], and comparatively have a worse understanding of their condition, impacting on the involvement of the HF patient in the decision making process.

### ***1.2.8.3 'A Good Death'***

Achieving 'a good death for all'[125] is one of the most prominent research priorities in health care today across the Western world[126]. This is reflected in various government policy documentation and strategies to improve and facilitate end of life care, including the Department of Health End of Life Care Strategy 2008[71], National Institute for Care Excellence Improving Supportive and Palliative Care for Adults with Cancer 2004[121] and Quality Standard for End of Life Care for Adults 2011[120]. Policymakers acknowledge the relative lack of whole-person care in years gone by, and encourage the consideration of various elements of what is perceived to comprise a good death, such as spiritual considerations, psychosocial care, emphasising patient need and choice, and the use of recently developed end of life care pathways for those who are in the last few days of life.

In the past century society has moved initially towards the scientific bio-medicalisation of healthcare, then away from it again as the perception of what comprises a good standard of health care has changed from the acceptance of the reductionist medical model to a more



holistic level of health care. The same shift in perception can be applied to death and dying and what is considered to be a 'natural', dignified death[127].

Treatments for terminal conditions such as cancer and HF have come along in leaps and bounds over the past few decades, with significant improvements in the management of pain, breathlessness, fatigue, and surgical procedures such as organ transplants and assistive devices including pacemakers and left ventricular assist devices. Long term (5 years or more) survival in heart failure improved from 20% in 1995 to 29% in 2004 in a large American study[128].

#### ***1.2.8.4 Comorbidities at the end of life***

Symptom burden for patients with HF nearing the end of life is significant, not only due to the nature of HF in itself but with the added impact of comorbidity. Whilst the majority of patients with HF are elderly, predisposing them to comorbidities due to age itself, 40% of patients with HF have five or more non-cardiac comorbidities[129] which impact on hospitalisations, mortality and morbidity. Age in itself is also a risk factor for developing both HF and frailty[130].

Examples of comorbidities include: chronic kidney disease, which is closely related to the severity of HF in patients, and is common in HF, with 39% experiencing renal impairment[131]. Anaemia is also common in HF, with studies reporting prevalence between 10-40%[130], and associated with increased morbidity, mortality, and hospitalisations[132]. Falls are common in the elderly with half of people aged over 80 years old falling each year[133]. Whilst HF may not necessarily directly be linked with falls, the impact of multiple comorbidities, polypharmacy, frailty, and impaired autonomic function in HF all increase the risk of falls[134]. Around 20-30% of patients with HF also suffer from chronic obstructive pulmonary disease (COPD). The combination of HF and COPD results in increased breathlessness and a catabolic state, reducing exercise tolerance[135].

#### ***1.2.8.5 Advance care planning and decisions***

Whilst the primary goal of healthcare is to benefit patients, by restoring or maintaining health as well as possible, naturally at some point treatment will cease to benefit the patient, fail, or in some cases the patient may refuse further treatment. Advance care planning encompasses all decisions taken by the patient and their clinical team to change or stop certain types of medical interventions, such as cardiopulmonary resuscitation (CPR).

#### 1.2.8.5.1 Do Not Attempt Resuscitation (DNAR)

Do Not Attempt Resuscitation forms are directives, given either by the patient or the clinical team that the patient is not to receive CPR. In the last stages of a life limiting illness such as HF, where death is imminent and unavoidable, CPR may not be appropriate and may not be successful, causing prolonged or increased suffering and ultimately a traumatic and undignified death. Indeed, clinical guidance states that CPR should only be administered when the clinical team believe that there is a realistic chance it will be successful in re-starting the heart and maintaining breathing. However, most patients with HF do not complete DNAR forms despite the progressive nature of the condition. In these situations the decision to attempt CPR could be discussed with the clinical team, with the final decision ultimately resting with the most senior member of the clinical team currently in charge of the patient's care.

The communication of DNAR decisions made by the clinical team should, according to a joint statement by the British Medical Association (BMA), the Resuscitation Council, and the Royal College of Nursing (RCN)[136], be afforded careful consideration especially when the patient has not expressed a wish to discuss CPR. The joint statement indicates;

*“When a clinical decision is made that CPR should not be attempted, because it will not be successful, and the patient has not expressed a wish to discuss CPR, it is not necessary or appropriate to initiate discussion with the patient to explore their wishes regarding CPR[136].” (pg 9)*

The authors of the joint statement go on to explain that patients should be informed of the DNAR decision in most cases (and stress the confidentiality of DNAR decisions with specific regard to family and friends), but for those patients who are aware that they are in the final days of their life, information about interventions which would not be clinically successful will be “unnecessarily burdensome and of little or no value” (pg 9) and therefore should not be explicitly informed of the decision.

#### 1.2.8.5.2 Device deactivation

Whilst devices such as implantable cardioverter defibrillators (ICDs) can reduce mortality in eligible patients, once the patient is close to the end of life it is often appropriate to deactivate the device to avoid the delivery of futile, repeated shocks. However discussing the deactivation of such a device rarely occurs due to uncertainty about when and how to initiate such discussions, and reticence of discussing death and dying common with other barriers to effective communication in HF[137].

## 1.2.8.6 End of Life Care Pathways for Heart Failure

### 1.2.8.6.1 Definition

Care pathways, also known as clinical pathways, integrated care pathways, or care maps, are used as tools to manage quality in healthcare and allow standardisation of care processes. As a method, care pathways were developed from prior work in the aviation and construction industry where ‘critical path methods’ were used to control and manage complex processes[138]. End of life care pathways were developed with the aim to ensure that high quality, person-centred care is provided near the end of life which is well planned, coordinated and monitored, while being responsive to the individual’s needs and wishes[139]. The End of Life Care Strategy[71] presented a general end of life care pathway which could be used in any setting, for any patient close to the end of life. This pathway is shown in Figure 5.

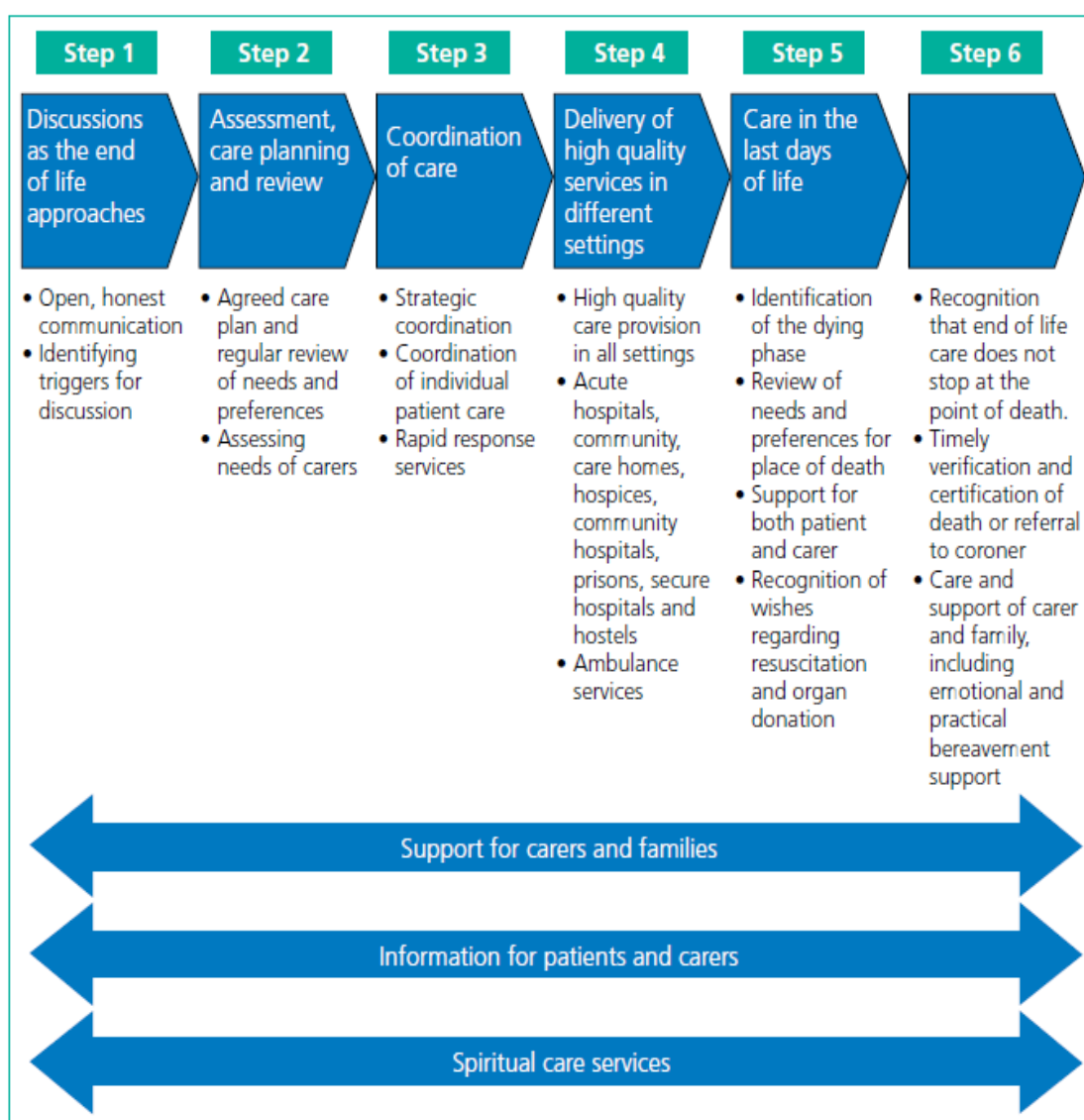


Figure 5 End of Life Care Pathway

Reproduced from the Department of Health End of Life Care Strategy, 2008.

#### 1.2.8.6.2 Why do we need structured end of life care?

Most end of life care is delivered in a generalist, rather than specialist palliative care setting[140]. The majority of individuals who die in industrialised countries spend the last year of their life in institutionalised care, such as a hospital, a care home, or a nursing home[140]. Despite the wishes of most to die at home[141], most will spend their final days elsewhere.

A recent research interest in providing specialist end of life care in any care setting has been cultivated over the past two decades, with patients and carers historically reporting poor standards of care, low levels of quality of life[25], and difficulties in symptom control/comfort measures[23]. It is argued that hospices are seen as centres of excellence for care of the dying, therefore to attempt to provide excellent palliative care in other health care arenas is seen by some clinical and academic commentators as futile and inappropriate, with standards never quite reaching those in a specialist hospice[142]. Consequently this feeling may become a self-fulfilling prophecy, leading to de-skilling and a sense of failure for staff working in generalist health care. However only 16% of cancer deaths and 5% of non-cancer deaths occur in hospices in the UK[71]. Many hospices struggle for funding, limiting bed space available, and patients are generally only successfully referred when it is clear that they will die within a certain period of time and that the hospice has the resources and staff skill set required for that patient. Clearly the current situation makes achieving good levels of end of life care for conditions such as heart failure provided by generalist health care imperative.

The latter half of the 1990s saw the introduction and development of care pathways for end of life care in hospitals[143] in order to encourage the competencies necessary to address the complex needs of dying individuals and their carers, effectively 'bringing the hospice into the non-specialist arena'. A care pathway is a set of medical and care practices coordinated and implemented for certain groups of patients. An expected course of events is charted out and clinical documentation becomes integrated into the care pathway documentation[144]. These procedures allow for outcome measurement, standardisation of care, and facilitates audit.

As most end of life care is delivered in a generalist setting, it was recognised that an easily accessible tool, applicable to all settings, was required in order to provide high standards of 'whole-person' holistic palliative care. Such a tool must be accessible to all health care practitioners and contain enough information for all domains of palliative care without being unwieldy and difficult to use. Using such a universal tool also confers other benefits such as the ability to audit and make comparisons between practitioners, settings, and Trusts. The

Department of Health published their 'End of Life Care Strategy' in 2008[71] to "bring about a step change in access to high quality care for all people approaching the end of life" in all care settings, and endorsed the use of care pathways in end of life care, especially the Liverpool Care Pathway for the Dying Patient.

### 1.2.8.6.3 The Liverpool Care Pathway for the Dying Patient

#### 1.2.8.6.3.1 Outline

Note to reader: At the time of writing the Liverpool Care Pathway was in the first stages of withdrawal as recommended by an independent review panel in their report "More Care, Less Pathway" (July 2013)[145]. No alternative has been specified. It is critiqued here since it was a key element of care for participants in the current study. Chapter 2 goes on to present a systematic review of the uptake of the Pathway for dying patients.

The Liverpool Care Pathway for the Dying Patient (LCP) is an integrated care pathway, jointly developed by the Marie Curie Hospice Liverpool and the Royal Liverpool University Hospitals in 2003. The LCP was originally developed as a tool to assist health care staff when caring for individuals dying of cancer in hospitals[146]. It has now been expanded to include all dying patients, regardless of diagnosis, in various geographical areas and services in both primary and secondary care.

The LCP provides an evidence-based framework for structuring multidisciplinary care for those in the last days of life, and facilitates audit by standardising the monitoring of care. The tool includes guidance on physical aspects of care such as comfort measures, anticipatory prescribing, discontinuation and review of interventions and treatment regimes, psychological and spiritual aspects of care, and considerations of the information needs of patients and carers[142]. The LCP is organised into three sections: initial assessment, on-going assessment, and care after death. Goals of care are contained within the tool, which the authors state were based on the best evidence of optimum care in the dying phase from both the available body of literature and current hospice practice. The implementation of the LCP is dependent on education led by palliative care specialists.

The LCP is cited by the National Institute of Clinical Excellence (NICE) Guidance on Supportive and Palliative Care (2004) as an example of good practice[121]. A patient is placed on the LCP when their clinical team make a decision that the patient is dying, and that two of the following four criteria apply: the patient is (i) bed bound, (ii) semi-comatose, (iii) only able to take sips of fluids, and (iv) is no longer able to take tablets[72].

#### *1.2.8.6.3.2 Strengths*

Since its implementation, the LCP has shown to facilitate documentation of care, which may then contribute towards high levels of structured care and multidisciplinary, proactive management of symptoms and comfort. One study revealed that symptom burden, assessed by both nurses and relatives, decreased after the introduction of the LCP to the ward[147]. Another retrospective case note review of symptom control with the LCP in use showed that 80% of patients were either fully controlled or only had one episode of symptoms with regards to pain, agitation, or respiratory tract symptoms[148]. Use of 'as required' medications increased significantly in a Scottish study assessing end of life care pre- and post-LCP implementation, and staff reported the LCP had assisted in communication between GPs, families and residents[149].

Further qualitative studies have revealed positive evaluation of the LCP by health care professionals. Hospital-based (non-specialist) nurses reported that the LCP provided clear, focussed guidance on care and symptom control which then cultivated greater confidence in caring for dying patients[150]. Specialist health care professionals also found the pathway helpful, acting as an 'aide memoir' to ensure consistency in the delivery of care, and acted as a useful base for training new members of staff[151].

#### *1.2.8.6.3.3 Weaknesses*

The National Care of the Dying Audit estimated that the LCP is in use in 68% of wards in England[152]. Whilst improvements in symptom burden and record keeping have been shown, no significant improvement has been reported in levels of communication[147]. This may be attributed to an over-systemization of palliative care, using the LCP as a 'tick box' tool rather than a prompt to discuss both biomedical and holistic considerations, communication, and intervention. Communication is regarded by patients and carers as one of the most important aspects of care provision[153], and various studies report poor levels of communication as increasing patient distress, poor symptom control, lack of satisfaction about quality of care received, and increases the use of alternative and/or unnecessary treatment[154].

Most generalist health care staff do not receive training on end of life/palliative care issues – and so whilst communication goals are provided for within the LCP, this is under the assumption that the staff member is at least adequately trained and confident enough to discuss end of life care issues with the patient and family. Further, NICE guidelines[71] state

that end of care must be broached and discussed with the patient much earlier than the one to two days before death that the LCP is intended for.

One fundamental issue with assessing the utility of the LCP is that, as some studies suggest[72, 155], many patients nearing the end of life are not placed on the LCP even in settings where the LCP is fully implemented[72, 155]. Either the patient is assessed as ineligible to be placed on the pathway according to its criteria, or the patient is not placed on the LCP despite being eligible for it. Consequently assessments of the positive effect of implementing the LCP may be skewed, as only the patients who clearly meet entry criteria are placed on the LCP and therefore included in retrospective audits[156]. The reasons for low uptake are unclear, and the decision making process surrounding staff assessment for patient placement on the LCP are not routinely collected within patient notes which makes it difficult to audit.

The entry criteria onto the LCP include an agreement within the clinical team that the patient is dying. Making a clinical judgement of dying is difficult, especially in non-cancerous illnesses with an unpredictable trajectory[72]. Often, comorbidities such as diabetes and heart disease exacerbate symptoms and impact the predictability of the patient's trajectory[53]. It is significantly more problematic to predict a dying trajectory for those suffering from non-cancerous illnesses such as HF and chronic obstructive pulmonary disease[72], due to these diseases being characterised by peaks and troughs in symptoms and function. The LCP was developed as an end of life pathway for those with cancer only, and has been retrospectively modified to fit other diseases. However many oncology patients nearing the end of life do not meet the set criteria for placement on the pathway[72], and no clear alternative seems to be specified. Very little is known about the utilisation of the LCP in relation to heart failure.

The Liverpool Care Pathway was recommended for withdrawal in July 2012 after the publication of the Neuberger report "More Care, Less Pathway". Members of the independent panel felt that whilst the clinical elements of the pathway were mostly sound, when used in an integrated care pathway crucial elements of care were ill performed, particularly communication with patients and relatives. Comments on the withdrawal included "The Liverpool Care Pathway was never meant to be the answer to the question "how do we start difficult conversations?[157]".

The clinical implications of such a recommendation are wide ranging. The independent panel made an urgent call to the Nursing and Midwifery Council (NMC) to provide guidance to nurses on common principles of good palliative care, particularly the support of oral nutrition and hydration. NHS England has advised clinicians in secondary and community care not to cease use of the LCP abruptly, especially where it is being properly used, and that the principles of good palliative care must be upheld whether or not the LCP was being used. With a history of poor press, hand in hand with other reports such as the Mid Staffordshire NHS Trust deaths – where concerns about an abnormally high mortality rate led to a public enquiry which described standards of care and communication, even in death, as “appalling[158]”, perhaps the general public may view such end of life care pathways as a pathway towards death in which they could experience poor standards of care and support. As the pathway was primarily used for cancer deaths[72], those with heart failure, as a group of patients, may not experience much change in their end of life care. Certainly several hospitals use some form of end of life care pathway – which may have several, if not all, principles of the Liverpool Care Pathway – however as only the Liverpool ‘badged’ end of life care pathway is to be withdrawn, there may be no change in how these hospitals provide integrated end of life care through a pathway. Nonetheless, the standardisation of end of life care is arguably what led to the downfall of the LCP, and clinical teams need to find a middle ground between providing holistic, supportive care for patients and their families whilst acknowledging and avoiding the sometimes constrictive and mis-used nature of standardised, systemised care at the end of life.



### 1.3 Chapter summary

This chapter has reviewed the literature on the burden of heart failure in the UK, and its implications for service provision and the patient experience. The epidemiology of heart failure demonstrates the contested nature of heart failure diagnosis and prognosis, and the variability of service provision, which sets the context for the overwhelmingly negative experiences of end of life care for patients with heart failure and their families. The literature highlights the problematic nature of end of life care in heart failure, including issues surrounding definitions of palliative care and end of life care, the recognition of the patient who would benefit from a palliative care approach, communication of a diagnosis and prognosis, comorbidities, coordination of care, identification of patients in the last few days of life, and questions over the most appropriate model of palliative care for those with heart failure – all of which can result in poor quality of life and a failure to achieve a ‘good’ death. However, little is known about the source or root cause of these challenges and problems, and in particular little is known about the way the dying phase is identified and communicated to patients, and a lack of understanding about the management of transition points from diagnosis to death at the interface between patients, family members and clinicians. There is an urgent need to understand the experiences of patients, their families and clinicians in planning for and managing end of life care. Thus this study seeks to explore these experiences for those at different stages of the disease trajectory, from the viewpoint of patients, carers and clinicians.

The preceding literature review identifies several strategies, service initiatives, and service reorganisations to address some of the problems and challenges that have been identified. A particular example of a service development involves the use of care pathways for patients with heart failure. The preceding review has identified the fact that little is known about the uptake of the Liverpool Care Pathway for the Dying Patient. Thus the following chapter presents a systematic review on the uptake of the Liverpool Care Pathway.

# Chapter 2 Assessing the uptake of the Liverpool Care Pathway for dying patients: a systematic review

This systematic review aimed to examine whether the well-known end of life care pathway, the Liverpool Care Pathway, was utilised for those dying of heart failure – and if so, how often it was used, and why. The rationale for this review emerged from initial stakeholder involvement and subsequent interviews (for the primary qualitative arm of the thesis) with clinical participants who highlighted that while the Liverpool Care Pathway was currently adopted at the study site, there were a number of frustrations concerning two of the key aspects of this study, namely, the identifications of the end of life phase and its relationship with end of life care planning. Interview data (Chapter 4) suggested weaknesses in the LCP for patients with heart failure because of challenges in identifying the end of life phase for this patient group, which required difficult judgements about the applicability and timing of the LCP. A subsequent literature review demonstrated there was very little empirical evidence about the Liverpool Care Pathway, in particular how often the pathway is used for patients dying of heart failure, or about reasons for uptake (or lack thereof). Thus the systematic review aimed to provide a national and international assessment in order to inform understanding about the identification of the end of life phase, and its relationship with end of life care for planning for patients with heart failure. This chapter reports on both the methodology used for this systematic review and its findings.

## 2.1 Introduction

Improving care of the dying in all clinical settings is now regarded as a major national priority in the UK[159]. In 2011, there were over 480,000 deaths in England and Wales[160] and in 2010, 53% of deaths occurred in hospital[161]; the most common cause of death in England and Wales being ischaemic heart disease, followed by stroke and cancer (the commonest being lung cancer) in 2010[162]. Despite recent Department of Health guidelines specifying the need to provide 'whole person' palliative care, many dying patients and their carers report low levels of comfort and satisfaction with care received[79]. Although advances have been made in cancer related end-of-life care, fewer improvements have been seen in non-cancer care with the consequence that patients with non-cancer related terminal illness often report discontent with care at the end of life[141], defined by the Department of Health as the last year of life[71]. Many service initiatives underline the importance of choice of place of death; despite this, only 21% of the 71% of patients who wished to die at home actually did so in 2011[141]. Historically, medical care has focussed on relieving biomedical symptoms caused by illness and this can lead to tensions between meeting the medical and physical needs of patients at the cost of psycho-social and spiritual aspects of care. Many individuals and their families report poor experiences of psychosocial care and communication breakdown when nearing the end of life[77, 163]. Sub-standard communication denies the patient and family the opportunity to plan for the end of life and to have their wishes discussed and enacted.

In recognition of these challenges, many attempts to integrate physical and psycho-social care have occurred with the most well-known being an integrated care pathway known as the Liverpool Care Pathway for the Dying Patient (LCP). This was jointly developed in the UK by the Marie Curie Hospice Liverpool and the Royal Liverpool University Hospitals in 2003 as a paper-based tool to support health care staff when caring for patients dying of cancer in hospitals[146]. It has now been expanded to include all dying patients, regardless of diagnosis, and has been implemented via local initiatives across the world (for example, Australia[164], Italy[143], Singapore[165]) in both primary care (including care provided by general practitioner (GP) practices including nursing homes and community care), and secondary care (including emergency care and specialist hospital care). This includes settings as diverse as renal care, nursing homes, and burn injury units. The LCP provides a framework for structuring and co-ordinating multidisciplinary care for the last 72 hours[166] of life, and expedites audit by standardising the monitoring of patient needs, symptoms and care. The tool includes guidance on physical aspects of care such as comfort measures, anticipatory prescribing, discontinuation and review of interventions and treatment regimes, and psychological and

spiritual aspects of care which draw attention to, and enact, the wishes of patients and their families where possible. In the UK, the LCP is referred to by the National Institute of Clinical Excellence (NICE) Guidance on Supportive and Palliative Care (2004) as an example of good practice[121], and integrated into the Gold Standards Framework in order to deliver the best possible care for those approaching the end of life. The Department of Health End of Life Care Strategy[71] (2008) specifically encourages commissioners and providers to ensure the availability of an end of life care pathway in acute hospitals, citing the LCP in particular, and Primary Care Trusts (PCTs) are “therefore strongly recommended to ensure that the LCP is adopted and its use audited in all locations where people are likely to die” (pg 67). Gauging the proportion of patients placed on the LCP is an important quality indicator for assessing end of life care[156], and PCTs are recommended by NICE[120] to audit and report its uptake. Yet PCTs do not routinely do so and although the National Care of the Dying Audit[167] indicates that the LCP is in use in 90% of hospital wards in England, the true uptake of the LCP remains unknown. More-over, the evidence base for the content and delivery of the LCP is poorly developed[168, 169]. Evidence of the uptake of LCP would inform further work to evaluate this important tool.

Since the introduction of the LCP, improvements have been shown in symptom burden and record keeping, but fewer advances in communication levels[170]. It is possible that the LCP results in over-systemization of palliative care, which is at odds with its founding philosophy – an equal privilege administered to biological and psychosocial elements of care given to those in the last days of life. Some authors[159] suggest that a ‘tick box’ tool such as the LCP does not encourage high standards of communication between health care staff and patients and their families, and that many of the psychosocial and spiritual facets of care addressed within the tool should be discussed with the patient and family much earlier than the one to two days before death that the LCP is intended for. What is unknown is whether these potential challenges impede the use or uptake of the LCP.

The LCP is based on evidence concerning cancer-specific palliation, and has been retrospectively modified for use in other diseases. There is acknowledgment that a clinical judgement of dying is difficult, especially in non-cancerous illnesses with an unpredictable trajectory[72]. Often, comorbidities such as diabetes and heart disease exacerbate symptoms and challenge the predictability of a dying trajectory[114, 171]. It is significantly more problematic to predict a dying trajectory for those suffering from non-cancerous illnesses such

as heart failure and chronic obstructive pulmonary disease[72], due to these diseases being characterised by peaks and troughs in symptoms and functional ability. Thus, many dying patients do not meet the requirements for entry onto the pathway, and those that do may not receive optimal disease-specific care. To further complicate the picture, many patients with cancer nearing the end of life may not meet the set conditions for placement on the pathway[72], although the true proportion is unknown, and no clear alternative seems to be specified. Assessing uptake of the LCP is the first step to establishing how suitable the tool is for those in the last days of life and why it is not routinely used in some areas, despite its strong (cancer-specific) evidence-base.

As noted earlier, the LCP has been adapted for use in non-cancer care but little is known about its utility or uptake in these settings. Thus the review sought to quantify LCP uptake in any setting. Accordingly, the aim of this study was to systematically review evidence of the eligibility, uptake and non-uptake of the LCP in any clinical and domiciliary setting. More specifically, the study aimed to provide a description of (i) the settings in which the LCP is routinely used, (ii) the proportion of patients eligible for the LCP in each of these settings, (iii) uptake of the LCP (at the patient level), (iv) reasons for non-uptake (at the patient level), (v) reasons for non-uptake of the LCP (at the level of the clinical setting).

## 2.2 Methods

### 2.2.1 Search Strategy

We (Rachel Stocker and Helen Close) sought to identify research which provided information on the uptake of the LCP from any published source. When first investigating the topic an initial search was performed combining the term “Liverpool Care Pathway” with terms surrounding uptake and use in cancer and non-cancer settings, however this generated very few results. It became clear that due to the manner in which these specific data were included in published articles, the search strategy should be expanded to simply “Liverpool Care Pathway”, as a specific phrase contained in any part of the search result including title, abstract, keywords, or full text.

A comprehensive search of healthcare literature was conducted incorporating data from 1990 to July 31<sup>st</sup> 2012 using MEDLINE, Embase, CINAHL, Cochrane Database of Systematic Reviews, and PsycINFO. In addition grey literature was searched with the same term of “Liverpool Care Pathway”, including CareSearch (caresearch.com.au), Google and Google Scholar searching,

and hand searching of library resources. Inclusion criteria were simply that the study must provide information concerning the proportion (actual numbers or percentage plus a denominator) of dying patients placed on the LCP, in any primary or secondary research study regardless of study design. All retrieved citations were reviewed independently by RS to assess eligibility according to inclusion criteria. A second researcher (HC) independently reviewed the titles and abstracts retrieved using the search strategy and verified the data extracted from the studies. References contained within studies meeting inclusion criteria were hand searched where present. Data extraction focused on the uptake of the LCP, disease group, geographical setting, clinical setting, gender mix, age range, and reasons for inclusion and exclusion.

### 2.3 Results

Use of the LCP was examined as a primary outcome in only one study[72]; the remainder reported use as descriptive audit data secondary to other outcomes or as an illustrative statistic.

After a comprehensive literature search, 229 articles were identified. After removing duplicates (n = 136), 93 articles were identified; 90 from database searches and three from grey literature. Titles and abstracts were independently screened by RS and HC and 41 full texts retrieved for further evaluation. Where results were included with no denominators (i.e. number of case notes and number of patients placed/not placed on LCP), authors were contacted where possible to access these data. From the screening process, 17 studies from January 2005 - July 31<sup>st</sup> 2012 were identified as meeting inclusion criteria. All study designs were described as a form of baseline audit, of these, n=2 were pre-post test designs. No studies focusing solely on heart failure were noted.

Please refer to the Appendix, item 1 (Table 6) on page 220 for a table describing study characteristics and data extraction.

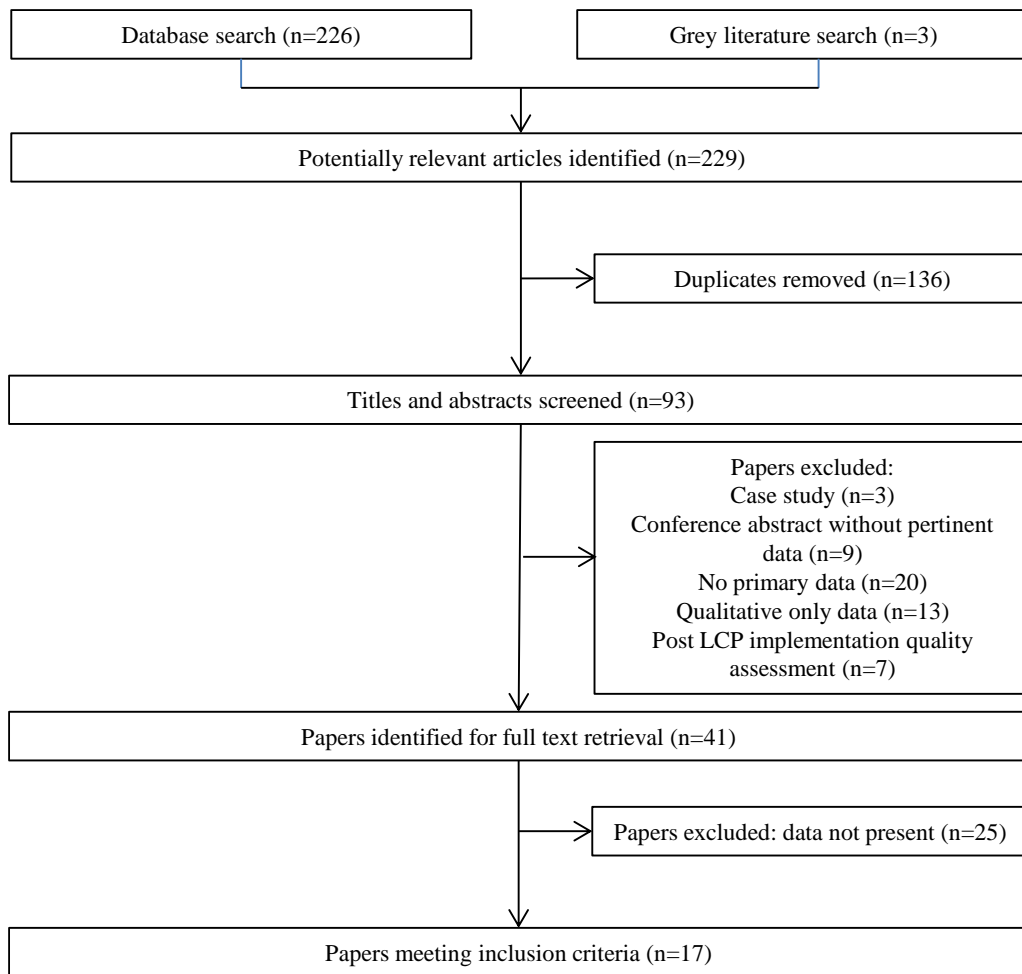


Figure 6 Study flowchart showing inclusions and exclusions

Of a total of 17 included studies, three international studies (Australia, Iceland, Holland) were identified, the rest being UK-based. Where reported (n=2), studies presented an age range of 21-103 years. Three studies reported mean age, collectively 80.5 years, while gender mix was around equal where reported (n=5). A total of 11 studies reported on the use of the original LCP, while 5 studies on a modified LCP. The LCP was used in the care of patients with a range of diagnoses including malignancies, dementia, burn injuries, and renal failure; cases were largely non-cancer although diagnosis was only reported in 10 studies. A broad range of clinical settings were represented including primary care (including domiciliary care) (n=1), secondary care (hospital and specialist care) (n=13), residential care homes (n=3), and hospices (n=4).

The number of patient case notes (clinical documentation) assessed ranged from 19 to 44256 (mean = 4217.1). The number of patients placed on the LCP ranged from 6 to 12647 (mean = 1002.9), and the number of patients dying without the LCP in place ranged from 7 to 31609 (mean = 3214.2). Taking all studies together, a total of 47.4% of dying patients were placed on the LCP although the proportion of those eligible, i.e. entitled to be placed on the LCP due to their presenting symptoms, or ineligible, is unknown. Further breakdown by primary diagnosis was not possible due to most studies not providing data on the use of LCP by diagnosis of patient. Further breakdown by care setting was possible, excluding one study[170] which presented results from multiple care settings and did not differentiate LCP uptake between these settings, and one study[152] which did not provide numerators and denominators (only percentage uptake); LCP use in hospice (n=4) was 78.9%, in care homes (n=2) was 32.9%, and in secondary care (n=11) was 23.3%. Only one study[72] provided complete data on which to assess the proportion of all dying patients eligible for the LCP; in this study 58% (236 of 407) were eligible for the LCP, of whom 81% had a cancer diagnosis and 51% non-cancerous diagnoses. In this study, 61% of patients died without the LCP in place, the majority (83.2%) of whom had a non-cancer diagnosis. A total of 236 patients were deemed eligible to be placed on the LCP, however 79 of these eligible patients died without the LCP in place.

Where reported (n=3), the mean length of time patients spent on the LCP was 45.05 hours. Five studies presented median length of time on the LCP, 33 hours, 33 hours, 29 hours, 38.75 hours, 63 hours (mean 39.35 hours). The latter study[170] indicated that the median duration of the LCP was longest at home (from 5 hours to 14.5 days) and shortest (from 1 hour to 3.7 days) in the hospital setting. The National Care of the Dying Round 2 audit presented a breakdown of median duration of LCP by diagnosis; those dying of cancer spent 30 hours



(inter-quartile range 12-65 hours) on the LCP, those dying of non-cancerous causes spent 35 (inter-quartile range 12-84 hours) on the LCP. One study[172] reported on 2 patients whose time on the pathway was much longer than other studies. One of these patients was placed on the LCP for three days, and then removed as no longer fulfilling the LCP criteria, only to be returned to the LCP two days later, remaining on it for another 12 days until death. The other patient had suspected brain metastases but was too ill to investigate and remained on the pathway for 10 days before his death. The remainder of studies did not report remission rates.

No specific information was given about the reasoning behind non-uptake of the LCP at either the ward level or the patient level, although five studies[172] [173] [174] [72, 175] presented possible reasons for LCP exclusion, including unexpected/unpredictable death[172] [173] [175], low levels of LCP training[172] and training schedules that failed to respond to high staff turnover[174], staff shortages[174] and patients simply not judged as fulfilling LCP criteria[172] [173] [72]. However this information was not gathered or analysed as part of a systematic collation in each of these five studies, only marked in the study discussions. Six studies[152, 167, 174, 176-178] reported the presence of LCP facilitators, including the National Care of the Dying audits who reported secondary care facilitators in 47% (2006/07), 39% (2009/09), and 52% (2011/12) of sites included in the audits respectively. The remaining three studies (two reporting on care homes[174, 176] and one[177] on secondary care) reported a facilitator throughout the study period, and in these three studies combined, the LCP was used for 38.9% of dying patients.

## 2.4 Discussion

The purpose of this review was to systematically identify the uptake of the LCP in any published study, in any setting and for any diagnosis/es. The LCP is a well-known and well-regarded palliative care tool and this study confirms that it is used in a variety of geographical and clinical settings. However, this study provides evidence that only half of all dying patients in studies of the LCP are placed on the pathway despite its availability. This raises questions not only about clinicians' levels of knowledge and awareness about the LCP, but also the suitability and applicability of this pathway. It is possible that clinicians are apprehensive or unaware of the utility of the LCP, but equally possible that they deem the LCP to be inappropriate for patients for unknown reasons. Our findings suggest that eligibility criteria were skewed towards patients with a cancer diagnosis but reasons for this remain unclear, and many studies did not include diagnosis, alluding to the possibility that multiple pathologies were contributory factors in each death which may complicate prognostication.

Further research is needed to examine the process of decision making when considering a patient for LCP delivery and about the quality of care experienced by those not placed on the pathway.

This study is the first to systematically review the literature on LCP uptake. The majority of included studies were of poor methodological and reporting quality and with one exception, did not systematically report the number or characteristics of patients eligible or using the LCP, or reasons for non-uptake. As the National Care of the Dying audits demonstrate, many wards have not introduced the LCP, with an estimate of 44% of wards participating in the first round of the audit using the LCP, and 66% in the second round. The reasons for non-introduction are uncertain at present. More robust reporting systems would allow for better understanding of the clinical contexts which welcome LCP or otherwise and might ultimately lead to the development of more responsive, context-specific pathways of care. LCP use was found to substantially differ between care settings, being used in the care of the dying for over three quarters of patients in the hospice setting, and only for one quarter of dying patients in secondary care. The percentage of patients placed on the LCP may have differed substantially if the second National Care of the Dying audit[152] had provided numerators and denominators.

We were unable to identify any prospective/retrospective systematic exploration of barriers or facilitators of LCP use. Five papers highlighted possible barriers and facilitators but there was no systematically collected evidence to support them. Pathway facilitators, availability of speciality palliative care teams, and high levels of structured education and support have been shown in other studies to increase end of life pathway compliance levels[168].

We recognise the limitations of a systematic review when seeking to understand complex reasons for uptake/non-uptake of the LCP. However, it is important to review the evidence in its entirety in order to inform a subsequent prospective study to examine uptake more closely. The systematic review uncovered very little data on eligibility at the patient level (only one out of 17 studies providing these data) and no empirical studies on non-uptake at the level of the clinical setting. Subsequently the appropriateness of the LCP eligibility criteria and reasons for clinical 'buy-in' remain unanswered questions which urgently require investigation.

Questions have been raised about the suitability of benchmarking quality based on the proportion of patients placed on the LCP. It can be argued that associating high-quality care with high proportions of dying patients placed on an LCP is an oversimplification, not least

because high quality LCP documentation may or may not be associated with high quality care. In addition, many patients either do not meet the LCP eligibility criteria or may receive high quality (non-LCP) care. In order to be placed on the LCP, a diagnosis of 'dying within 1-2 days[72]' must be made by the clinical team. Our findings suggest that this is not straightforward; in contrast with cancer, it can be more problematic to predict dying in diseases with an unpredictable trajectory such as organ failure and in one study, unpredictable death was identified as a reason for low LCP uptake. Consequently, the entry requirements specified by the LCP may be inappropriate for those dying of some non-cancers. The aim of the Gold Standard Framework is to provide a 'gold standard' of end of life care for all dying patients, with the LCP the only pathway specifically recommended for use; however, our study suggests that this may be an unattainable goal for variable disease trajectories and their impact on LCP eligibility. Despite attempts to develop disease-specific pathways using the LCP as a starting point (for example the BM-LCP[173]), these have thus far failed to reach clinical practice in a systematic way. There is an urgent need for prospective studies to evaluate the impact of the LCP on the quality of care for patients with cancer and non-cancer diagnoses.

Factors which clinicians may take into account are the wishes and needs of a patient. Introduction of an LCP requires open and honest discussion about death and the LCP might be seen as a 'one way street[159]' in which there is clinical reluctance to place patients on it if they are not 100% sure they are dying. Similarly, media reports of care pathways involving morphine and other sedating drugs may condemn this systemisation of care by associating it with euthanasia[179]. The stated aim of the LCP is to improve the process of care, rather than bring about a particular outcome and as such, it is possible for patients to recover sufficiently to be removed from the pathway and enter a chronic illness maintenance pathway. However the true extent of remission is unknown.

Complications surrounding attitudes and communication of death related issues are persistent and enduring. Death is regarded by many as 'the last taboo', with anxiety, fear, and misinformation continuing into the 21<sup>st</sup> century. The National Council for Palliative Care set up the 'dying matters' coalition with the long term aim of empowering people to talk about and engage with death and dying in a more confident and well-informed way[159]. Perhaps in future, this could include discussion of the LCP and its application.

## **2.5 Conclusion**

This systematic review illustrates that less than half of dying patients are placed on the LCP, possibly due to eligibility requirements and inadequate staff training and support. The

implications of this for the quality of palliative patient care (with or without the LCP) are unknown. There is an urgent need to investigate the decision making process involved when deciding on the LCP as a care plan, particularly prospective studies assessing prognostic decision making, communication of the need for an end of life pathway, the decision making process surrounding patient eligibility criteria for entry onto the LCP, and the actual uptake of the LCP for eligible deaths. Further research should also elucidate the outcomes for those who do not receive this package of care (eligible or not), and the suitability of the LCP itself for dying patients (particularly those with non-cancer diagnoses).

# Chapter 3 Methodology and Methods

This chapter details the methodological approach to the study, including a detailed consideration and critical analysis of grounded theory. A rationale is given for the choice of methodology and methods, sampling strategy, and modified constructionist grounded theory data analysis, with a particular focus on the co-production of data in this study. The research procedure including ethical approvals, recruitment, and data collection are described and justified.

### 3.1 Research question and aims

This study aimed to examine the perceptions, attitudes and experiences of end of life care for those with a diagnosis of heart failure, their carers, and their clinicians. To explore this in depth, the primary research aim was *to explore patient, carer, and clinician experiences of prognostication and the transition point from palliative and end of life care in heart failure*.

Particular research questions were:

1. How was the process of prognosis-giving experienced by patients, carers, and clinicians?
2. What factors do clinicians take into account when deciding when the transition from active to palliative care should occur, and how do they communicate this?
3. What is the experience of the consultation interaction between patient, carer and clinician?
4. How do patients and carers understand information given about their condition (during appointments and from any other source), and how do they construct meaning from this information?

These questions were intentionally exploratory, in order to understand if, and how, palliative care communication occurs between clinicians and patients/carers.

### 3.2 Philosophical approach

The literature suggests that researchers should consider what they bring to the research 'table', including prior experience, judgements, and ethical and political stances[180], as this shapes the formulation of research questions and the manner in which we go about answering them. When commencing this research, and indeed any research study, I was aware that as a researcher I should define and explicate my own philosophical assumptions which might influence the qualitative research I was about to embark upon. This is the nature of research philosophy.

To this end, Crotty[181] suggests that researchers should put 'considerable effort' into four questions when embarking upon a research study; What methods are proposed for use?, What methodology would govern the above choice and use of methods?, Which theoretical perspective lies behind this methodology? And; what epistemology informs this theoretical perspective?

Crotty[181] goes on to define each question further (reproduced verbatim);

*“Methods: the techniques and procedures used to gather and analyse data related to some research question or hypothesis*

*Methodology: the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes*

*Theoretical perspective: the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria*

*Epistemology: the theory of knowledge embedded in the theoretical perspective and thereby in the methodology.”*

Whilst each single element of research informs the other in some way, one can distinguish a hierarchy within these four elements. Epistemology, as a theory of knowledge, directs and informs the choice of theoretical perspective. Methodologies are informed from within a theoretical perspective, and methods are informed by the chosen methodology.

I found these questions not only imperative to attempt to answer early on in my research study, but also to revisit throughout the study especially during analysis. The answers lay partly within the research question and partly within myself as a researcher. My research questions were intended to be exploratory, bearing in mind the relative lack of research on the topic particularly using longitudinal methods. I wanted to produce a ‘thick’ description of the experiences of prognostication for clinicians, patients and carers. As such I did not feel that quantitative methods would provide me with the tools to fully explore these questions. Quantitative methods are more helpful when seeking to compare data in a systematic way, and/or make generalisations extensively within and from a specific population or between populations[182]. Through my literature review I was already aware of quantitative studies which demonstrated differences in heart failure mortality, morbidity, self-reported concordance rate of prognostic communication between patient and clinician, and proportions of patients with HF who accessed palliative care (amongst other services), and others. I felt that in order to illuminate and expand on the reasons for these results, and to explore from bottom-up experiences of prognostication, qualitative methodology and methods would be inherently more useful. My hierarchy of research for this study therefore looked like Figure 7;

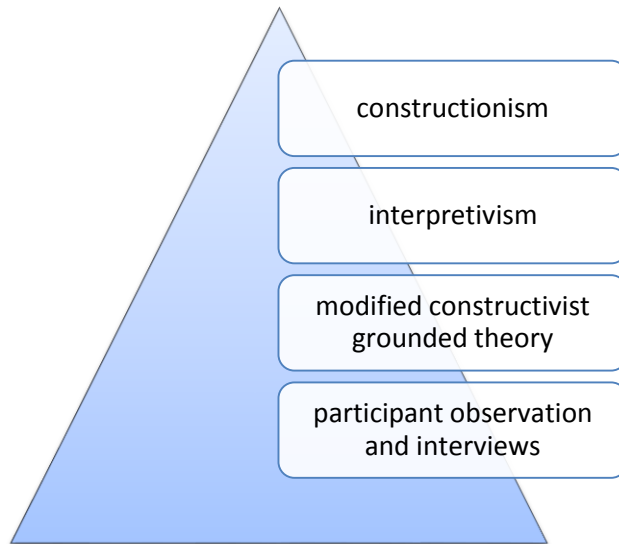


Figure 7 My research paradigm

### 3.2.1 Epistemology: constructionism

Constructionism has been defined as;

*“the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context[181].” (pg 42)*

As the word suggests, meaning is not objective, not to simply be discovered, but is constructed by human beings as they engage with the world that they are interpreting. Objects in the world may be ‘pregnant with potential meaning[183]’ but actual meaning – as much as meaning can be determined – exists only when human beings engage with them. This does not mean, on the other hand, that meaning is simply subjective. Constructionism posits that meaning is not created, but is constructed, as a result of individuals and groups working and re-working with the world and objects contained within it. In this sense, objectivism and subjectivism are brought together.

### 3.2.2 Theoretical perspective: interpretivism

Interpretivism, as a theoretical perspective, is embedded within the wider epistemology of constructionism. It is constituted of a set of assumptions which are concerned with the way the word is shaped – and therefore using different theoretical perspectives to view the world shape different ways of researching the world[181]. As a perspective, interpretivism is very different to positivism in that it is concerned with attempting to understand and explain human and social reality – as opposed to revealing an objective, detached, universal reality.



In other words, interpretivism “looks for culturally derived and historically situated interpretations of the social life-world[181]”.

### **3.2.3 Choice of constructionism and interpretivism for the current study**

The choice of constructionism and interpretivism for this study seemed to align themselves with the research question for this study. The experience of communicating and experiencing palliative and end of life issues in heart failure is inherently different between each clinician, patient, and carer. The research literature revealed many different clinician practices and attitudes towards palliative and end of life care in heart failure, and subsequent patient outcomes both psycho-social and clinical. Clearly, every single participant in the study might have had a different viewpoint, and constructivism and interpretivism allows for this.

As interpretivism is embedded within constructionism, interpretivism also lies behind the choice of research methodology. In this study, a constructivist grounded theory methodology was chosen to guide and inform study development, which was later modified according to the needs of the study imposed by the co-production of data, the need for reflexivity and the rationale for a systematic review (Chapter 2) which then informed further data analysis. Section 3.3 explains and discusses this choice further.

## **3.3 Methodology**

### **3.3.1 Grounded Theory**

This section describes the tenets of grounded theory and critically analyses the application of modified constructivist grounded theory methodology in this study.

#### **3.3.1.1 Choice of Grounded Theory**

The choice of (a version of) grounded theory for this research project was based on the flexibility and viability of the method for the research aims and objectives, the explicit guidance this methodology offers for data collection and analysis, and the approach providing the ability to go beyond description and into hypothesising, conceptualising, and theorising derived from participant experiences[184]. In this sense, a theory being ‘grounded’ refers to developing a theory from the bottom (ground) up, directly emerging from the data source and being open to unexpected directions, rather than top-down, which would involve testing a pre-conceived hypothesis, as is the case for positivism.

The grounded theory itself is posited on an individual’s interpretation of their reality and in this case, a phenomenon (heart failure) and its impact on their interpretation. Employing a grounded theory approach to understand a phenomenon provides, as Glaser and Strauss

argue, a systematic analytical method with its own internal logic enabling the researcher to generate theory, which consequently provides abstract theoretical explanations of social processes[185].

Gelling maintains that grounded theory is particularly useful for researchers working in health service research projects, who are interested in understanding more about the problems of 'the provision of care for relatives alongside that of the patient[186]'.

### **3.3.1.2 *Origins of Grounded Theory***

Grounded theory was first developed by American sociologists Barney G. Glaser and Anselm L. Strauss. At the time of writing their seminal book 'The Discovery of Grounded Theory[187]' in 1967, research in the social and health sciences was characterised by positivism with primarily quantitative methodologies designed to test a pre-determined theory against data to be collected – '*a priori*'. Qualitative research was then seen as unsystematic, biased and anecdotal[185], occupying a sub-ordinate space within the body of research methodologies. Glaser and Strauss contended that to enter into research with a pre-conceived expectation of the results was deductive rather than inductive, and so could never adequately provide rich data surrounding any given phenomenon as the presuppositions and judgements of the researcher could obfuscate the data collection and subsequent analysis. In order to distinguish grounded theory from quantitative positivistic paradigms popular at that time, Glaser and Strauss provided detailed systematic guidance to conduct grounded theory that would provide validity as well as concrete, stepped guidance to quantitative methodologists.

### **3.3.1.3 *Methodological Influences on Grounded Theory***

Grounded theory itself derives its theoretical underpinnings from pragmatism and symbolic interactionism. Informed by interpretivism, symbolic interactionism "assumes human beings construct and reconstruct the meaning of reality in a constant interaction with the self and others[188]" (pg 196). The nature of reality is therefore fluid and differs for each individual depending on their internal and external interactions with the world as they perceive it. This lies at odds with the positivist tradition of one universal 'truth' of the nature of reality. However, Glaser has not entered into the conversation surrounding the comparison of grounded theory to other methodologies/philosophies such as symbolic interactionism, as he dismisses the applicability of other positions in his belief that adopting a parallel perspective of this sort dilutes and reduces the broader potential of grounded theory[185, 189]. This precipitated the theoretical 'split' from Strauss.

The question of philosophical influences on grounded theory led second-generation grounded theorists to develop methodological frameworks for grounded theory methods underpinned by various philosophies. It is argued that grounded theory itself, whilst still rigid in its essential methodological stance and procedures, is fluid enough to allow these influences whilst still maintaining and being worthy of the label of grounded theory. However influential scholars in this area, such as Charmaz, still consider that there is a set of methods essential to grounded theory research design that must be used in order for the final product to be considered as such[190].

#### *3.3.1.4 Versions of Grounded Theory*

Many scholars[185, 188, 191] argue that there was, and still exists, a significant split between Glaser and Strauss in the early 1990s with regards to the finer points of grounded theory methodology. This split has led to many defining grounded theory as either ‘Glaserian’ (classical) or ‘Straussian’, with later versions such as constructivist grounded theory developed by other researchers. The Glaser-Strauss split centres on the use of literature, specifically before data collection, and the use of defined ‘coding paradigms’. In the case of literature reviews, Glaser considers that if a review were to be completed before data collection and analysis it would jeopardise the ability of the researcher to be free and as open as possible to the discovery and emergence of concepts, problems, and interpretations from the data. Creswell[192] challenges the Glaserian perspective of entering the field ‘knowing nothing’ by suggesting that open mindedness does not equate to blank mindedness, and researchers still require knowledge of the general topic area, pertinent research questions, and perspectives which contribute to the clarification of the research focus. This is illuminated further by Glaser himself in 1978[193], emphasising the message to be taken for the prior use of literature is that ‘it is vital to read, but in the substantive field different from the research’. I found Creswell’s stance on grounded theory more appropriate for the current research project, particularly as I felt Glaser’s theoretical imperative of leaving a literature review to the very end of the research project to be both pragmatically and theoretically unmanageable. Conducting research in the NHS requires a literature review to successfully pass ethical approval. Pragmatically, a lack of prior literature review would also make it nearly impossible to gain research funding. Additionally I was aware of the imperative to make an original contribution to research, which would only be possible with prior knowledge of the existing literature. I felt that a full literature review provides a scientific and ethical rationale for the project, and to that end completed a literature review to assess the current body of research in end of life care in heart failure, including areas requiring further study. Furthermore, as part

of the current thesis, a systematic review was undertaken to assess the uptake of the well-known end of life care pathway, the Liverpool Care Pathway. As discussed further in Chapter 2, the rationale for this was borne from interviews with clinicians who described frustration and a lack of knowledge surrounding the use of end of life care pathways for those with heart failure. As such, this process was iterative – borne from data collection with clinicians, but again requiring a literature review in order to explore this important finding emerging from the data.

Strauss later went on to develop his own work with Juliet Corbin in their 1990 text “*Basics of Qualitative Research: Grounded Theory Procedures and Techniques*[184]” and advocated for early literature review – flagging the possibility of students becoming ‘enamoured with a previous study (or studies)’ which may detract from their ability to analyse and generate knowledge, recommending that the resulting literature review is used with caution. Strauss, and later Charmaz, support the use of a literature review to inform an upcoming research project provided it does not prescriptively direct research design and analysis. Strauss also advocated for the use of coding paradigms, including the systematic search for causal conditions, context, action strategies, and consequences. Glaser rebutted Strauss & Corbin’s work intensely, stating that these methodological changes were not grounded theory as it was intended and would simply provide a general qualitative analysis of data.

#### 3.3.1.4.1 Constructivist Grounded Theory

One of the more recent and popular versions of grounded theory used today is constructivist grounded theory, developed by Kathy Charmaz in 2005. Charmaz advocates a social constructionist perspective, embracing differing realities and the complexities lying within each person’s life-world. Creswell describes this type of grounded theory as;

*“[lying] squarely within the interpretive approach to qualitative research with flexible guidelines, a focus on theory developed that depends on the researcher’s view, learning about the experience within embedded, hidden networks, situations, and relationships, and making visible hierarchies of power, communication, and opportunity[180].” (pg 87)*

Charmaz goes on to suggest that inflexible coding frameworks, jargon, and conceptual maps employed by Straussian grounded theory detract from the intention of grounded theory itself, and represent a move back towards a positivist paradigm. Using Strauss and Corbin’s heavily prescribed methods of conducting grounded theory research may actually “serve more to befuddle researchers than to escort them through this intricate and exciting, although admittedly intimidating practice of applying GT to research[194].”

Upon reading Charmaz' work on constructivist grounded theory and comparisons between this and other versions of this methodology, I agreed with her argument that Strauss & Corbin's use of coding paradigms and relational statements assume the existence of an external reality – which was at odds with my own, interpretivist theoretical perspective. I also agreed with her statement that “data do not provide a window on reality... rather, the ‘discovered’ reality arises from the interactive process and its temporal, cultural and structural contexts[195]” (pg 524). Consequently, data produced in a constructivist grounded theory study can elicit multiple meanings as the researcher is immersed in the data, using active coding language to keep the participant's lives in the foreground. This meets the ethical obligation to ‘describe the experiences of others in the most faithful way possible[196]’ (pg 540).

To that end, I decided to use a modified version of constructivist grounded theory (further discussed in section 3.3.2), as I felt it fit both with the interpretive nature of the research questions and aims, and my own personal philosophical stance as a researcher.

#### ***3.3.1.5 Procedures of Grounded Theory***

Whilst there are numerous philosophical influences on different versions of grounded theory, the methods of grounded theory analysis remain essentially the same. In essence, to analyse data collected with grounded theory appropriate methods, one must read and re-read the text (usually transcripts of dialogue and any field notes), and discover/label variables (categories, concepts, and properties) contained within, and their interrelationships. In order to openly perceive and discover variables a researcher must enter the research with an open mind and no preconceived hypothesis gained from the prior literature or their personal experiences. The ability to do this increases the ‘theoretical sensitivity’ of the research and is an important element of grounded theory procedure.

### 3.3.1.5.1 Stages of Constructivist Grounded Theory analysis

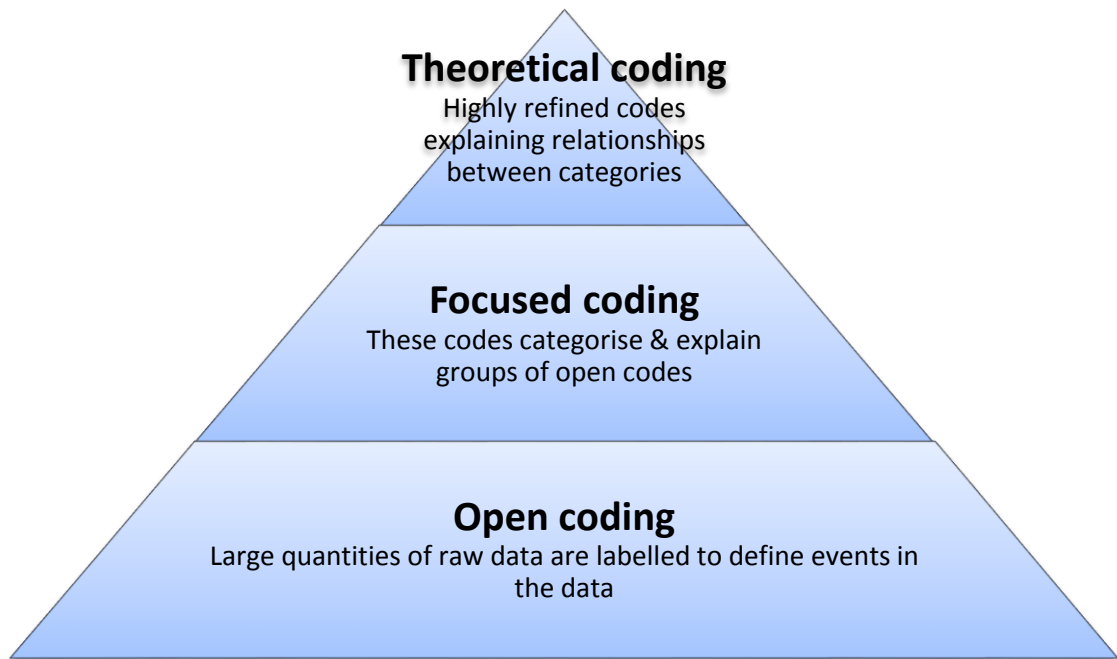


Figure 8 Hierarchy of grounded theory coding stages

### 3.3.1.5.2 Coding

Grounded theory coding “generates the bones of analysis[185]”. Codes can be described as the first, pivotal link between collecting data and developing an emergent theory – defining what appears to be happening in the data. In practical terms, coding allows the researcher to condense large bodies of data into smaller, more manageable units. Specific coding stages are outlined below.

### 3.3.1.5.3 Initial (open) coding and categorisation.

Open coding is the first step of data analysis, and can be briefly described as the categorisation of segments of data with a short name that simultaneously summarises and accounts for each piece of data. Each line, sentence, or paragraph is read and labelled in order to answer the question; “What is happening here?”. Micro-analysing in this way forces the fracturing of the substantive data (interview transcriptions in this case)[194], and ‘opens up’ the inquiry[197]. Codes are conceptual labels, both abstract and concrete. These codes, therefore, show how the researcher selects, separates and sorts data to begin an analytic account[185]. An example of open coding in this study can be found in the Appendix, item 2 on page 226.

#### 3.3.1.5.4 Focused coding

Focused coding is the second step of analysis, and is the process of relating the open codes to each other. The researcher seeks out causal relationships, context, intervening conditions, action strategies, and consequences. Focused codes are more conceptual than open codes, as the researcher moves towards selecting codes which synthesise and explain groups of open codes. As such, the most significant and/or frequent codes identified during open coding are incorporated into focused codes. This involves making a decision as to which initial codes make the most sense to categorise the data “incisively and completely[185]”. An example of focused coding in this study can be found in the Appendix, item 2 on page 226.

#### 3.3.1.5.5 Theoretical coding

Theoretical coding is the final stage of coding. As open codes are the bones of the analysis, theoretical coding and integration becomes the resultant skeleton. The researcher selects one particular category to be the core category, and relates all other categories – developed previously during focused coding – to this core category. This explicates relationships between categories to become hypotheses, to be integrated into a theory, and reintegrates the previously fractured (during open coding) story.

#### 3.3.1.5.6 Theoretical sampling

Theoretical sampling is an on-going element of grounded theory analysis, beginning from the first stages of open coding right through into the final generated theory. Glaser and Strauss[187] (pg 45) describe this as “whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges”. The researcher therefore has the ability to re-enter the field if necessary (and feasible) to sample further in a more direct manner, as prescribed by the emerging theory. This maximises opportunities to explicate focused and theoretical coding more, especially to determine the limits and variance within each category and the properties contained within.

#### 3.3.1.5.7 A note about coding

An important element of interview and other methods using discourse data to be considered is that the researcher must be aware of the power of language and its ability to confer meaning on observed realities. Our codes arise from the participant’s language, and indeed the language of the researcher. The codes become the researcher’s codes, constructed from their language and their interpretation of the data. This may seem at odds with the importance placed on researching with no pre-conceived concepts in grounded theory.

However, the process is interactive – from the interaction when collecting data, to the repeated interaction with the data whilst studying and re-framing participant’s statements in the mind’s eye. Paying close attention to coding – “Study your emerging data[193]” increases the likelihood of understanding a participant’s tacit meaning and subsequently forming relevant, applicable representations of the data. Further reflections about co-production of data, and reflexivity in data collection, are located in section 3.3.2.

#### 3.3.1.5.8 Constant comparison

Making comparisons between data (e.g. between one interview and another, and between data and emerging theory) as often as possible allows for theory to emerge. Once a theory becomes apparent, the researcher can then compare the theory to the data. Consequently, constantly comparing data with other data, and data with theory, ensures a constant iterative process, and a theory ‘grounded’ firmly in the data. Indeed, “coding starts the chain of theory development[198]” and constant comparison is an intentionally circular element of grounded theory analysis, intertwined fully with all stages of coding and subsequent theory to allow researcher sensitivity to the emerging theory.

#### 3.3.1.5.9 Memo writing

Memoing, as the name suggests, quite literally involves the researcher writing a memo to him/herself about their ideas of what they feel is happening in the data, as they collect, listen to, read, and re-read through the transcripts. The concept of memo writing was deemed vital to constructing a grounded theory by Glaser and Strauss, as they “capture the frontier of the analyst’s thinking[193]” (pg 83). Memos can therefore serve as a useful tool to construct theory, and depict the development of theory as data collection and analysis has progressed. As with theoretical sampling, memo writing can and should occur throughout the research process.

During this study I identified the use of audio (voice) recording to assist the writing of grounded theory memos. Recording my thoughts and feelings almost immediately after leaving the participant’s home or place of work using the voice recorder I had just used to interview them with helped me greatly to remember context, environment, and emerging theorising and ideas. I co-wrote a paper with my supervisor (Dr Close) on this novel method and the published, open access version can be found in the Appendix, item 9 on page 270.



#### 3.3.1.5.10 Saturation

During focused coding, eventually the rate of return (the discovery of new categories) diminishes and interview data no longer adds anything new to what you already know about a category. Once this occurs, coding ceases for that category.

#### 3.3.1.6 *Challenges of Grounded Theory*

Conducting a grounded theory study is extremely time consuming, by the nature of interviews, transcribing, and analysis. Others note the formulaic, prescribed method which, it is argued, may impact on creative interpretation which is one of the important principles of qualitative research. However the procedures of grounded theory provide rigour, and was developed in response to a positivistic desire for rigorous scientific procedures. To Charmaz, grounded theory must move on from its positivist origins and must incorporate many of the methods and questions posed by constructivists over the past twenty years to become a more nuanced and reflexive practice[185]. As long as the guiding principles and stages of analysis are used systematically, then it is argued that this still constitutes grounded theory practice as Strauss and later researchers would deem it to be.

### 3.3.2 **Reflections on the use of Grounded Theory**

Whilst constructivist grounded theory seemed the most appealing and logical choice of methodology for the current study, upon reflection (once data collection had concluded) it became apparent that I had in fact developed a modified version of this methodology by virtue of the longitudinal nature of my research, the discussion of emotive issues with patients and carers, and the necessary focus of my thesis on pre-determined questions about terminal illness and palliative care. The 'constructivist' element of the methodology ultimately provided data that was not merely interpreted by the researcher (as in 'pure' grounded theory) but was in fact co-produced during and in between the interactions (particularly in the intellectual and emotional spaces between interviews and observations). Whilst this co-production was of course less likely in the initial interview (and therefore the findings from these interviews would be grounded in participants' own belief and perceptions), co-production became more of a reality as a result of the longitudinal study design. This means that data was co-produced between the researcher and participants via a reflexive process in which data was a product of the dynamic interaction between the researcher's own changing interpretations and beliefs about the emerging themes[199], and in part as a result of the participants' views which might also have changed over time – at the second (six month) interview. The reflective spaces between interviews and observations were just as important in this regard for participants; patients and carers may have explored the issues raised at the

initial interview with their clinicians, or others, before the second interview – reflections which may not have occurred if they had not participated in the study. Additionally, as a researcher I was coming to the second, six month interview with ideas already formed about the individual participant and the data from the group, as a whole, from the initial interview period. This recognition is an important element of researcher reflexivity[200] – examining both oneself as a researcher, and the research relationship – in qualitative research. During data collection, I strived to maintain close attention to this reflexivity in order to protect the ‘grounded’ nature of the data, through the constant comparative method, extensive memo writing, and careful crafting of interview schedules (discussed later). However, I now recognise the extent to which data became co-produced by virtue of the longitudinal research design, data collection in later interviews, and the shared interpretation of these data. I found that there was little to no discussion of these issues in Charmaz’ work[185] on constructivist grounded theory. The tensions between the competing demands of constructivism within Charmaz’ constructivist grounded theory, and the need to establish a long-term relationship with patients and carers in order to discuss difficult topics, meant that for the current research study the approach used should most accurately be described as a modified constructivist grounded theory.

### **3.4 Research Procedure**

The previous section of this chapter detailed the choice of research paradigm and methodology – modified constructivist grounded theory – for this project. As detailed above, I chose modified constructivist grounded theory as I felt the inherent reflexive nature was the most appropriate for analysing such a sensitive topic. The current section details the research procedure of the study with regards to how and why participants were selected for recruitment. Both of these sections contain important information to fully understand data collection method choices discussed in the following section.

#### **3.4.1 Selection of Data Sites**

Having established the research area and aims, it was then necessary to identify appropriately feasible and accessible environments in which to collect data. The literature suggests that little is known about the experience of prognostication at different disease stages. Early discussions with key stakeholders suggested that an appropriate sampling location might be a cardiology outpatient department in a district general hospital since this would result in a description of heart failure experiences rooted in routine, pragmatic NHS care at all disease stages. The North East of England has among the highest incidence of cardiovascular disease in the UK,

thus a site with existing research infrastructure in County Durham and Darlington NHS Foundation Trust (CDDFT) was selected to provide a sample of patients and clinicians. Clinicians, therefore, would be working in any NHS site within CDDFT and patients and carers would be receiving care from secondary care at Darlington Memorial Hospital which is part of CDDFT.

Patient appointment observations were conducted at the Heart Failure Clinic at Darlington Memorial Hospital or in the case of home visits, at their home. Patient and carer interviews were conducted in their own home. Clinician interviews were conducted at their place of work, i.e. Darlington Memorial Hospital or general practice. The dispersal of participants in a grounded theory study can 'provide important contextual information useful in developing categories[180] (pg 150)' and a conscious decision was made not to interview patients and carers in a clinical setting so that the context of their home lives would feed into their narrative at interview.

### **3.4.2 Operationalising 'heart failure patient'**

As previously discussed in Chapter 1, heart failure is a complex and difficult diagnosis currently characterised by different physiological mechanisms. For the purposes of this research, three categories were relevant; heart failure characterised by left ventricular systolic dysfunction (HF-LVSD), heart failure with preserved ejection fraction (HF-PEF), and non-echocardiogram confirmed heart failure. The final group are usually seen solely by primary care, and are diagnosed with heart failure based on the recounting of symptoms without an echocardiogram to confirm. In Darlington Memorial Hospital, the secondary care cardiology team require that any heart failure patient being cared for within the service is 'confirmed' with an echocardiogram. A distinction between HF-LVSD and HF-PEF was not made as discussion with key stakeholders in the DMH heart failure service suggested that pragmatically they are treated as the same group. For the purposes of the present project, it is argued that those with unconfirmed HF represent a qualitatively different group with different health needs and a contrasting health care experience. Thus, this group were excluded from the study. Patients and carers were recruited solely from the DMH heart failure team. Consequently, both HF-LVSD and HF-PEF patients, confirmed with echocardiograms, were eligible to participate.

### **3.4.3 Sampling strategy**

A purposive sample was used to identify patients who satisfied the above criteria to participate in the study and provide experiences of heart failure care. The use of purposive

sampling in grounded theory research is considered useful and logical, as the researcher must gain access to individuals or groups who are the 'gatekeepers' to local knowledge and provide rich information surrounding their perceptions, attitudes, and experiences of the wider phenomenon of palliative and end of life care in heart failure. Once heart failure patients were identified from the above criteria, it was considered prudent to separate patients into three groups; newly diagnosed, stable, and those judged by the clinical team to be in the last year of life (advanced). This grouping was made possible by the heart failure nurse team who identified eligible patients and placed them into one of the three above categories. By doing so, we considered that this would allow a comparison of communication surrounding palliative and end of life care issues between the three groups, ensure a representative cross section of patients were included in the study, and allow the data to show distinctions between groups if the data showed differences.

Patients were sampled from the local Primary Care Trust, and their carers were asked to participate as part of the patient's participation (snowball sampling within each dyad; i.e. one participant, the patient, identifies the next participant – the carer). A purposive sample was also used to identify clinicians for recruitment into the study. Cardiology specialists working in CDDFT were approached in conjunction with one of the consultant cardiologists based at Darlington Memorial Hospital. GPs were approached via existing links with Durham University, and specialist heart failure nurses working in the CDDFT heart failure team were approached via the same consultant cardiologist based at Darlington Memorial Hospital. The effect of possible selection bias was seriously considered, as clinical colleagues may have been influenced by their existing links with Durham University including like-minded colleagues working in clinical research. This possibility was lessened somewhat by all consultant cardiologists working in CDDFT, and nearly all specialist heart failure nurses working in the DMH heart failure team agreeing to participate in the study. With regard to patients and carers, the specialist heart failure nurses helping with recruitment were asked to hand study information to all patients and carers unless they were deemed to pose a possible threat, in order to reduce possible 'personal' selection criteria such as concerns the patient or carer may become upset. See Section 3.4.4 for further information on the procedure of sampling and recruitment.

#### ***3.4.3.1 Theoretical sampling in this study***

The ability to re-enter the field in order to collect new data to study a particular category or phenomenon proved useful. Originally, only patients with carers were recruited into the study. However one patient with no carer expressed a desire to participate, and in interview

spoke of her change in views about palliative and end of life care once she split up from her husband. It was decided that this should be explored further, to ascertain whether or not single patients had a different experience or perception of palliative/end of life care issues. I re-entered the field and recruited two additional single patients (three in total) to explore this further. The results of this theoretical sampling can be found in the patient and carer findings section.

#### **3.4.3.2 Sample size**

Deciding an 'ideal' sample size for the current study was difficult. In qualitative research, the concept of saturation can help to specify the limit of recruitment. Saturation is defined as the point at which data analysis ceases to return any new concepts or codes – a diminishing rate of return. Once saturation is achieved, recruitment ceases. However this means that in order to be completely open to new concepts appearing in the data, sample size cannot be absolutely specified prior to study recruitment. Whilst it was imperative to adhere to saturation guidelines, the practicalities of interviewing many participants was considered as an important factor – especially considering the time limited nature of undertaking a research study and the cost implications of travelling for interviews, and the time taken to transcribe and analyse resulting data. Creswell[180] (pg 157) recommends 20-30 individuals for a grounded theory study, whilst Morse[201] (pg 225) advocates between 30-50 interviews. It was decided that for clinicians, as many interviews as possible would be set up with a minimum number of 10, and if saturation was achieved before the conclusion of scheduled interviews that the remaining interviews would be cancelled. In reality, all clinician interviews were conducted and saturation occurred near to the final round of interviews. Fourteen clinicians were interviewed – seven cardiology specialists, four general practitioners, and three specialist heart failure nurses. In the case of patients and carers, thirteen patients and nine carers were recruited. These were split further into patient diagnostic group, and attempts were made to evenly spread the numbers in each group; newly diagnosed (n = 4), stable (n = 5), and advanced (n = 4). This provided a total of 36 participants, with 17 of these participants participating in a 6 month follow-up interview – 53 interviews in total in the entire study. These amounts slightly exceed what both Creswell and Morse advocate for sample size, however the number of participant groups in the study and the longitudinal aspect of the study for patients and carers required a larger sample size in order to ensure data saturation within sub-groups (disease severity).

### ***3.4.3.3 Practical limitations***

As this study was a PhD project it was deemed prohibitively difficult to arrange funding for a translator/interpreter for those with special communication needs or difficulty in understanding verbal or written information in English. Moreover as patient participants were unwell already with heart failure, using a translator or interpreter may have prolonged the interview to such an extent that the patient would have found it difficult to participate. Consequently, only patients and carers with a good level of English and ability to communicate were recruited into the study. Clinicians and nurses recruited into the project had a good standard of English as part of their work.

As discussed earlier it was decided to recruit solely patients with an echocardiogram confirmed diagnosis of heart failure. There is a body of patients with non-echocardiogram confirmed heart failure which theoretically could have been included in the study. However these patients comprise a qualitatively different group with different health needs, and recruitment would have been unfeasible due to the significant amount of work required to identify these patients from GP registers. These patients also may not be aware they have a recorded diagnosis of heart failure which would make recruitment difficult. Due to these practical limitations a decision was made to focus on patients with an echocardiogram confirmed diagnosis of heart failure.

### ***3.4.3.4 Inclusion/Exclusion Criteria***

Inclusion criteria for patients:

- Over the age of 18
- Receiving care from County Durham & Darlington NHS Foundation Trust
- A recorded diagnosis of heart failure
- Capacity to consent as assessed by the clinician
- Willingness to participate

Inclusion criteria for carers:

- Over the age of 18
- Must care for a patient participating in the study (no standalone carers)
- Capacity to consent
- Willingness to participate

Inclusion criteria for clinicians:

- Must work within the County Durham & Darlington NHS Foundation Trust for recruitment and travel purposes
- Specialist area in heart failure, either as a specialist or a GP/nurse with a specialist interest
- Willingness to participate

Exclusion criteria for patients:

- Diagnosis or clinical suspicion of mental health difficulties including dementia, or anything that would compromise ability to consent and/or bring about distress over and above what they may have already experienced through their illness.
- Unwillingness to participate

Exclusion criteria for carers:

- Diagnosis or clinical suspicion of mental health difficulties including dementia, or anything that would compromise ability to consent and/or bring about distress over and above what they may have already experienced through caring for someone with heart failure.
- Unwillingness to participate

Exclusion criteria for clinicians:

- Do not work with heart failure patients regularly
- Unwillingness to participate

#### **3.4.4 Process and procedure of recruitment and data collection**

Clinicians (GPs, heart failure nurses, and specialists) were identified from the local Primary Care Trust and approached, via convenience sampling, through existing links with Durham University and the Wolfson Research Institute for Health and Wellbeing. GPs and specialists were approached via email, attaching an invitation to participate, information sheet and consent form (see Appendix, items 3, 4, and 5 on pages 228, 233 and 246). Heart failure nurses were approached by myself in person to participate, and given hard copies of the above forms.

Interviews with clinicians lasted 15-45 minutes. Table 3 shows characteristics of clinicians who participated in the study.

Clinician category	Clinician specific job title
Specialists (n=7)	Consultant cardiologist (n=5) Sub-speciality (n=2)
GPs (n=4)	GP (n=3) GPSI (heart failure) (n=1)
Specialist heart failure nurses (n=3)	Specialist heart failure nurse (n=3)

**Table 3 Clinician participant characteristics**

Patients were sampled as previously discussed from the caseload of the heart failure clinic at Darlington Memorial Hospital, and their carers were asked to participate as part of the patient's participation (snowball). Prior to ethical approval a meeting with the Darlington Heart Failure Support Group was held to discuss the project and recruitment methods. Originally, patients and carers were to be approached 'cold' with a letter sent to their address. However it was identified that some patients are not aware of their diagnosis, and members of the support group did not deem recruitment by letter to be the most appropriate or potentially successful method. After discussions with the heart failure clinical team, it was agreed that they would approach patients themselves verbally with the study and at the same time hand over study documentation which would have been sent out by letter. This provided an opportunity to alleviate any patient or carer concerns about their diagnosis, and allow the approaching clinician to explain the study in more depth. However potential issues of coercion were identified by Durham University School Ethics Board and it was agreed that clinicians approaching patients for participation must be aware of this ethical practice, and consequently place no pressure on patients or carers to participate.

Once patients and carers had read the study information, signed consent forms, and returned them, I contacted them to arrange to observe their next appointment with the heart failure team, and advised that I would be approaching them immediately afterwards to arrange a mutually convenient date for interview. Depending on the severity of their heart failure and/or their general health, patients are seen either in the heart failure clinic by heart failure nurses or specialists, or at home by heart failure nurses. Observations of appointments were conducted with most patients where possible, and consisted of the researcher sitting in and voice recording the appointment. No notes were taken during the appointment. Immediately afterwards, a mutually convenient time was arranged for interview with the patient and carer. I also contacted the clinician (all specialist nurses) who conducted their clinic/home visit appointment to ascertain if the patient was either newly diagnosed, stable, or in advanced



heart failure. Table 4 shows characteristics of patients and carers who participated in the study.

Patient code	Carer code (if applicable)	Patient disease status	Participated in 6 month follow-up?
PT2	CR2	Advanced	Yes
PT3	CR3	Advanced	Yes
PT6	(N/A)	Stable	Yes
PT7	CR7	Newly diagnosed	Yes
PT8	CR8	Stable	No (both withdrew due to ill health)
PT9	CR9	Stable	Yes
PT10	CR10	Advanced	Yes
PT11	CR11	Newly diagnosed	Only CR11 (PT11 died before the 6 month follow-up)
PT12	CR12	Newly diagnosed	Yes
PT13	CR13	Stable	No (uncontactable)
PT14	(N/A)	Stable	Yes
PT15	(N/A)	Newly diagnosed	Yes
PT16	(N/A)	Advanced	Yes

**Table 4 Patient and carer participant characteristics**

Note: PT6 had a carer who was unable to participate in interview due to cognitive-related communication difficulties. PT14, PT15, and PT16 did not have a carer and were recruited as a result of theoretical sampling (see below for further information).

Interviews with patients and carers were conducted solely at their homes. On arrival, I reintroduced myself and explained again what the interview would consist of, that it would be audio recorded, and how long it would last. I ensured that the participants had retained a copy of the signed consent form and information sheet. I asked participants if they would be happy to be interviewed separately, however in cases where the patient was visibly frail or the patient or carer preferred not to separate, interviews were conducted in the same room. In practice, out of the ten patients with carers (i.e. in a dyad), three patients preferred their carer to be in the same room (whilst still being interviewed separately) – however one of these three patients’ carers (the carer of PT6) did not participate in interview due to cognitive communication difficulties. These preferences held true for two of the three patient/carer dyads at the six month follow-up interview – the remaining dyad (PT8 and CR8) withdrew from the six month follow-up interview due to ill health. The planned intention was to interview patients and carers separately to allow their stories to come through, and indeed seven

patient and carer interview dyads were conducted in this manner (the remainder being patients without a carer). However, pragmatically I knew I needed to give patients and carers the choice of being in the same room during interviews, especially when unwell, despite the possible influence of the patient or carer being present in the room whilst the other spoke about emotive issues – which may not have been discussed between them prior to their involvement with this research. Interviews lasted between 20-45 minutes with each participant, following an interview guide (see the Appendix, item 7 on page 263) which included questions about their appointment, and their wider experiences of communication surrounding their prognosis. Following the interview, both participants were thanked for their time and advised that I would be contacting them in six months' time to interview them again.

Patient and carer interviews were repeated at six months (see the Appendix, item 7 on page 263 for guide) to assess any changes in understanding or reported communication, and to understand their journey over the prior six months. Figure 9 shows participant time and event flowchart for the study to further illustrate research procedures.

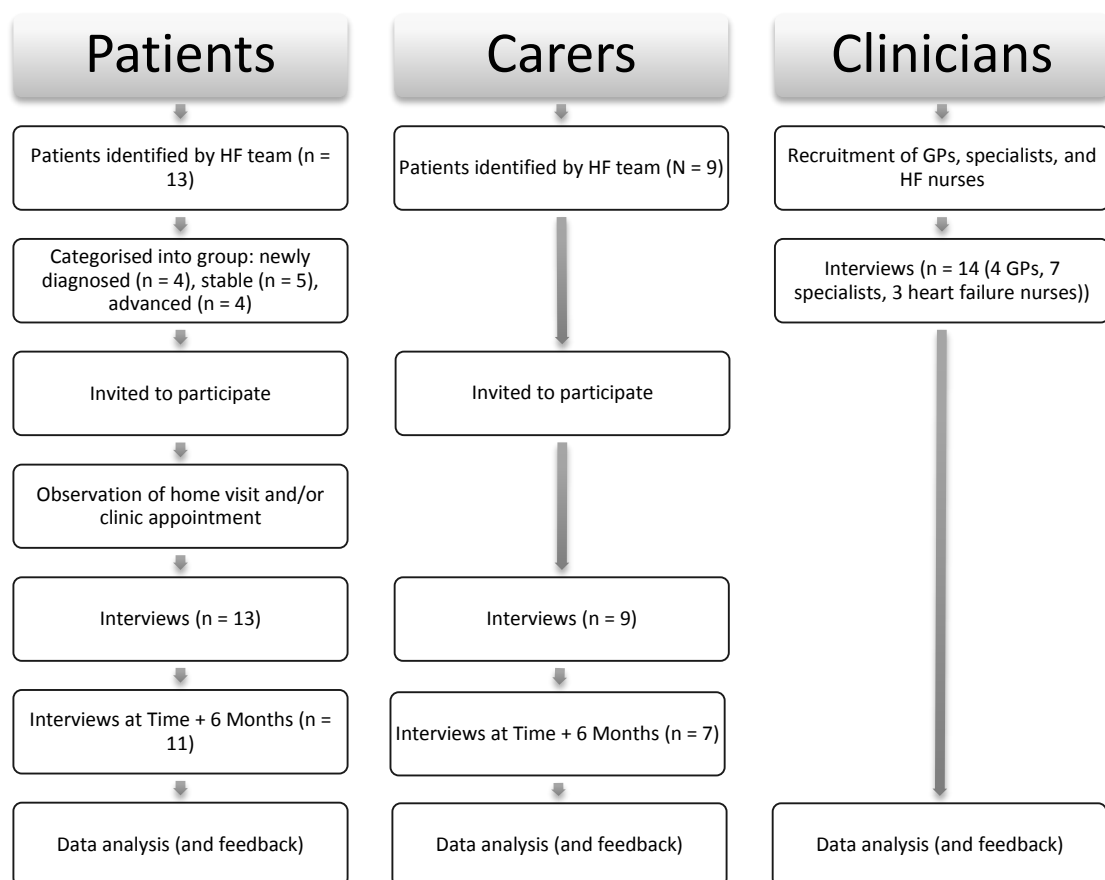


Figure 9 Participant event time flowchart

As rapport had already been established, all participants welcomed me into their homes and updated me on their life gone by over the past six months. This helped not only to gain data illustrating their changes in prognosis experience and understanding, but also cultivated trust between participants and the researcher which served me well in asking relatively difficult questions.

During recruitment I was approached by one of the heart failure nurses with a patient who did not have a carer, who wanted to participate in the study. I decided that it would still be a valuable observation and interview to conduct and to that end, the patient participated in the study. During her interview she spoke at length about only having considered palliative and end of life issues after she became single through divorce. When analysing this observation and interview and going through the process of ascertaining saturation, I realised that this was an important element of the data which needed to be explored further through theoretical sampling. To that end, two more patients without carers were recruited to explore further, and their analyses are also presented in the patient and carer analysis chapter.

### 3.5 Methods

The prior sections of this chapter describe and discuss the research paradigm, methodology, and research procedures for the study. This information is vital to understand information in the current section, which details how methodology choices and available opportunities to collect data in a clinical setting then went on to inform the subsequent choice of methods for data collection – both from a theoretical perspective and a discussion of how it was applied in practice.

Two forms of data collection were used, observations and semi structured interviews. When assessing the existing literature in the area of prognosis communication in heart failure, I identified that the majority of studies used solely interviews, or observations, or quantitative (survey based) methods. No qualitative longitudinal studies existed at that time. It seemed that in order to fully assess the experiences of prognostication communication in heart failure, combining a (more) objective observation of clinical encounters with semi structured interviews with patients and carers shortly afterwards would provide a fuller, thicker description and subsequent grounded theory of what patients and carers *perceived* happened in the clinical encounter versus what was *actually* said, and would also provide a good basis for establishing rapport for interview and the ability to tailor some of the interview questions to the specific clinical encounter.

### 3.5.1 Observations

#### 3.5.1.1 Discussion of observational methods choice

Observational methods are very useful for collecting data in qualitative research. I decided to use observations to address two of the four research questions:

1. How was the process of prognosis giving experienced by patients, carers, and clinicians?

and,

4. How do patients and carers understand information given about their condition (during appointments and from any other source), and how do they construct meaning from this information?

Observing clinical interactions (between clinician/patient and carer) as a nonparticipant – i.e. as an outsider with no direct involvement[180], allowed me to audio record the interaction whilst having no direct input at all.

Conducting observations in this manner – with a clinician in the same room, during a clinical encounter, also went some way to legitimise my role as a researcher and helped to establish a level of rapport that became useful in the subsequent semi-structured interview, especially when asking participants to ‘disclose detailed perspectives about responding to an action or process[180]’ (pg 154). However I was mindful not to appear as a clinician or to help determine any decisions about the patient’s care. A further discussion of power relationships and research settings in this study can be found later in this section.

#### 3.5.1.2 Application of observational methods

Observations of nurses’ home visits and heart failure clinic appointments were conducted with patients. One observation was conducted (where possible) per patient, either at their clinic appointment or at their nurse-led home visit appointments (patients generally only receive one or the other – the decision about which depends upon how ill they are). Once the patient and carer had been approached by their heart failure nurse and consent had been agreed I contacted them to arrange to observe their next appointment. The observation itself consisted of sitting in the room (clinic or at their home) with the clinical interaction being recorded with a Dictaphone. I planned to observe what was said during the appointment by any participant, and also to record – afterwards – details of the encounter which the Dictaphone would not pick up, such as the physical setting, facial reactions, and personal

reflections which would add further detail to the description of the scene[202]. Quite often these personal reflections became part of memo writing. I was particularly interested in any discourse surrounding prognosis, deterioration, advance care planning, and any palliative or end of life issues.

#### 3.5.1.2.1 Research relationships in observational methods

When observing clinical encounters, I was very aware of the manner in which I presented myself – both in a literal sense and in an unspoken sense. Methodological research literature identifies the importance of acknowledging and being conscious of how the researcher presents his/herself to participants and the effect this may have on the emerging research relationship[203]. It was essential to help patients and carers understand that I was not a clinician, and also that I was not ‘assessing’ or ‘testing’ any participant in the encounter. To that end, the clinician conducting the appointment introduced me (in person – the patient and carer had already agreed to participate during a prior clinical encounter and read information sheets detailing the above) and explained again verbally my role as a researcher.

Dress and appearance was another consideration. Whilst I did not feel it was appropriate to dress too casually as I wanted to present a professional, credible researcher identity, I also did not wish to dress in business wear as this can be intimidating especially to participants who may have been retired or out of work for some time. I decided to wear ‘smart’ trousers and a short sleeved (to comply with anti-infection guidance) blouse.

### 3.5.2 Semi structured interviews

#### 3.5.2.1 Discussion of semi structured interview methods choice

Semi structured interviews were chosen as they confer the ability to retain flexibility whilst allowing a greater degree of standardisation than unstructured interviews, which are more suited to obtaining thick descriptions of individual culture. As my research questions and aims were designed to explore meaning and perceptions, semi structured interviews seemed most appropriate as they encourage the interviewee to share rich descriptions of phenomena while leaving the interpretation or analysis to the researcher[204]. The nature of semi structured interviews allow the topic guide to be built upon and expanded, or reduced if necessary[205]. This is especially relevant in longitudinal research, where topic guides for later interviews can be crafted based upon responses, and interesting concepts, brought up in initial interviews. This flexibility affords researchers the ability to maintain normal interactional involvement and allow the sequence of topics to flow naturally, whilst still managing the quality of data produced. Nevertheless, within grounded theory methodology I was aware that modifying

interview guides for the second (six month) interviews, and subsequent interaction and responses within that interview, may therefore re-frame the data to become more co-constructed data, rather than grounded data. In practice I found that participants often skipped (unknowingly to them) to a question situated later in the interview guide. The flexibility of using a semi structured guide meant that I could allow this to happen organically and deem this to show, in participant's minds, how certain topics were related to each other – for example, prognosis and death, or diagnosis and comparisons of others they knew with heart problems. Although the importance of reflecting on the co-constructed nature of later data is highlighted elsewhere, within each interview, primacy was given to the importance of the participants' own perspectives and thus the direction and flow of interviews was determined largely by the participants.

### *3.5.2.2 Application of semi structured interview methods*

A single semi structured interview lasting between 15-30 minutes was conducted with clinicians to explore their experiences of prognostication and communication in heart failure. For patients and carers, a semi structured interview of between 20-60 minutes was conducted separately with the patient and their carer after their appointment had been observed, to discuss the appointment, and their wider experiences of communication surrounding their prognosis. This interview was repeated at six months to assess any changes in understanding or reported communication. As discussed in 3.4.4, three patients and carers preferred to be in the same room during each other's interview. Whilst the intention was to still gain separate dialogues of experiences, in practice the patient or carer not participating in interview at that time chipped into the other's interview at points, to illustrate a point the other was making, or add other detail. One of the positives of this occurrence was that I had an additional insight into the relationship aspects between them through the dialogue. However a downside is that there may have been things left unsaid by either the patient or carer as they would not wish to repeat it, for whatever reason, in front of the other person.

#### *3.5.2.2.1 Research relationships in semi structured interview methods*

As with observational methods, the importance of appropriate dress was acknowledged and I wore smart-casual clothing to conduct semi structured interviews. However the research relationship between myself and participants developed much more at this point, as much more interaction was taking place than the prior observation. At times it was difficult to avoid becoming too emotionally involved with participants, particularly patients and carers. Prior to the current study I had experienced very little serious ill health in my family or peer group, and had not witnessed many instances of seriously ill people struggling to breathe or go about

their daily life. Whilst I was mindful that I would witness and interact with seriously ill people, I felt sad after some interviews when it was clear that the patient and carer were struggling to cope, and I felt a loss when I was advised two of my participants had died shortly after interview. I was glad to be able to speak to my supervisors and my family for support at that time.

Prior to interviewing I spent some time considering the research relationships I would develop during interviews. Some scholars assert that there is an asymmetry of power in this relationship, and argue that completely free and open dialogue is almost impossible to achieve in a research interview even with the assurances of anonymity and confidentiality[180]. An interview dynamic is unequal in the sense that the interview is directed mostly by the researcher, based on their research agenda and the researcher's interpretations. I felt that it was important to make clear that whilst I did control the research process; participants had chosen to participate of their own free will and with full informed consent.

I was also aware that my student status and age influenced the research relationship. Several patient and carer participants were interested in my studies, what my plans were for the future, and my life outside of the PhD. I was happy to chat with these participants about my life without going into too much detail, and I found this seemed to help some participants to talk about such an emotive subject with me. However, again I was mindful that mutually sharing aspects of our own lives could lead to emotional involvement[206], particularly with longitudinal qualitative research, and worked to maintain an appropriate distance.

During clinician interviews the research relationships were a little different. I was aware that the clinician I was interviewing had much more clinical expertise than myself, and had seen many more ill patients with heart failure. At several points I felt a little uncomfortable asking questions about their decision making process surrounding communication of a prognosis, as clearly they had more experience both in a clinical sense and, I felt, more experience of what might be best, psychosocially, for the patient. At these times I reminded myself of the benefits my status as a non-clinician afforded when conducting health research such as the current study, potentially entering the research field with fewer preconceptions which may have influenced myself, the participant, data collection, and data analysis.

Finally, I was aware that some participants, particularly patients and carers, may assume that I was training to become a clinician. Correction of these assumptions when demonstrated was



essential. However when being asked about their views of the future and of their prognosis, two participants (one patient, one carer) gave their answer, one of which clearly demonstrated a misunderstanding of the progressive nature of heart failure – which I left uncorrected – then asked me if they were correct and if “there was something they needed to know”. I had been prepared for questions of this sort by my supervisors and my response, leaning heavily on my status as a non-clinician, was that I genuinely did not know and a recommendation that they contacted their HF team if they wanted to speak about it further.

#### 3.5.2.2.2 Development of interview guide

Developing a list of topics to be covered in an interview was the important first step in constructing the interview guides. Multiple sources were approached for their opinion on the most useful topics to cover, including my supervisors who both have a clinical background, a GPSI – general practitioner with a specialist interest (in heart failure), and patients with heart failure themselves.

Initial questions posed to patients and carers consisted of asking how long they (or the person they care for) have had heart failure, and ascertaining their recollection and feelings about the appointment I observed, if this was possible before the interview was scheduled. Posing more straightforward, nonthreatening questions towards the start of the interview can have the effect of ‘easing’ the possibly slightly apprehensive participant into answering questions posed, and facilitates open discussion and rapport[198]. It was identified that asking patients and carers direct questions surrounding palliative and end of life care would be ethically perilous, as well as possibly frightening. This posed difficulties in how to ‘ask the question without asking directly’. Ultimately it was determined that patients and carers would be asked about their prognosis as communicated to them by their clinical team, and how they felt about that information. Open questions were used whenever possible to allow the participant to give detailed answers, and probes and follow-up questions were used extensively especially when patients and carers spoke of end of life or palliative care of their own accord. See the Appendix, item 7, page 263 for patient and carer interview guides. To help ensure full coverage of the topic, a summary question was included at the end to allow participants to add anything.

#### 3.5.3 Alternative methods of data collection

Focus groups were considered for both patient/carer dyads and clinicians. This would have allowed both individual perceptions of the role of palliative and end of life care in heart failure and a general group consensus. However many patients participating were either housebound

or found it difficult to travel, and differing knowledge levels surrounding the terminal nature of heart failure or indeed the diagnosis itself may have caused distress if exposed to it during a group setting with other non-clinicians. Focus groups with clinicians would have been relatively easier to conduct, however clinicians included in this study were sampled from different geographical areas such as Durham, Darlington and Middlesbrough which would have made travelling to a central location more difficult especially considering busy work schedules. Additionally, one danger of using focus groups is that merely a consensus view would have been reached, which would not have illuminated the breadth and depth of honest clinical accounts. I concluded that the most fruitful way to involve patients, carers and clinicians in data collection would be to travel to each patient and carer's home, and clinician's place of work individually, and allow them to tell their stories individually, the description of which may not have been as deep in a busy focus group setting.

It should be noted that qualitative interviews, and the data produced as a result of them, are not a representation of a positivistic, objective representation of a phenomenon. Rather, they are a product of an interaction between researcher and participant. Whilst qualitative interview methods have suffered criticism for being too 'messy', the inherent reflexivity and ability to explore topics as and when they come up are a core strength of this method of collecting data – something which I believed valuable to exploring the difficult topic of heart failure and prognostic experiences. In addition, conducting observations of appointments prior to interviewing served to provide more of an objective record of the interaction upon which the first part of the interview was based on. Using triangulation in this manner boosts the rigour and quality of qualitative interview research[198].

#### **3.5.4 Triangulation**

Triangulation in research is defined as using two or more approaches to investigate a research question, in order to boost the validity and reliability of the methodological approach and the ensuing findings. This can involve using several kinds of methods (such as interviews and observations) or data (such as interview transcripts and photographic diaries). The combination of methods generally strengthen a study[207]. However Barbour cautions that mixing methods within one paradigm, such as qualitative research, since each method within this paradigm has its own assumption in “terms of theoretical frameworks we bring to bear on our own research[208] (pg 353)”. Nonetheless constructionism, as the current study epistemology, values multiple realities and the investigation of these realities – therefore it can be argued that in order to gather valid, reliable data, triangulation should be employed if possible to provide diverse data sources for a representative analysis. Consequently

triangulation in this study, and in qualitative research in general, can be defined as “a validity procedure where researchers search for convergence among multiple and different sources of information to form themes or categories in a study[209]” (pg 126).

Both data and methodological triangulation were employed in the current study. Data triangulation consisted of *time* (interviews conducted then repeated at six months for patients and carers), *space* (clinical setting vs. home setting) and *persons* (clinicians, patients and carers). Methodological triangulation consisted of a combination of observations and interviews to collect data.

### 3.5.5 Transcription

There is strong opposition from Glaser[191] to the audio recording of interviews, arguing that it is inefficient and generates reams of superficial data. However Creswell[180] contends that audiotaping is a necessity in accurately and completely recording information in order to provide a rich data set. Writing down everything that occurred in an observation or interview is impossible, and I used a combination of audiotaping both observations and interviews, and writing/audio recording my own notes, thoughts, and feelings after each interaction. Indeed, I felt that only taking notes after each observation and interview would compromise the findings of the research, as human memory is finite and prone to outside helpful and unhelpful influences. I also felt that taking notes during observations or interviews would negatively impact on the rapport and social interaction I had worked to establish with each participant, particularly as I would have been unable to make eye contact throughout. Audio recording observations and interviews also allowed me to pull verbatim quotations from participants which were extremely useful in the construction and illustration of codes and categories, and in some cases became the codes themselves (in vivo codes[210]). Stern warns of the overreliance of recorded interview data and subsequent transcriptions, suggesting that not only does this serve to further overwhelm the researcher with data, but that researchers are “in grave danger of developing a rich description of the social scene rather than a theoretical one[211]” (pg 118).

All observations and interviews were recorded using two Dictaphones. Using two instead of one went some way to ensure that if one were to fail, the other would still pick up the speech. Indeed on two occasions the batteries ran out on one of the Dictaphones, and thus the speech file was retrieved in whole from the remaining Dictaphone.

Transcription was conducted either by myself or by NData, a professional transcribing company. All interviews were transcribed verbatim, a total of 53. I transcribed mostly using

Dragon Naturally Speaking 11 software, which involved listening to the interview recordings through headphones and repeating the speech into the computer microphone. Whilst this method was still more time consuming than employing a professional transcriptionist, transcribing time was cut down significantly with the additional benefit of allowing me to re-experience the interview through the recording, remember my thoughts and theorising at that time, and pause transcribing to write notes (which would, in some cases, form memos) on what I felt was happening in the data and why. In the case of professionally transcribed interviews, I listened to the recording again to ensure accuracy of transcription and to write notes and start to theorise as above.

Due to the amount of transcribing required for interviews, observations were not transcribed verbatim. Instead, observations were listened to and notes taken of the main points and themes, particularly of any dialogue relating to prognosis or the future, in order to pose relevant questions at interview. Once observations were listened to, had there been anything substantial to analyse, project timelines would have been amended to perform transcriptions and line by line analysis. However the main aim of conducting observations was to try to understand what was 'unsaid' in the consultation rather than what was said and observations did not, in the end, provide any data surrounding discussion of prognosis or the future.

### **3.5.6 Ethical Procedures**

A number of ethical considerations and procedures were employed in order to carry out the study, as required by Durham University and NHS REC.

Informed consent was obtained from all participants. This meant providing participants with a Participant Information Sheet (see the Appendix, item 4, page 233) which included information about the purpose of the study, the research team, the funding body, data use and management, and what participation would entail – such as place of observation and interview, length of time, general topic of conversation, and so on. Participants were also informed that participation was voluntary, that it would not affect their care whether they decided to participate or not, and that they were free to withdraw up until a certain date. Whilst ensuring the inclusion of all of the above, it was important to strike a balance between too much and too little information, which may deter potential participants or curtail spontaneous views.

It was recognised that anonymity and confidentiality were ethical practices important to maintain especially with the sensitive nature of the research topic. All participants were given a code (such as PT1, CR2, HFN3), and all data pertinent to participants such as transcriptions

were coded in this manner. An electronic code-break document – to identify names and addresses relevant to each code – was securely stored on my University computer, and completed informed consent forms were stored in hard copy in a locked drawer in my University office. This ensured that the identity of those taking part were not known outside the research team.

Confidentiality of participant's information was ensured throughout the project in line with the Data Protection Act and the NHS Code of Confidentiality and indeed in this thesis; comments reproduced cannot be attributed to individual participants.

#### ***3.5.6.1 Ethical Approvals***

Ethical approval was firstly obtained from Durham University School of Medicine and Health Ethics Committee (5<sup>th</sup> September 2011), then NHS Research Ethics Committee (REC) Sunderland using the Integrated Research Approval System (IRAS) (7<sup>th</sup> December 2011). Institutional approval was then given by the local Research and Development office of Darlington Memorial Hospital (23<sup>rd</sup> January 2012). Three amendments to the project were made afterwards, consisting of two minor changes in wording on the consent forms and an extension to the date of withdrawal. All three amendments were accepted by NHS REC and R&D.

#### ***3.5.6.2 Data management***

In line with ethical procedures, all data were stored securely either on my password protected computer at Durham University or in the researcher's locked cabinet at Durham University.

All data were backed up regularly, and all materials from the project are archived securely at Durham University until 1<sup>st</sup> June 2016 as provided for on informed consent forms. The thesis will be deposited in Durham University's e-theses repository as required by University regulations.

#### ***3.5.7 Risks and Hazards***

Issues surrounding potential participant and researcher harm were identified, both in the form of practical safety considerations for myself, and as a result of discussing a sensitive topic such as palliative and end of life care. All participants were given an understanding of what the research observation and interview would centre around, and the researcher was mindful of working within the interview to recognise signs of participant discomfort and deal with them accordingly; to check willingness to continue, offer to cease the interview, simply moving on to another question in the interview guide, and ensuring time at the end of the

interview to respond to any anxieties or concerns. Participants were given a 'Useful Information Sheet' (see the Appendix, item 4, page 233) which contained information on available support which participants could refer to afterwards if necessary. For myself, I was mindful that discussing prognosis and end of life care might be emotionally difficult. I was glad to have the support of my supervisor who has a clinical background in palliative care nursing, and other sources of support such as Durham University's Nightline service, the British Heart Foundation, and my friends and family.

Patients and carers were interviewed in their own homes, which could be seen to pose a risk of harm to the patient, carer, and/or myself. Participants were screened during observation in clinic, and it was decided that any patient or carer deemed to pose a risk (in the view of the consultant, heart failure nurse or myself) were not interviewed alone. Upon conducting the study, no patients or carers were deemed to pose a risk. A lone working policy was also arranged to conduct interviews in order to minimise risk, which included checking in with my supervisor no later than two hours after the interview commenced.

### **3.6 Chapter summary**

In this chapter the research aim and questions have been detailed, the philosophical approach of constructivism explained and critically discussed, and linkages made between this approach and the resulting choice of modified constructivist grounded theory as a methodology. Observational and semi structured interview choices of method have been discussed and justified, and subsequent research procedures detailed.

# Chapter 4 Clinician Analysis

Presented on the following page (pg 89) is the grounded theory framework of clinician perceptions and attitudes towards end of life care in heart failure (Figure 10). The core category of prognostic ambivalence is presented, along with sub-categories of uncertainty, reality and mediation. Each category is then discussed in turn throughout the chapter.

Quotes are denoted as follows:

[GP] is a general practitioner, including general practitioner with a specialist interest

[HFN] is a specialist heart failure nurse

[SP] is a cardiology specialist

[SS] is a secondary care clinician with a sub-speciality of cardiology.

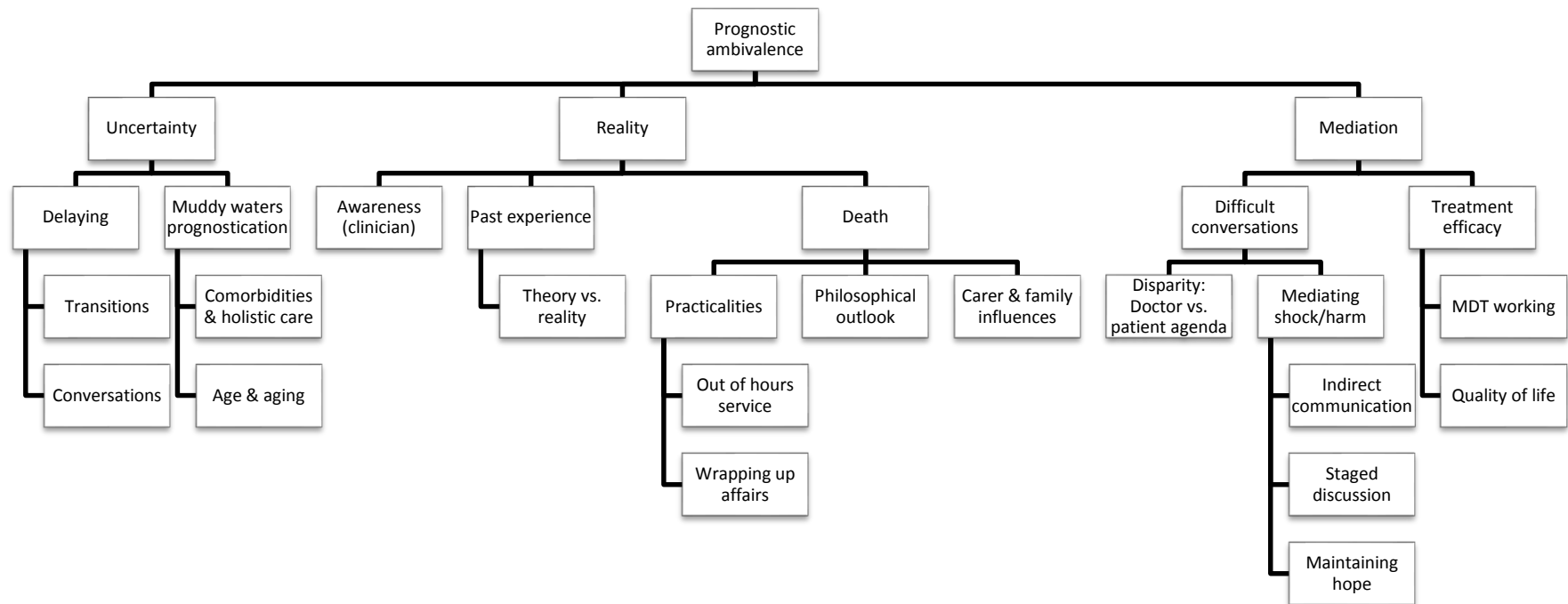


Figure 10 Grounded Theory framework of clinician analysis



## 4.1 Uncertainty

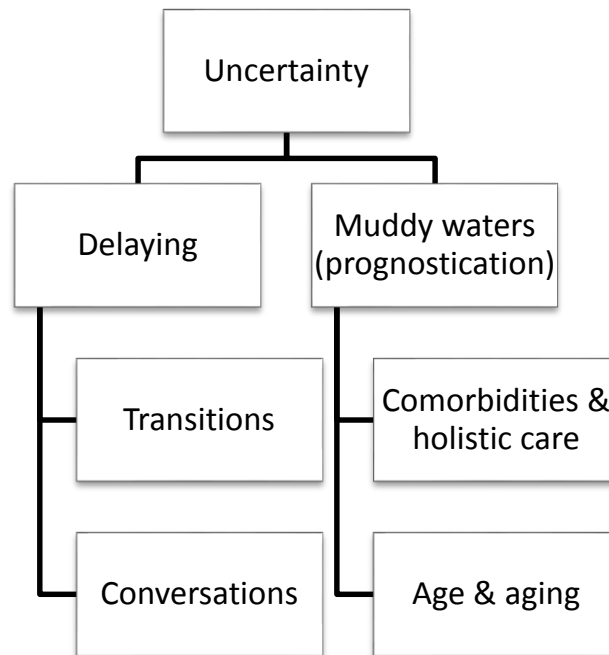


Figure 11 First core category: uncertainty

Uncertainty was one of three core categories emerging from the data. All clinicians reported uncertainty in various aspects of treating heart failure.

The first sub category identified, of the core category of uncertainty, was delaying. Clinicians reported delaying various elements of care, mostly due to their uncertainty of how to proceed.

### 4.1.1 Delaying

#### 4.1.1.1 Transitions

A sub-category of delaying was identified as ‘delaying transitions’, which primarily included a transition from active to palliative care. Clinicians were asked in their interviews how they decide when to stop treating a patient actively, and switch focus to palliative care. Uncertainty lingered over this transition point, and the effect of delaying conversations and considerations about palliative care were evident in their decision making process. Many clinicians spoke of transitioning a patient once they felt curative medicine no longer held any answers in their practice;

*But there comes a point where you decide, you know, that attempting resuscitation with paramedics jumping up and down on your chest just isn't worth it any more. [GP5]*

Some felt that palliative care as a speciality was inherently the polar opposite of active care and viewed it as very separate from their usual curative care;

*Erm, you're checking their blood tests all the time, doing this that and the other, at what point do you say well let's stop just striving to keep them alive 6 months longer and actually let's just make sure that their last few weeks or months are as high quality possible? [GP5]*

However palliative care was also identified by others as lying on a continuum of treatment and illness, i.e. to phase in palliative care alongside active care;

*I think it's more, knowing when the right time is, because it's a grey, it's like a spectrum it's not a yes or no [for palliative care]. [GP4]*

Palliative care was perceived in different ways amongst clinicians. Some specialists did not understand what palliative/hospice care involved, whereas others had a good understanding. Societal attitudes towards hospice were mentioned, especially clinician's perceptions that palliative and supportive care charities such as MacMillan and Marie Curie are seen as cancer care only. Heart failure nurses tended to speak more about the supportive, holistic nature of hospice care and the local hospice in particular was championed as providing beneficial supportive care to heart failure patients.

*I think they've [MacMillan] got a problem in that they are promoted as a cancer charity, and I think they do all terminal care, and I think the hospice in particular is quite good for other terminal illnesses, not just cancer. [GP5]*

*I think patients see, if you start talking about going over to the hospice to be seen, and refer them to palliative care specialist people, you are basically telling them that they've had it. You know, so unless the perception can be taken away that actually, we're doing this to try and improve things before you get to that stage, then they can understand that. [SP2]*

*But I don't know much about hospices, to explain to them, how is that different from home. [SP3]*

Specialists in particular spoke about the decision to transition to palliative care, and the practical aspects of doing so, being a task assigned to the heart failure nurses as the most appropriate clinician placed to undertake. There was a sense of specialists actively ceasing treatment, drawing a line under it, and passing the patient onto palliative care as another speciality with no further input seen as necessary from themselves;

*So when they [patients] are, when they get to that point [requiring palliative care], I have fulfilled my role really of trying to control their heart failure. I tried to control it as best I can, and if I can't do any more, it's somebody else's job to sort that out. [SP2]*

*[Palliative care] is a heart failure nurse job. The heart failure nurse will contact them and liaise with them, and say that this is palliative care. But I mean, I'm not involved with that much end. I more or less just pass them on. [SP3]*

#### **4.1.1.2 Judging 'terminality'**

All clinicians acknowledged at some point that heart failure will ultimately result in death. Some clinicians were very clear in communicating that that this would consequently categorise heart failure as a terminal illness;

*And I think it's a bit like cancer, I don't think you can get round it. Cancer's cancer, terminal heart failure is terminal heart failure, and I don't think there's any way round it. [HFN1]*

However many clinicians felt that that heart failure does not carry an imminent threat of death or being close to death, therefore in their opinion any terminal conversations could, and should, be delayed until the patient is identified as terminal;

*Certainly heart failure's got as high a mortality rate as some types of cancer, erm so it is, or it can be seen as a terminal illness, erm, depends on the severity... So for most people with heart failure they're not imminently terminal, erm, with the new treatments, probably the mortality rate is much less than it used to be. So there isn't much sense having the terminal discussion with them until they're reaching the terminal stage. [GP5]*

*Well I think that's what you have to do [explain the prognosis] in heart failure when you recognise that it's a fatal condition when it gets to that point [end stage]. [SP2]*

Accordingly, before a transition from active to palliative care is identified, a stratification and consequent transition from 'non-terminal heart failure' to 'terminal heart failure' seemed to be applicable from clinician's descriptions of their practice. Clinicians felt that they 'must' recognise that their heart failure patient had transitioned to a 'terminal heart failure patient' in order for them to consider palliative and end of life care issues, but acknowledged that this does not happen often enough.

#### 4.1.1.3 *Blurred boundaries*

Making a judgement of 'terminality' detailed previously requires the clinician, at some point, to decide when a patient was no longer for active treatment. The boundaries between active and palliative care were described as blurred, both when making a distinction between active and palliative care in HF but also blurring the type of care a patient was receiving. Whilst some clinicians felt that there was a very definite 'switch' between these types of care, others felt that the transition was less noticeable;

*There isn't a sort of point at which you say, yeah, that's [NYHA class] the one! [to start considering PC] [GP2]*

*I suppose with heart failure it's always palliative care in a way, because there isn't a cure [GP5]*

*With heart failure, they tend to stay on the heart failure drugs right up to the end. Erm, and it's really just adding in other things as necessary. [GP5]*

As some heart failure drugs are used both in active and palliative care, this may contribute towards the lack of distinction in clinician minds between medical active and medical palliative care.

Others felt that 'mild' or 'minor' heart failure may not comprise a diagnosis of full-blown heart failure but rather mild dysfunction;

*So lots of people have, er, minor degrees of heart failure, and the echocardiogram's now very sensitive at picking up minor degrees of left ventricular dysfunction. Erm, and I suppose, you know, do you order heart failure, or what, when, is it heart failure only when it starts to cause them symptoms? [GP5]*

Note: European Society of Cardiology guidance describes the diagnosis of heart failure as both the presence of LVSD and symptoms in the patient.

#### 4.1.1.4 *Crisis*

Whether the clinician regarded palliative care as a switch or as a gradual process, all agreed that identifying signs that the patient was in health crisis were indicators of the requirement of palliative and end of life care;

*It's usually been after at least one or two admissions to hospital, and where you would be contemplating yet another admission. And sometimes you're saying, actually this isn't helping you and maybe we need to look at another strategy. [GP2]*

*Often what would initiate [the transition] would be an acute illness, so that they become unwell, and then you think right what do we do now, do we get them to hospital and intervene and pull out all the stops or do we say, do you know what, this is where quality of life takes over from quantity, and make a decision based on that. [GP4]*

#### **4.1.1.5 Indicators to transition**

Clinicians were asked how they decided that their patient needed to transition to palliative care. A range of responses were elicited. Most initial responses centred on recognising that the limits of active care had been reached, i.e. that nothing was working despite maximum tolerated treatment. As such, palliative care would only be considered (if at all) when routine, active care was seen as negatively affecting the patient. Once probed further, a mixture of clinical indicators and holistic, psychosocial based indicators to transition were identified;

*Sometimes you can base it on blood results, you can get a picture that certain things are starting to tail off and deteriorate, and in our experience that sometimes means that you know, things are progressing more quickly... but most of the time [the patient will] actually recognise that they've just not been very well themselves for quite some time. [HFN3]*

*Trying to be scientific as opposed to what seems to be the right thing to do at the time, is refer to the hospital admissions, that's a common one, so if people have been in with an exacerbation, you send them off and within a pretty short time they are in again and in trouble again.. I think when people start getting class four symptoms, that is something that would trigger it, when they are obviously disabled by it and especially when you can't turn that round with your therapy... And when patients lose a lot of weight as well. When they start to get cachectic looking, and it's not just fluid it's muscle bulk. [SP2]*

*It's mainly guided by the symptoms, if somebody is obviously very very breathless, looks very weak, not able to eat or drink or enjoy food, that's a sort of situation where we would decide about stopping active treatment and going on to palliative care. [SS1]*

*(interviewer: Can you tell me about how you decide when a patient requires palliative care?) Oh, when nothing is working really. They are on the maximum tolerable treatment and there's not much to offer and they are still experiencing heart failure, they are still in the clinic and struggling. [SP3]*

*Sometimes patients will look depressed, some of them will come in here and when a patient has been previously very positive when they came in, and they are more negative about things now, they are just tired and fed up with it. [SP2]*

Most of the descriptions of clinical indicators were accompanied or prefaced by a response that a transition decision is more based on the feeling, or sense, that a patient is struggling to cope. Heart failure nurses in particular described using their perceived ability to gain a more holistic picture of the patient, their home life, their symptoms, and using these plus clinical indicators to guide the transition decision;

*I have a very sort of touchy-feely approach to a lot of what I do in medicine as well, sometimes you can't put your finger on it as such but you just get a sense that the patient is in trouble sometimes, or a sense that the patient needs a conversation about it. [SP2]*

*There are some guidelines that we can use, but I think more often that it's a total practicable approach that we use, you know your patient, you know when they're not getting any better. [HFN2]*

#### **4.1.1.6 Time constraints**

Many clinicians felt that the limited time in consultations did not allow for prognostic issues to be addressed, hence this was another, uncontrollable, reason for delaying;

*Erm, so just practically speaking, you know, I guess we don't have, maybe it's an excuse, but we don't have the time or the opportunity to sit down and actually think of, oh let's talk about what might happen in the future. [GP4]*

Patients were perceived as also being aware of the time constraints especially in the heart failure clinic, and therefore expect different types of consultations depending on the setting;

*You've obviously got less time in clinic... But patients tend to expect different things I think from a clinic appointment as well. They come knowing that they're coming for that assessment, erm, for example the titration clinic, they generally know after the first appointment that they're coming for us to review their medications, to assess how they've been, and possibly increase, you know, change meds. So I think they come with a different perception and idea to clinic appointments as well. [HFN3]*

As newly diagnosed and stable patients are seen in clinic wherever possible, this limits the overall consultation time patients and carers receive with regard to their heart failure. The restricted nature of clinic appointments, and the prior expectation of both patients and clinicians of what clinic appointments are 'for' (biomedical rather than biopsychosocial), for patients who slowly decline, could result in a poor palliative and end of life experience as they

might miss out on the vital home visit consultations and the more holistic, supportive care conversations associated with them;

*Other people that might have lived with this for years and years and years, and it's just got a bit worse and a bit worse and a bit worse. And then finally we give it a name, and we give it some treatment, and they just tick along... And they're the ones that I think we miss out on, the good palliative care experience, because they're just, they tick along slowly. [HFN2]*

#### **4.1.1.7 Delaying conversations**

Thirteen consultations with patients were observed, and conversations focused almost solely on pharmacological medical management of symptoms. During interview, clinicians spoke of delaying various conversations with patients. Giving a prognosis and speaking about the related issues of palliative and end of life care were often delayed as much as possible;

*[so, at what point would you have the conversation about, thinking about the end, and wrapping up your affairs?] Erm... I can't, I can only think of, it tends to be when people are really, completely, immobile with breathlessness I think. When it's very obvious. Erm, and we're really getting to the bottom end. [GP2]*

*So I suppose only when they're getting onto levels 3 and 4 [NYHA scale], when they're getting severely symptomatic, that you're likely to have a discussion with them about the fact that this is gonna affect their longevity. [GP5]*

This procrastination was recognised by some to be sub-optimal;

*I guess the difficulty is when you have those discussions? ... at what point do you then bring in the discussion? And I think it's probably the same with patients with cancer, we don't have those discussions when we should, really. Erm, which is earlier rather than later. It tends to be, you wait till a crisis and then you have the discussion which is often too late, isn't it? [GP4]*

*for chronic illnesses where it's not cancer, I think we are too slow in maybe bringing that decision up, people are just left to be managed and just keeping on with the routine management, and then you suddenly think, you know, oh we've got a box to tick on the computer that says this person needs their something checked. [GP4]*

However others felt that discussing anything to do with prognosis whilst the patient was receiving active treatment was cruel.

*You know when you've got them on whatever medication you can get them on, and you've considered devices and you know they're not gonna get better, then I would*

*have the conversation at that stage, rather than right at the diagnosis because it's almost like saying, you know, I'm afraid you've got heart failure, you'd better start thinking about how you're gonna die. I think that is almost cruel. [GP1]*

#### **4.1.2 Muddy waters (prognostication)**

The second sub-category identified of 'uncertainty' was the difficulties in prognostication in heart failure. The term 'muddy waters' was taken from one GP interview as an in vivo code. Clinicians described almost complete clinical uncertainty in giving a prognosis for heart failure, particularly in the newly diagnosed, despite developments in medical care (described later, alongside the actual prognostic conversations).

Various elements of the disease were described as unpredictable, including mode of death and longevity. Many clinicians alluded to prognostication statistics and clinical indicators but were unsure how to use them for prognostication;

*It is difficult because we know that when people have got a New York Heart Classification of four, that they've got a 50% chance of dying. Still a lot better than that. But, do you have that conversation the minute somebody, er, gets a New York Heart Classification of four, because you're gonna be wrong half of the time. [GP2]*

*Er, so hitting level four heart failure and even being there for a few months isn't a guarantee that that's where you're gonna stay. Erm, nor is, sort of, speed of deterioration. [GP2]*

Communicating a prognosis and subsequent palliative care was dependent on making an accurate prognosis;

*Would I consider exploring palliative earlier? I think it's often difficult because you, it's very difficult because it's very difficult to predict how a patient is gonna go. [GP1]*

... despite the more-or-less uniform acknowledgement of the terminal nature of heart failure;

*Prognosis, yeah you've got me thinking because obviously we all know that heart failure does have a very poor prognosis, although better than it used to. [GP4]*

GPs also spoke of a team struggle with prognostication and making a palliative care transition decision, that specialists and heart failure nurses found the decision difficult as well.

It was further recognised that prognostication difficulties led to a lack of skill when treating patients close to the end of life;



*I suspect our skills with the end of life in heart failure are less good, because you're often less sure as to when something might happen. [GP2]*

However, from the clinician's perspectives, clinical indicators and guidelines did not provide any further illumination when considering palliative care.

*I think the big difficulty is really deciding when it's palliative. ... Erm, so, because there don't appear to be any clear criteria as to what we mean by palliative or end of life. [GP1]*

Often GPs spoke, sometimes derisively, of having to simply guess a prognosis in situations where they were required to for a transition decision, or a practical imperative such as completing the DS1500 form (for increased monetary benefits in the last six months of life) and the clinical inability to do so – hence the reluctance to prognosticate at all;

*But I don't specifically go out of my way to tell them, you're looking at, you may only have a few months to go because that's pure guesswork, and I can think of at least one heart failure patient who I thought was gonna die years ago and it took years for him to actually die. Yeah, so we're not gods, we don't know. [GP5]*

*Erm, disability living allowance look at it as being within 6 months, so you're supposed to guess that somebody's gonna die within the next 6 months for them to be able to claim disability living allowance. [GP5]*

The unpredictability of the disease also led to difficulties in coordinating services;

*In-patient treatment for end of life care isn't the sort of few days duration that they [hospices] can actually logistically manage, that they run out of bed space if they start taking in... they aren't really, er, clear how long the piece of string that they've got hold of is. [GP2]*

#### **4.1.2.1 Comorbidities and holistic care**

Clinicians often spoke of comorbidities as 'muddying the waters'. Pure heart failure facilitates predictability and choice of treatment as it is easier to pinpoint the origin of symptoms and the trajectory of decline;

*it's easier to attribute any change in somebody's ability and condition, to the one illness, you're not looking to see whether, oh could it be a urine infection, if they're not feeling good that day. It's probably down to that. [GP2]*

*you very rarely get someone with solely heart failure. They will almost always have multiple co-morbidities, so ischaemic heart disease, diabetes, COPD, all the rest of it.*  
[GP4]

Clinicians illustrated the treatment of heart failure as often a misnomer, as heart failure is so often accompanied by other diseases. Whilst specific drugs would be prescribed for specific heart failure symptoms, the treatment of 'heart failure' was shifted to treating the 'whole person' with their tapestry of illnesses and symptoms;

*So, you tend to be, end up just managing [comorbidities] as a whole, as part of the whole condition.* [GP4]

*There's no signs you could say right well if their ejection fraction is, you know, and their oxygen levels are this, and this and this, every single person's different. So it's having to take each person's, because all their comorbidities are different, their opinions about quality of life vs. quantity, their family's feelings are different, their age, not per se makes a difference but just affects how many comorbidities they have.*  
[GP4]

*I think because some of our patients are so chronically unwell, they've got COPD, they've got a lot of these things that, telling them something else on top is just, to their mind, maybe going to be treated by another tablet.* [HFN2]

Whilst in the case of 'pure' heart failure, often with younger patients, GPs spoke of a likelihood of treating it more aggressively;

*I mean you do get guys, I've got a guy in his 50s, 60s, who's had ischaemic heart, had an MI, and then developed heart failure. But he's actually pretty well otherwise. So then I think, yeah we'll do everything we possibly can to manage it intensely, his heart failure. [patient with no comorbidities]* [GP4]

Within GP4's interview there were contradictions about the role patient age plays in the type of care the patient ultimately receives – whilst GP4 says age per se does not make a difference, they go on to say that they would treat younger patients, who often have fewer or no comorbidities, more intensely than an older patient. This may lead to questions surrounding the perception of HF as to what age it is 'unnatural' or 'unfair' (i.e. in younger patients) and at what age it is more 'expected' in the elderly - and consequently may be treated less aggressively.

However the presence of comorbidities and the patient obviously struggling with these was described as facilitating conversations and considerations surrounding palliative care;

*I'm, strangely enough I'm happy having that conversation [about palliative care], sometimes, tend to be the ones who are, er, multi, who've got lots of co-morbidities, and saying look I'm not gonna make your breathlessness that much better, let's stop going into hospital shall we. [GP2]*

#### **4.1.2.2 Age and aging**

Alongside the impact of comorbidities upon uncertainty was the impact of aging. Clinicians described the two often going hand in hand, with heart failure seen as simply being part of the natural aging and deterioration process;

*I'm even I suppose a little bit sceptical about this mortality at 5 years or whatever, that they quote. Just because they tend to have so many other co-morbidities, erm, it doesn't really tell you, you know, oh heart failure's the worst thing possible because you die. Well, altogether, actually is it, your body's slowing down and malfunctioning everywhere, and the heart failure's one of the things that happens. [GP4]*

Heart failure was often spoken of as a contributory factor to death rather than the cause, in the elderly;

*I think when you get into 80s and 90s, you're again, it's a contributing factor. But maybe, there may well be other things going on as well. [GP2]*

*If you get very elderly people with lots of other things wrong with them, it's only part of a mass of things that's going to catch up with them eventually. [SP2]*

Consequently, the presence of heart failure was seen as merely increasing the chance of being tipped over the edge;

*You can't be absolutely sure that actually, yes you've [elderly person] got heart failure, and it's probably, that bit is probably quite stable, but it won't cope with another insult. And the chances of having that second event, the pneumonia, the fall, er, the other intercurrent illness, become more frequent and more likely, the older and more immobile you become. [GP2]*

Two specialists related their perception of elderly patients with heart failure as being more accepting of the uncertainty of the prognosis (whether this uncertainty was communicated or not) and indeed the presence of serious illness;

*But those who are, the majority of them are 75, 78, 80 years old people, who experience, who survived all of their life with quite good experiences in the past. And*

*they probably used to think that the end has to come, at some point. So they are not disappointed, they don't expect answers to be 100% correct. [SS2]*

*And I think elderly people tend to know that as well, I mean I talk to people in their 80s. They know that they've got, you tell them that they've got heart failure, they kind of know that's something quite serious. [SP2]*

*Some patients are quite accepting and it's almost like, well, you know, something's got to get me, and I've had a good life. The younger patients tend to take a little bit longer to accept things. [HFN3]*

Younger patients were deemed to have different communication needs with regards to prognostication. Whilst older patients were thought to be more accepting of a serious, life limiting illness, younger patients may be being considered for transplantation and more interested in the possibility of a cure. Prognostication in younger patients was different not only in the sense that it is seen as easier (due to fewer comorbidities), but also that their prognosis has a different impact on their life such as with their career, family, and social life;

*Erm, the other problem that you have with younger people is whether they're being put forward for heart transplant. So you're kinda having two conversations at the same time, er, and naturally they're not interested in the end of life conversation, they're interested in the conversation about, am I gonna get a call from the transplant team tomorrow. [GP2]*

*Heart failure is being diagnosed younger and younger and we do have a cohort of young patients. And I do think their communication needs are sometimes different because they've got issues in their lives that maybe somebody who is a generation older than them wouldn't necessarily be dealing with. [HFN2]*

## 4.2 Reality

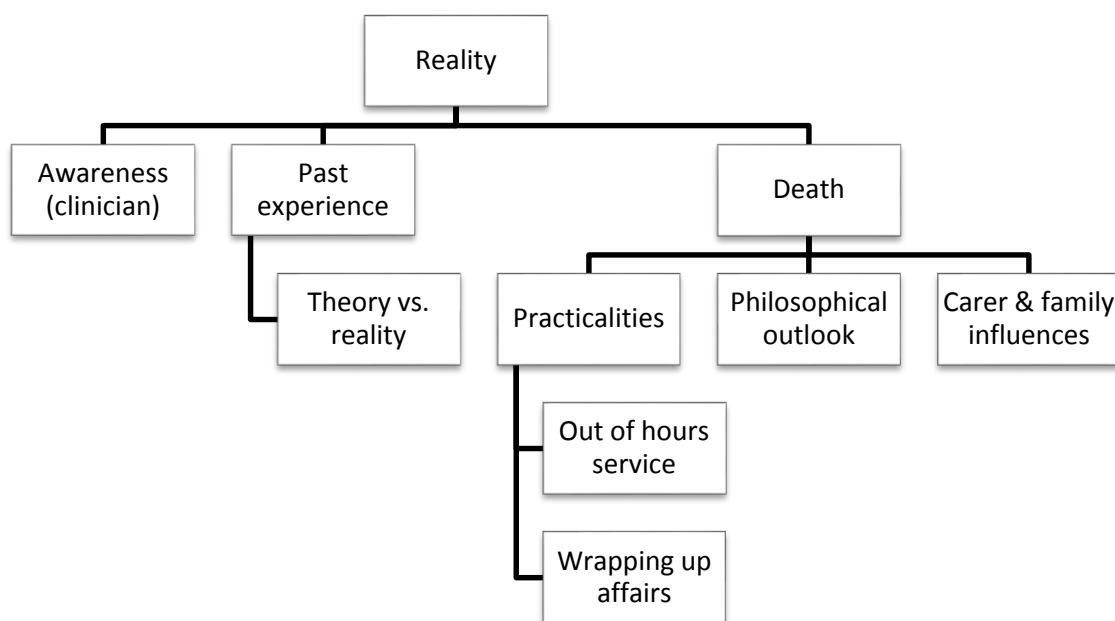


Figure 12 Second core category: reality

The second core category emerging from the data was named reality. Clinicians spoke of the existential reality of death in general, but did not feel that it applied to individual patients with heart failure. The practicalities of end of life care services were discussed but again mostly not discussed as being part of their clinical practice for heart failure.

### 4.2.1 Awareness

Most clinicians felt that the medical community should be aware that heart failure is a terminal illness, and thought that current levels of awareness were poor which might be a reason why palliative issues are not discussed.

*Things are a little bit better, er, in that people [clinicians] are more accepting that heart failure, it can be a terminal process. [GP2]*

GPs in particular spoke of the need to increase awareness. They felt that this may promote both conversations with the patient, and their prescribing of appropriate palliative care drugs;

*It's like every area of our work, it's increasing awareness of it, er, so that we're being more prone to think, of yeah I wonder if we should have that conversation now rather than later? [GP4]*

*And I think GPs are probably more aware of treating it as a terminal illness, erm, so we are prepared to go in with things like morphine or whatever other symptom relief they might need as a terminal thing. [GP5]*

Palliative care services were perceived as being promoted heavily for cancer whereas hospices and other services, on the whole, treat terminal care of any illness. However, again clinicians spoke of the difficulty of managing awareness of the various nuances with heart failure care with the time limited nature of consultations.

#### 4.2.2 Past experience

When speaking about palliative care in heart failure, many clinicians reflected upon their past experiences. Clinicians used many of these past experiences to communicate how difficult it is to treat an unpredictable illness such as heart failure, and some conversations drew on their experiences of ‘getting it wrong’, possibly as a way of explaining why the topic is, on the whole, not brought up routinely;

*I've seen it with ones where we're fairly certain, and even then you're still wrong sometimes, they live on much longer. [GP5]*

*I'm thinking, I've got two patients in my head. One was a gentleman, must be about ten years ago, who did get to the stage of being pretty much bed-fast, he had housekeepers and carers coming in pretty regularly. And he was, we had a conversation about end of life, and yeah, he wasn't gonna get better. But I'm also thinking of a guy who progressed fairly rapidly from level two to level four heart failure. And then has plateaued out, for the last three or four years. And he's probably only grade three heart failure at the moment. [GP2]*

Many clinicians spoke of their experiences of speaking with patients about end of life issues and the choices their patients made presumably with that information;

*The majority want to die at home, if I think back over the years. There are exceptions, erm, and, you know, I can think of two, one a young chap in his late 30s who didn't want to die at home because he didn't want his two young children to, erm, think of home and death, of Dad. And more recently, an elderly lady died in the hospice because, er, her elderly husband just couldn't cope, I mean she was 94 and he was 96, so, and she had valve disease with end stage failure and died peacefully in the hospice. [GP1]*

Two specialists also described their personal past experiences as informing their practice. One specialist was born and trained in another country, and relayed the different culture of prognosis communication. He went on to illustrate that his practice is based on his training abroad, with very little acknowledgement of modifying his practice based on his current work

here. He did not feel the need to modify his communication for the British culture which, he felt, tends to be more open and honest with patients which was something he was not so comfortable with in comparison;

*Well, you have to take into consideration that my background of work as a cardiologist, I've worked most of my time in [country]. And, er, and there is a slight difference in the way that information is given to the patients there... you don't tend to inform the patients straight away and don't ask me why, but it is the way it is, and that's acceptable for all, for both patients and doctors... I think that they tend to be more open with the patients here... Sometimes it is not easy to compromise between both attitudes. [SP4]*

The second specialist went into detail about a significant adverse life experience they had. This specialist spoke of reflecting often upon this experience, and drawing upon it when breaking bad news to a patient;

*I think I've been more conscious of the need to [be empathetic] since I was in that situation where somebody told me some very bad news, and I had to deal with it. And I remember at the time what it felt like, and now I try and think, what would the patient feel like, being told something really bad, as I was. [SP1]*

Many clinicians perceived a 'theoretical' imperative to relay a prognosis to heart failure patients, and to do so earlier rather than later. However this theory was deemed to be ignorant of the realities in practice clinicians face when making a prognosis and subsequently communicating that prognosis;

*Erm, ideally you should [speak about prognosis at diagnosis]. But it doesn't always work that way in practice. So, erm, in theory yes. But in practice, if that patient is in shock or in denial or very upset still about the fact that they've got heart failure, because the term itself causes, is a scary term. [HFN3]*

### **4.2.3 Death**

Despite many clinicians delaying and/or avoiding the subject of death with their patients, death as a subject was spoken about openly during interviews.

#### **4.2.3.1 Practicalities**

##### **4.2.3.1.1 Out of Hours services**

In addition to a more philosophical discussion about death, practical issues of caring for a patient close to death were described, especially with out of hours services. Clinicians spoke

of their frustrations with out of hours service availability, feeling that the hospital is an inappropriate place to die, but also feeling unable to do much about it. Despite these frustrations, several clinicians, particularly heart failure nurses, spoke of planning for future care;

*Er, and yet, even in this area where we've got really good services, it sometimes, it does sort of, unravel at weekends because there's no weekend cover from the specialist heart failure nurses and relatives panic or carers panic and they end up in hospital, and er, die in hospital, which is not what the patient wanted. [GP1]*

*Often the patient ends up in hospital. Which, erm, is often not the right place to be, to die. [GP1]*

*You can put in place the best plan on earth, but if the relative panics on a weekend because the patient isn't deteriorating the way they thought they would, then they'll call the out of hours and invariably, out of hours will admit, unfortunately, because they don't have a great deal of choice, and that's what they'll do. [HFN3]*

*You can plan anticipatory care as often as you want but there will be something that's just completely off the wall, that you could have never planned for. [HFN2]*

#### 4.2.3.1.2 Wrapping up affairs

Another practicality clinicians felt important to speak about near to the end of life was to 'wrap up affairs'. This primarily consisted of financial considerations such as making a will, but also included communicating to the patient that they should do anything they want to do, e.g. go on one last holiday to see relatives, or anything else they'd want to do, whilst they were still fit enough;

*[describing speaking with a patient] So is there anything important you need to do, like any financial affairs you need to put in place, maybe now is when you should be doing it. [SP1]*

*I think people quite often just like to have their house in order. They like to know what's coming and what the future holds and what they may need to do in terms of getting family sorted and houses in order. [HFN2]*

However other clinicians reported only speaking to their patients about wrapping up their affairs if they felt that they needed to do it – how they came to that feeling could not be explained;



*Unless I'm aware they've got relatives in Australia that they want to see, or things they need to do, then it may be worth, well it is worth talking about, have they got a will drawn up, powers of attorney, things like that, if they might need these sort of things.* [GP5]

#### **4.2.3.2 Philosophical outlook**

As with aging being a topic linked to difficulties with prognostication, aging was also framed alongside death as something unavoidable, and a philosophical outlook was maintained and communicated to patients by many clinicians, possibly as death is both inevitable yet so unpredictable in heart failure. Some arguably superficial comments were made about death in general;

*Well, yes we're all gonna die, and yes heart failure does increase your chances of dying, you know, earlier.* [GP1]

*We're all terminal, we're all going to die, it's just a question of when.* [GP5]

Communicating prognosis issues and speaking about death was described as something which cannot, and should not, be a universal template. Clinicians felt that it was important to consider patient's individual differences when thinking and speaking about death;

*I think it depends on their personality, you know, you've got some patients who are very calm, logical, philosophical, others who have always been anxious, panicky, you know, it also depends on what support they have around them, and you know, perhaps anxiety, panic of carers, relatives, rubs off on the patient.* [GP1]

GP5 suggested that elderly patients were aware of the consequences of untreated heart failure;

*Because they know what's gonna happen [if patient doesn't take treatment], they're gonna get breathless and if they get too breathless, they die.*[GP5]

However the same GP also accepted the utility of having a conversation about death regardless;

*I mean with any of these sort of terminal illnesses, it's always worthwhile, erm, discussing with the patient and their relatives the fact that, you know, they might die tomorrow, next day, or it could be a week or it could be longer.* [GP5]

GP5 also spoke about the topic of death as being more acceptable in the past compared to present day.

*[in the past] doctors wouldn't rush to people they knew were gonna die, so you'd get there and see what the situation is. Ambulance men would use their common sense whether or not to try and resuscitate. [GP5]*

Patient's wishes for death were, however, universally accepted as something to respect and strive to achieve despite not being met on many occasions;

*There are things obviously like, you know, mode and place of death, stuff where a lot of people do have opinions and, erm, wishes that maybe aren't taken into account. [GP4]*

Despite this universal acceptance, no action to change the status quo was identified.

#### **4.2.3.3 Carer and family influences**

Sometimes carers and relatives were seen as influencing clinician communication surrounding palliative and end of life care, and indeed their involvement was sometimes described as disruptive especially if the family were not previously involved in the day to day care of the patient;

*They [family] haven't seen the decline [in the patient] themselves, and at that point it's difficult to accept that no more can be done, they want everything possible done for them. [SS1]*

*[speaking about recent patient] So we've reached a stage where it was decided that he's not for any more active treatment. The family thinks, why are we stopping, why we are not treating him? They were, initially, unhappy yes. And that's why we ended up having a few discussions with them... The way we got them to understand... in this case, there is some religious issue as well, about stopping treatment for this patient. And we did explain to them that erm, treating actively sometimes may be more harm than doing good. [SP7]*

Others described the impact heart failure has on close relatives, particularly partners. Often, place and type of palliative/end of life care were changed as the clinical team felt that the patient's partner could not cope with the burden of looking after a dying person;

*And more recently, an elderly lady died in the hospice because, er, her elderly husband just couldn't cope. [GP1]*

However the general feeling amongst clinicians was that family members are very much involved in the care of the patient and as such, discussions and decisions about care were made as a team;

*Oh [I would] always [involve the patient and carer in PC discussions], I don't think you can without absolutely saying, again, either the patient or the carer has to be involved either initiating the decision or discussing it. Erm, absolutely, I don't think you can do it without. [GP4]*

*For the nursing home I cover now, we've had a discussion with the relatives about DNR forms, or hospital admissions, so we know where we stand for each person. [GP4]*

## 4.3 Mediation

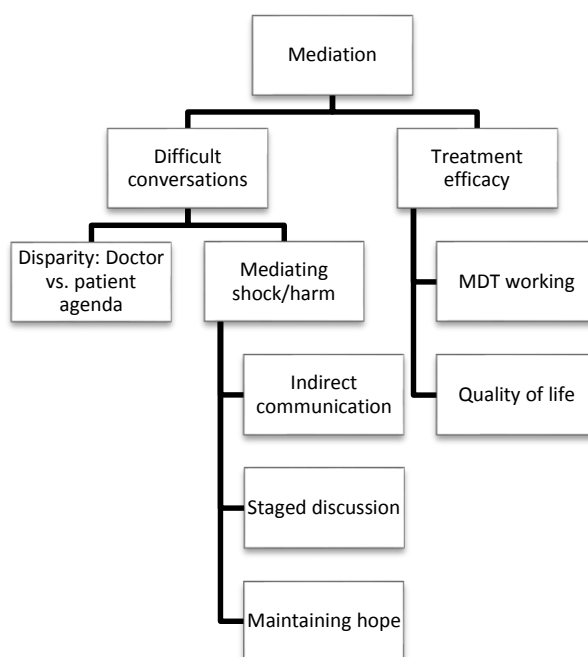


Figure 13 Third core category: mediation

The final core category emerging from data analysis was termed mediation. This was so named as clinicians spoke of difficult conversations with patients with heart failure, mediating what was revealed to the patient and their family. Conversations were significantly influenced by the fact that treatments for heart failure have improved in recent years, alongside multidisciplinary team working, both of which were felt to have improved mortality and therefore lessened the need for difficult conversations to occur.

### 4.3.1 Difficult conversations

Conversations surrounding the diagnosis, management, treatment, and prognosis of heart failure with patients and carers were often described as difficult. Prognostic and palliative/end of life care issues were particularly difficult and contributed towards the delaying of this information, described previously. This section focuses on these conversations if/when they actually occur, and the steps taken by clinicians to mediate the amount and type of information relayed to patients and their families.

#### 4.3.1.1 Giving a diagnosis

Some clinicians spoke of their dislike of the term 'heart failure', they felt it was too emotive and inappropriate for the patient to hear.

*I mean, how would you ... explain heart failure to someone? I would always try and not use that term, although I probably tell them that this is the medical term, it is heart failure... I don't like the term heart failure because failure just sounds like you're about to pop it which generally speaking they're not. [GP4]*

Explaining the diagnosis in layman's terms was important for clinicians as they felt it facilitated patient understanding. Relating heart failure to the gradual 'failings' of other parts of the body as a natural symptom of ageing was commonly reported;

*in simple language, accurately or non-accurately, it basically just means that the muscle of the heart isn't working as well as it was, 5 years ago or whatever, just like the muscles in their legs probably aren't either. Erm and so it's just working harder to pump the blood around, so that's kind of how I would explain it. [GP4]*

Clinicians also felt that it is important for their patients to understand the cause of their heart failure and explain that when giving a diagnosis;

*I suppose it's [diagnostic conversation] going to depend on what the cause of the heart failure is. [GP5]*

Heart failure nurses in particular spoke about using creative approaches to both explain the condition and the origin of the condition in ways in which the patient could access and understand – connecting the dots for them;

*Erm, and then the patient may say well what's caused that?... And then of course we have to talk about the signs and symptoms of heart failure, which a lot of them still have but then they can relate it back to why it's all happening. [HFN1]*

*[The patient] might then say I don't understand anything about [their heart], you really have to start from scratch, explain in the anatomy, the anatomy and physiology of the heart, drawing pictures of the heart to show them that it's probably the left muscle that's got enlarged and is failing a bit, so they really understand what's going on. We have models of hearts as well that we can show them, so we can show them a normal sized heart, and a heart that's got heart failure. So they can look at that and think, oh yes, you know. [HFN1]*

Heart failure nurses also spoke about often having to relay a diagnosis to a patient as they hadn't been told directly, despite their visit being precipitated by the patient having an acute admission to hospital and being diagnosed with heart failure. Specialists and GPs did not speak of this.

*A lot of patients that are discharged from hospital with heart failure, aren't told they've got heart failure. [HFN1]*

Promoting patient education was deemed to be helpful to treatment adherence by all clinicians.

*So getting them to understand why they need the treatment and what the benefits they might expect from that are. [GP5]*

*I think that that's a very big part of the treatment of heart failure, the input from the nurses in terms of their advice, their education about heart failure, the management of drugs, exercise programs, that is probably even more important than medication is that we give them. [SS1]*

#### **4.3.1.2 Giving a prognosis**

Prognostic and palliative/end of life care conversations were often intertwined with one another. Many clinicians reported only giving a prognosis alongside palliative/end of life care conversations, and some reported never giving a prognosis at all. Prognostic messages often centred on the 'admittance' of the clinician to the patient that they did not know, and clinicians negotiated this particular aspect of communication in different ways, including morality;

*[describing average interaction with patient] ... But I honestly can't give you a date, a time, or a length because quite often I'd be wrong, so it'd be wrong of me to do that. [GP1]*

*Why bring up their prognosis when you don't actually know the answer? And secondly, because it may be 5, 10 years and so people do immediately think, why is the doctor talking to me about my place of death? [GP4]*

Many clinicians spoke of prognostic conversations with patients centring on the natural process of aging, with most heart failure patients being elderly. Often clinicians would anchor prognostic uncertainty on the nature of humanity, living and inevitably dying;

*But if you're telling somebody that you know, they're old and they're gonna die, should we be telling all 80 year olds that they're gonna die! Because, you know, in the next, whatever their life expectancy is, it's not gonna be that great, the older we get. The fact that you've got heart failure just speeds that process up a bit, and it's often hard to put a figure on it. [GP5]*

Timing of prognostic discussions was a topic which provoked different reactions in clinicians. Many clinicians found it difficult to speak about a prognosis for fear of upsetting the patient. Others spoke of constructive discussions and avoiding prognostic conversations when they felt that they would be of no use;

*And if you can't do anything to change that [terminal nature of HF], then you know, what's the gain for anybody in terms of scaring them? It makes, makes a difficult conversation for us, it leaves the patient upset and miserable at the end of it, erm, and at the end of it all, who's gained, and what have they gained? So I don't think it's just a personal avoidance, there's nothing positive to be gained from it. [GP5]*

*It is just difficult to decide on when to bring [prognosis] up. If it's brought up too early, then they might just be, they might not get it. Some patients, it might affect them negatively, and they might feel that there is nothing to look forward to and there is no hope and it might have a very negative impact on them. But on the other hand, there are some people who would say that I would like to get these things done that I want to do, I want to plan that. [SS1]*

Another clinician felt that speaking about palliative/end of life care might, rightly or wrongly, provoke the clinician into feeling that they have failed the patient, hence their decision to avoid the subject entirely. Either way, the majority of clinicians reported that they would not speak about a prognosis, or palliative care, early on in the disease course with various reasoning such as cruelty and deeming the issue to be non-constructive to treatment;

*[I would only have the conversation once treatment was failing] rather than right at the diagnosis because it's almost like saying, you know, I'm afraid you've got heart failure, you'd better start thinking about how you're gonna die. I think that is almost cruel. [GP1]*

*So, you're not gonna have those discussions when someone's diagnosed with diabetes or heart failure. [GP4]*

*There's no point scaring them to death for something you can't do too much about. [GP5]*

Some clinicians reported experience of patients asking them directly for a prognosis, others remembered this occurring rarely – to discuss 'the elephant in the room';

*[when asked if they get many instances of the patient wishing to discuss how long they've got left] No. very, very rarely. Erm, relatives, say with patients with dementia*

*or people that aren't completely with it are much more common, but actually with the person, very rarely. [GP4]*

*But not very many patients say to me, look is this very serious? Am I going to die of it? That doesn't seem to happen very often in my experience. [SP2]*

*[int: Are you ever asked [about prognosis?]] Yes, a lot. [int: A lot?]] Yeah, when patients, especially when they're hitting, they're at a poorly stage. They'll say, come on (name), how long have I got? You know. [HFN1]*

*I have [spoken about PC issues] when I've been asked it directly. [GP1]*

Parallels were made with cancer, where clinicians felt more able to speak freely about palliative and end of life issues, and at an earlier point in the disease trajectory. Some clinicians described how they would speak to a patient with cancer;

*I'd always say to them [patient with cancer], how much do you want to discuss? You know, how much do you want to know, and how much you want to discuss about the future? And some people will say, I don't wanna know any more. Just take each day as it comes. And other people will be like, I wanna know everything, and anything I can possibly do.[GP4]*

However whilst the importance of prognostic conversations with cancer patients was recognised, just as with heart failure patients, palliative care issues were often left uncommunicated even in this group;

*I wouldn't necessarily separate it from other non-cancer patients. Erm, and so I think when I see one of our cancer patients, we know that things like their choice of place of death isn't always, isn't usually discussed beforehand... I suppose if there was a QOF target, you know, have you discussed place of death with this person, with a terminal illness? Erm, it probably would make us do it, sadly! [GP4]*

One GP was clear in speaking about simply avoiding what they deemed to be unnecessary conversations, unnecessary due to their inability to cure heart failure. Again, cancer was seen as easier to speak about;

*Well I don't know about other doctors, I don't like having difficult discussions [about prognosis, with patients] I don't need to have. Life's difficult enough already, why make it more difficult? I suppose because of the lack of being able to do anything about it. I don't mind telling someone they've got skin cancer but we can do something about*



*it, we'll cut it out or whatever. Erm, or if it's spread then you've gotta have the difficult consultation. [GP5]*

#### **4.3.1.3 Disparity: doctor vs. patient agenda**

One strong element which clinicians felt made heart failure related conversations between themselves and their patient difficult was a perceived negotiation of information required by either party, and the wish of either party to communicate information they felt was important to get across to the other – such as information about symptoms and functional ability. This negotiation extended to prognostic communication, where clinicians spoke of ‘fishing’ for information which they felt was required for them to make an assessment as to how much information the patient and carer want to know about the future. Some clinicians also spoke of how patients would communicate seemingly unrelated information about their life;

*They start asking completely unrealistic things about, you know, so Doctor when will he be well enough to go on his holiday to America? That sort of thing. And I'm sort of sitting there thinking, I've just had this conversation about the severity and the complexity of the problem! [SP1]*

This mismatch between perceived priorities was described as frustrating at times, however other clinicians maintained that whilst this information may not be directly relevant to the clinical condition, it was still relevant to the patient and therefore to maintain a holistic view of care, these conversations were still maintained.

Almost all clinicians spoke of the sometimes limited ability or limited willingness of patients and carers to absorb and understand information especially regarding their prognosis.

*Sometimes with some patients despite your best efforts of what you think you've said, the patient clearly hasn't taken it in, or doesn't want to hear, or doesn't understand what you're saying. [SP1]*

*I mean there's always blocks, and patients don't take on board all that we tell them, and likewise we don't necessarily hear all the subtle messages we're getting from them. [GP5]*

Clinicians felt that they needed to make a distinction and subsequent judgement of patient *ability* to absorb information vs. *willingness* to absorb information. This was reported as sometimes difficult, and clinicians felt reluctant to push the boundaries too much;

*I had one of my patients, [he] had no idea what I was trying to say at all. Okay. And I had to, it was, it was quite difficult to decide, should I be more blunt here? Or should I just accept that he doesn't really want to know, and he wasn't the brightest chap, and I just decided that he had his wife there, and just decided in the end not to say too much more at that point. [SP1]*

This would suggest that there may be, from the clinician's perspective, an element of denial in some patients and carers as to the prognosis, a possibility that patients and carers are simply misunderstanding what clinicians are trying to tell them, or indeed that this information has not been communicated in the optimum way for the patient and carer.

Heart failure nurses also spoke about perceived differing patient agendas especially with regards to diagnostic and prognostic communication. Nurses found negotiating these sometimes difficult especially when trying to plan for end of life care with the patient;

*And some people, there will be one specific thing that they can't move past something that they quite often, they'll have an agenda, sometimes their agendas are quite different. [HFN2]*

Despite these communication difficulties, heart failure nurses discussed referring to palliative care, and specific conversations with the patient and their family around what palliative care can offer them;

*[We speak about palliative care] in terms of what symptoms and what support we would like to offer them and what plans we would like to have in place, but quite often that doesn't match with what patients want to talk about, what they feel is important. [HFN2]*

One heart failure nurse found that having these conversations was difficult, especially when they felt they had to push a little to get vital end of life preferences from patients;

*9 out of 10 patients prefer to stay at home and to die at home, and we then have to have that conversation with them, which is, where do you want to die? Because they might to say, well I want to stay home, I don't want to go into hospital, then you have to say, but where would you want to die? And that is really awful, having to say that to somebody, you know? [HFN1]*

Clinicians also described differences between them with regards to their ability to communicate with patients. Whilst heart failure nurses spoke of their perceived ability to maintain a holistic viewpoint and subsequent communication with patients and carers due to their ability to make home visits, one GP thought there were differences in holistic communication between primary and secondary care in general especially with regards to communication skills training;

*I do actually think that that's where GPs are, in my opinion, a lot better than secondary care doctors because... I think we have a better training around doctor-patient communication, holistic care, understanding not just the medical aspects but the social aspects and the interactive aspects of our patients. [GP1]*

#### **4.3.1.4 Mediating shock/harm**

Related to the sub-category of disparity of informational needs was the mediating of shock/harm for the patient. Clinicians felt this imperative to avoid harming the patient both in a medical, administering treatment sense but also to avoid harm with how much they revealed to the patient, and when. This became an important sub-category of mediation due to the sheer amount of time clinicians spent speaking about this subject in interview, and the different strategies and ways detailed which they felt would mediate information given to the patient and carer.

Some clinicians, mostly specialists, asserted that they were regularly asked by the patient's family not to reveal the prognosis to the patient and so the specialist respected the family's wishes;

*And actually the relatives are the first ones to tell you, 'please please please, don't tell Doctor, my husband, or don't tell what you just told me about the prognosis, he shouldn't know, please I beg you'. [SP4]*

Heart failure was described as a condition which the general public know very little about, especially in comparison with cancer.

*Certainly I think heart failure, unlike cancer, it doesn't give an indication of some, a disease with a high mortality. Heart failure is often thought of as having a heart attack or having heart disease. [SS1]*

*People know that, they will know about all who have had cancer and have died, or things like that. So they know that if you have cancer then the prognosis is not likely to be good. Whereas when somebody comes into hospital with heart failure, they get*

*better with the medications and go home, so it's sort of, it's not in the same league as having cancer, so the expectations are a little bit higher. [SS1]*

If the clinician felt that the seriousness of the situation needed to be illustrated in order to promote concordance or speak about end of life issues, he or she would do so;

*I might use that term [heart failure] to the relatives, if I thought that patient was going to perish imminently or I thought their prognosis was very poor and they were likely to die within the next few months then I might well say that to the relatives, I might speak to the family. [SP1]*

*If I feel there's enough sign that things aren't going to go well, that I would engineer some discussion with the relatives, even if the patient doesn't ask, okay. [SP1]*

*I mean the only reason for scaring them at all is to get them to comply with treatment. [GP5]*

*Just the term itself [heart failure]. People don't know what it means. You know, sometimes, you have to explain that it's more serious than they thought. [SP2]*

*Some people have some sort of denial and you have to break that, to say that this is really serious and it's probably going to kill you, it's as bad as cancer. [SP3]*

#### 4.3.1.4.1 Abstract and indirect communication

Prognostic conversations tended to be reported as indirect, especially when communicating the terminal nature of heart failure. Not speaking about curing the disease was often equated to a terminal discussion by clinicians;

*it's really just talking about, erm, controlling symptoms, not talking about curing things, so with cancers very often you talk about not being able to cure it, it's about controlling it. Erm, so for heart failure very much it's about controlling the disease process rather than being able to cure them of this. [GP5]*

*I always say it can't be cured. We can never cure it, a bit like diabetes, sometimes I say that, it can be an awful disease, it can be well managed but we can't cure it. [HFN1]*

*And you always, especially with advanced heart failure, tell them that this condition is not curable. [SP3]*

Clinicians often spoke of hinting the prognosis at patients in order for them to ascertain how much they wanted to know, or simply to break the prognosis to them in what they thought to be a more indirect, less hurtful manner;

*Other patients might, erm, not ask such a question, and sometimes I give a few, if I feel that their heart function is very poor, and there isn't somewhat, not an imminent danger to them but that the likelihood is that things aren't going to go very well over the next year or so, then I will probably try and dangle a few more carrots in front of them to try and see if they ask the question. [SP1]*

*[I'd say] "I just wonder how much longer there is". Alright. And I just say that, and usually I don't say anything after that. And I just wait, and there's usually a silence... Sometimes I just say, I feel I've said enough, and I say, look I think you need to think about what I've said, and discuss it with your family, and then maybe we can talk again next time you come. [SP1]*

When speaking about a prognosis, either from being asked directly or just as part of a consultation, clinicians reported describing statistics of the possibility of sudden death or the longevity a patient can expect. However this reported narrative was abstracted to the point where the statistics were outlined, then the focus was drawn back to speaking directly to the individual patient and suggesting, in some cases, that whilst the statistics are there, that doesn't mean that the patient will fit into those statistics;

*So, when I talk about the disease trajectory and we talk about the fact that there is a higher risk of sudden death, that tends to bring in with patients, the up and down nature of the illness. [HFN3]*

*So you tend to say, well statistically speaking we are looking at that, but er, that period, statistics, there are patients that, for whatever the reasons is, do much better than that, and their life expectancy even, theoretically is that, they actually er, live and with a good quality of life. [SP4]*

Some specialists spoke about implantable cardioverter-defibrillators (ICDs) and related devices. When a patient is being considered for a device, specialists thought that having a conversation about end of life with the patient was important to achieve. However this conversation centres on changing the mode of death rather than prolonging or preventing death;

*When we talk about a lot of these heart failure patients, they are often referred to have our device or a defibrillator, so in those patients we do bring this topic up, and we just say the reason why we are putting a defibrillator in is to stop your heart from going into an abnormal rhythm, and to get it back, to stop you from dying suddenly... as there is an intervention [device] which could change the mode of death, then it's probably, I find it easier then to discuss dying in that situation. [SS1]*

*Then you'd have to have a conversation about end of life, when you discuss the device, because if you're gonna discuss about a defibrillator then you've gotta talk about why you're putting it in. [SP1]*

#### 4.3.1.4.2 Staged discussion

Prognostic discussions were often described as being staged. Clinicians suggested that elements of the prognosis were revealed more and more in later consultations, and more direct communication was reserved for when they considered the patient to be in end stage heart failure. Honesty was spoken about often, as both a moral imperative and being liberating for clinicians. However again, honesty was not universal and was also staged in the same manner;

*[after prognosis discussion] and then they usually say thank you doctor. And sometimes people say, oh I'm glad you've been honest with me. [SP1]*

*[int: Do you tell patients their prognosis?] Not really, not unless they ask for it. Or if the condition is quite bad, it's quite serious, they'll go into hospital and they probably won't make it out. Then I will tell them. Or if it's really bad, they have multi-organ failure for example, so not just heart failure. They're not going to do well. So the ones that are bad, yes. [SP3]*

*It just comes down to trying to get all of the information over as best you can, or drip feeding it, or supporting it with information, and maybe just working with the patient over a few visits to try and get over what it is that you feel that you need to tell them about. [HFN2]*

*Quite often those conversations are something that you will have again and again in various different guises. [HFN2]*

#### 4.3.1.4.3 Maintaining hope

Maintaining hope for patients and their relatives was a strong theme running through clinician interviews. Hope was seen as very important to maintain for different reasons, primarily to ensure the psychological wellbeing of the patient and their family. As clinicians described the difficulties in prognostication, hope was, in a sense, easier to maintain because of the uncertainty about when a decline would actually occur in a patient and the significant improvements in treatment in recent years (described in further detail later). Speaking about a prognosis early in the disease course was looked upon unfavourably as it was seen to impact on any hope the patient has.

*People love to sit there and tell you, ooh the doctor said I'd be dead five years ago and I'm still here! And I sit there and think, you know, because you've been living with that hope ever since, really. [SP1]*

*It's something [communicating prognosis] that I'm probably not very good at really. For those who are doing well. I prefer to avoid it, if they're coming in and saying I'm fine, then I can't say oh well this may kill you in five years. [SP3]*

*It is just difficult to decide on when to bring this [prognosis] up... Some patients, it might affect them negatively, and they might feel that there is nothing to look forward to and there is no hope and it might have a very negative impact on them. [SS1]*

Speaking about a prognosis was sometimes described as 'certifying' the patient that they were about to die, or that they were drawing a very distinct line which once crossed, could not be taken back;

*And always, even if I have a dying patient, I still talk to him and to the family and say that there is still chance that he may pick up. I don't give them the certificate that they will die very soon. [SS2]*

*We don't ever say [there's nothing more we can do] to our patients, we know that there is nothing more that we can do but because we're constantly changing things, we're constantly giving them new medicines or titrating things or, I don't know. [HFN2]*

#### **4.3.1.4.3.1 Doctor-patient relationship**

Forming and maintaining a good doctor-patient relationship, if/when possible, was seen as valuable especially when discussing difficult subjects with patients and their families, and for prognostication in itself. Clinicians described constructing a relationship as fairly 'fuzzy', and viewed the ins and outs of it as something difficult to 'put your finger on';

*But sometimes it's the softer things such as how somebody looks at you, how they behave to you, how their body languages, that you can't get that feedback from the patient. [HFN2]*

*But other patients, you know, I form quite a good relationship with and, erm, when I feel the time is right I would introduce the subject [of prognosis], there's not a set way that I would introduce it. [SP1]*

Heart failure nurses were seen as having more time to build a relationship with a patient and their family, and so are better placed to discuss prognostic issues. Specialists spoke of the

opposite, not being able to maintain a good relationship with the patient, as often they would only be involved with their care at certain points such as an acute admission to hospital, and simply not having the time to build up a relationship in an outpatient setting;

*And I think that's the benefit of having specialist nursing, we've got the time to be able to revisit things again and again with the patient, and the medics just don't have the time sometimes to tell them. [HFN2]*

*But maybe because we, I talk about myself, maybe I haven't followed the patient for a long time to come to the point to say, your prognosis is poor, or good, or whatever. [SP7]*

The lack of continuity of care was mentioned by many specialists, as their role often only necessitates seeing a heart failure patient during admission or perhaps when considering a device. Heart failure nurses were seen as the clinician with whom the patient would build up a relationship, with the specialist's input only when complications occur that necessitate consultation from the nurse. One GP voiced their concerns about fragmentation of care, and poor continuity of care;

*What does sort of concern me about, er, the NHS currently is that there has been quite a lot of fragmentation of care. Erm, you know, starting it from the point of access in an emergency going from being the GP on call years ago to now, 111 or the walk in centre, or an accident and emergency centre, or an out of hours doctor. But also, there's been fragmentation of nursing services, erm, and you know, you've now got different layers of nursing, you've got junior nurses, sisters, community matrons, specialist nurses... So I do sometimes find there's ... less continuity of care. [GP1]*

The ability of heart failure nurses to provide continuity was seen by specialists and GPs not only to benefit the patient, but also the family, particularly when the patient dies. One nurse explained she felt this gives the nurses closure as well as helping the carer to adjust to their bereavement;

*I mean I phoned [bereaved carer] not so long ago because we do bereavement visits and follow ups, she was in the garage sorting out, she says oh I feel great, you know! So I think if you get that right, right at the end, you've not just helped somebody die at home with dignity, but you help the carer as well in all that grieving process. [HFN1]*

Another part of this theme was the importance of mediating the doctor-patient relationship. Some clinicians felt an imperative of not getting too caught up in the patient's life, and detaching emotionally when necessary, especially when speaking about end of life issues.



*You have to be emotionally detached from that, and professional, and just stand back and let the patient wail, and get it out. And then move on. [SP1]*

At the same time, some clinicians spoke of feeling empathy with their patients, sadness when the patient passes away, and considering how they would feel if they were put in the patient's shoes;

*My experience is that most die in hospital really. It's really sad, because all of those people you really know. Even though you know it's coming, it's heart breaking. Because all of them really, will still be with it, until the last day or two. [SP3]*

*And similarly you could have somebody who's the same age as me, married with the same age children, that you're having that discussion with. [HFN2]*

*I get, find in my old age, now, older age, now, that I just get drawn into this misery of emotion! And I just think, ohh! [SP1]*

Maintaining a good relationship was also suggested as encouraging the patient to report their symptoms – which would then better inform the clinician about treatment options for symptom control;

*So it's getting the patients to identify, what is actually bothering them, what can we improve that would give them better quality of life? [HFN3]*

Ultimately difficult conversations were avoided for many different reasons described above. However one GP was brutally honest as to why;

*[int: And would you have a conversation with the patient about the fact that you're thinking more about comfort at this point?] Erm... I try and avoid difficult conversations! [GP4]*

#### **4.3.2 Treatment efficacy**

The final theme running through clinician interviews in relation to mediation is the efficacy of treatments, particularly drug treatments. These have improved significantly in recent years and clinicians were keen to speak about their use, particularly for prolonging life and lessening the impact of symptoms.

*We've got better ACE treatment and know more what we're doing with beta blockers. So we're seeing slightly less of it [HF]. [GP2]*

*I mean, we, when I first started, what 9 years ago, it used to be they're all dead within 5 years and a lot of them were. But now I've got patients on my books for that length of time, so it's proving that if they're on the right treatments, they're gonna live longer. [HFN1]*

*[Treatments were] so different five years ago, 10 years ago, it's so different now. [SS2]*

#### **4.3.2.1 Framing prognostic conversations around treatment**

Most clinicians, particularly GPs and specialists, described prognostic conversations as being framed around treatment options and treatment changes. Palliative care was often regarded as a change in medications, rather than a change in the wider paradigm of care and treatment. Some clinicians, particularly heart failure nurses, viewed it as both, but mediated how much the patient and carer knew about the transition to palliative care by framing it around treatment options and changes rather than discussing the wider shift of care;

*The only time I probably would have mentioned [prognosis] directly to the patients are when patients come into hospital severely decompensated, where they are very breathless. And in that situation sometimes then I would probably sort of say that there are other things that should help you which keeps you comfortable, and we are looking at morphine which might help you with the pain, might keep you, reduce the breathlessness. And you may not need to take these medications because they're probably not helping you a great deal, but we would stick with something which keeps you comfortable. [SS1]*

*[describing talking to a patient about PC] And we need to be, we're not stopping treatment, but we're looking at different treatment now. [HFN1]*

#### **4.3.2.2 Multidisciplinary (MDT) working**

Multidisciplinary team working was deemed by all clinicians to be vital in the management of heart failure patients. Some clinicians spoke of good practice with regular team meetings with different specialities, whereas others saw a lack of team discussion. GPs and heart failure nurses mentioned consulting specialists and Macmillan nurses when they felt their skill set did not extend to the specific patient's needs. Conversely, only one specialist spoke about liaising with GPs.

*What we do in my practice is that we have monthly meetings with the, sort of, the palliative, the team. And who comes to that are all the GPs, the district nurses, the*

*Macmillan nurse, erm, and er, occasionally we have a hospice nurse there if we've got a patient in the hospice which isn't very often. With heart failure. [GP1]*

*It has to be a team approach, and I mean, if the team approach doesn't work, then often the patient ends up in hospital. [GP1]*

*I also feel that communication, that we're reaching that point, from cardiologists, would be helpful. Some cardiologists are really good about saying, we've reached the point at which I'm unlikely to make a difference and I should stop trying to, because that helps us then to have, to repeat the conversation and not look for some better cardiologist, or something more that they can do. [GP2]*

*You sometimes get help if you're running into problems, you might get help from specialist services, the cardiology service, the heart failure service, Macmillan nurses, or whatever. [GP5]*

GPs in particular spoke of their responsibility as the 'lead clinician' for the patient, having 'ultimate responsibility' for that patient;

*Ultimately we're the responsible clinician for that patient, I think a lot of the responsibility falls on us to communicate it, and coordinate everything. And we're having to do that more and more, actually. [GP1]*

MDT working was also described as communicating across specialities and clinician groups. In particular, heart failure nurses were seen as a vital conduit of information to both GPs and specialists. Whilst this worked well most of the time, one specialist described their experience of struggling with an uncooperative GP;

*I do think a big role of the specialist heart failure nurses is that supportive role, and acting as a conduit to their general practice, to secondary care if necessary, and if that isn't providing anything more, to the hospice. [GP1]*

*I've had other situations where I've found it extremely difficult to persuade the GP that the problem is not solvable. And that, you know, I had one over in [town] where the GP kept sending repeated letters saying that the patient needed their problems sorting out, they needed this sorting out, they needed that sorting out... I spoke to the GP and said, look, I said this woman needs a palliative care package at home, she's dying, and that's how she needs to be cared for. He says, well I can't do that! And I said, why not, what else do you do, you know? [SP1]*

#### 4.3.2.2.1 Ownership of care

When speaking about treatment, clinicians worded the way in which they spoke to patients with a sense of ownership of care and treatments offered. Related to the element of taking responsibility for the patient, when discussing treatments clinicians would suggest that they were personally offering treatments, and personally governing the terms that they used when speaking about heart failure;

*Usually I tell [patients], you know, there's nothing much that I can do for you to improve the symptoms of this. [SP3]*

*I tend to explain to the patient that we've got to the stage where unfortunately we have no more treatments we can offer. [GP1]*

The term 'heart failure' in itself was controlled by some specialists;

*So I don't usually say to a patient, you have heart failure. Okay, all right. I just find it, myself, a bit over the top, a bit forceful. [SP1]*

*I don't always use the term heart failure at that point [diagnosis], but later on at some point when I start introducing medications I will say that these medications have been shown to keep things stable in heart failure. [SS1]*

Whilst personal ownership of care was exercised, team work was seen to feed into this as a supportive mechanism, especially when treating end stage heart failure;

*If you tell somebody, you feel more supported if you say that together, we have come to this conclusion [that the patient is close to death]. So you feel that you are not letting somebody down. [SS1]*

#### 4.3.2.2.2 Singing from the same hymn sheet

All clinicians valued MDT working as it helped them to come to a consensus when treating a patient, acknowledging and using the views of different specialities to come to a conclusion as to what the next steps should be in the patient's care. However this did not always occur despite universal acknowledgement that it helps;

*I think what would probably help was a more joined up approach about when you've given an indication that the problem is terminal, that's you know, then everybody who's involved in the patient's care needs to kind of be singing from the same hymn sheet. And where I think things go wrong is when there's a breakdown in that process, okay. [SP1]*

*But it probably would help if the heart failure nurses and others could meet them regularly to talk about some of these patients, who we have seen a significant decline, and then we could probably all arrive at a consensus, we could say that this is the time to start planning. [SS1]*

*I always ask, tell [patients] I'm going to speak to [specialist]... and then I would come back from that conversation and say, you know, we've discussed all the options, we feel you're on the optimum treatment that we can give you. [HFN1]*

MDT working also extended into using new centralised record systems so that all treating clinicians can access notes from all tiers and specialities of care;

*We also use System 1 now which is new, which is a computer system which the GP surgeries use here, erm, but the nurses didn't [before], so it means we can talk to each other now. We can put alerts on the system, do not, erm, this patient is not for resuscitation, this patient's preferred place of care is home. [HFN1]*

However limited knowledge of the different forms and systems used between care tiers often hindered clinician efforts to ensure comprehensive care for patients informed by input from all medical professionals involved in their care;

*I know there are now these new forms [for recording advance directives] that can be used in community and cross between things, but nobody on the ward seem to be very familiar with them yet, and I've asked about it for these heart failure patients but nobody seems to know what I'm talking about. Even though it was on the news, they don't understand what I'm talking about. [SP1]*

#### **4.3.2.3 Quality of life (QoL)**

Quality of life was deemed to be an essential part of care, to be maintained both during active treatment and palliative care. The term quality of life was often seen as synonymous with palliative and end of life care, being the most important consideration when making the transition between these care specialities;

*[describing conversation with patient] Other people just continue to fill up with fluid and get breathless, and we have ways of ensuring that you don't suffer from that. [GP1]*

*It's really just optimising the treatment to improve their quality of life. There are some drugs which are designed specifically for reducing the impact of the heart failure, so*

*improving survival, and others which are more for symptomatic relief, where there's perhaps less good evidence of them being, erm, effective in improving survival. [GP5]*

*If they [the patient] are with it enough then you come to the decision in thinking, actually we're now gonna be looking at, I just look at it as we're now aiming for quality of life rather than quantity of life. [GP4]*

#### **4.4 Chapter summary**

This chapter has presented results from general practitioners, cardiology specialists and specialist heart failure nurses who participated in interviews for the current study. Whilst the reality of death was acknowledged, this was compartmentalised in such a way that it was not deemed as applicable to their own patients due to the clinical uncertainty of prognostication. Prognostication was a staged event whereby clinicians came to terms with their patient having a poor prognosis privately, often in line with 'trickling down' staged prognostic information to their patient, if they deemed it relevant. However the data demonstrated clear evidence of good practice around addressing symptoms and working in a multidisciplinary team, particularly heart failure nurses who involved palliative care services on a needs based approach, discussing it when appropriate with the patient and carer. All clinicians found communicating a poor prognosis to be difficult, often equating it to 'certifying' death to a patient. Several felt under skilled in this area – particularly specialists and to a lesser extent, GPs – and/or they felt that it was simply not their role to communicate a prognosis. Similarly, several clinicians felt that palliative care was not part of their role.

The following chapter will report observation and interview findings from patients and carers involved in the study.

# Chapter 5 Patient and Carer Analysis

Presented on the following page (pg 129) is the modified constructivist grounded theory framework of patient and carer perceptions and attitudes towards end of life care in heart failure (Figure 14). Core categories of the start of health problems, living in the present, and living with an unknown future are presented along with their sub-categories. Each category is then discussed in turn throughout the chapter.

Quotes are denoted as follows:

[PT] is a patient with heart failure

[CR] is a carer of a patient with heart failure.

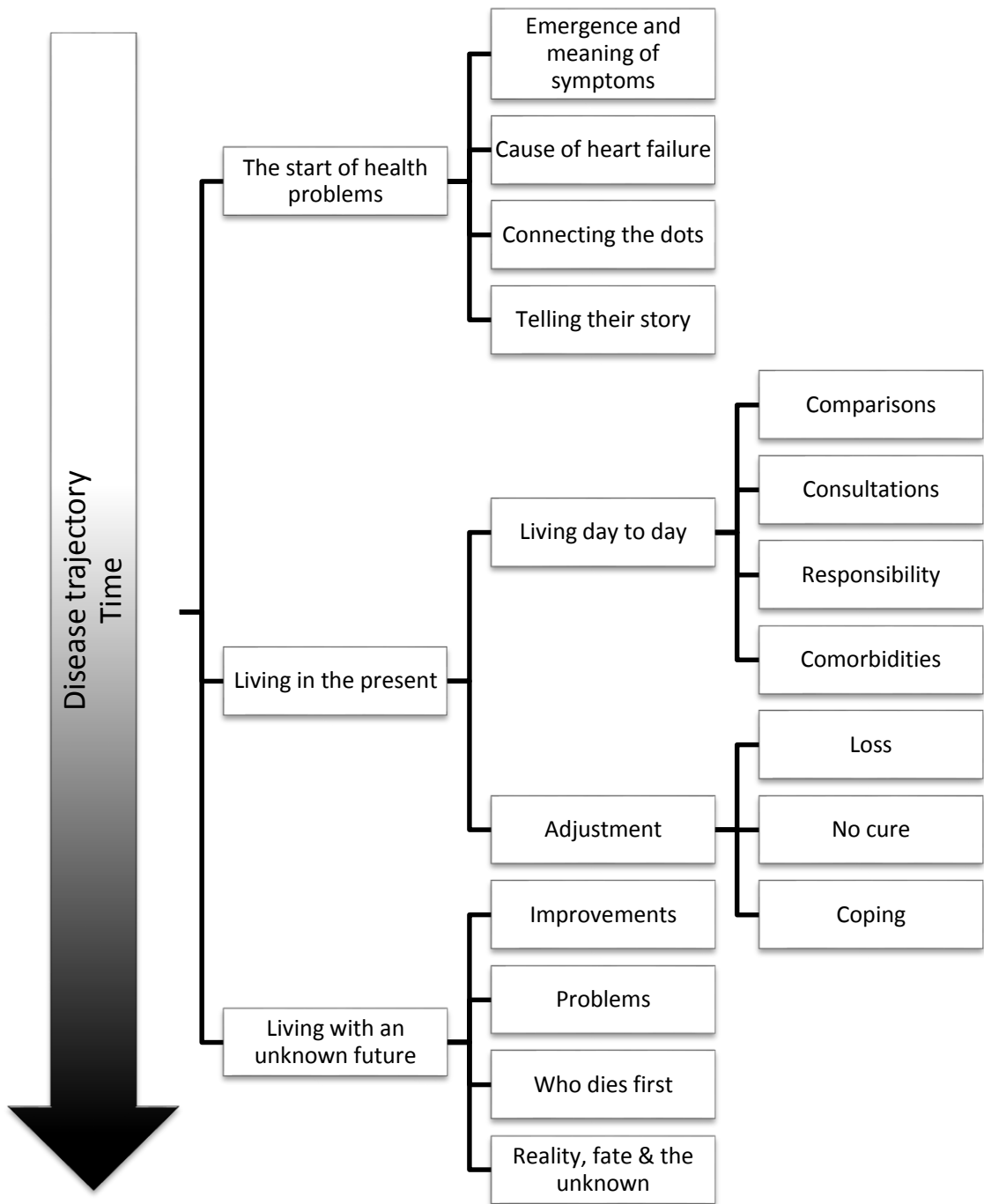


Figure 14 Patient and Carer explanatory framework



## 5.1 The start of health problems

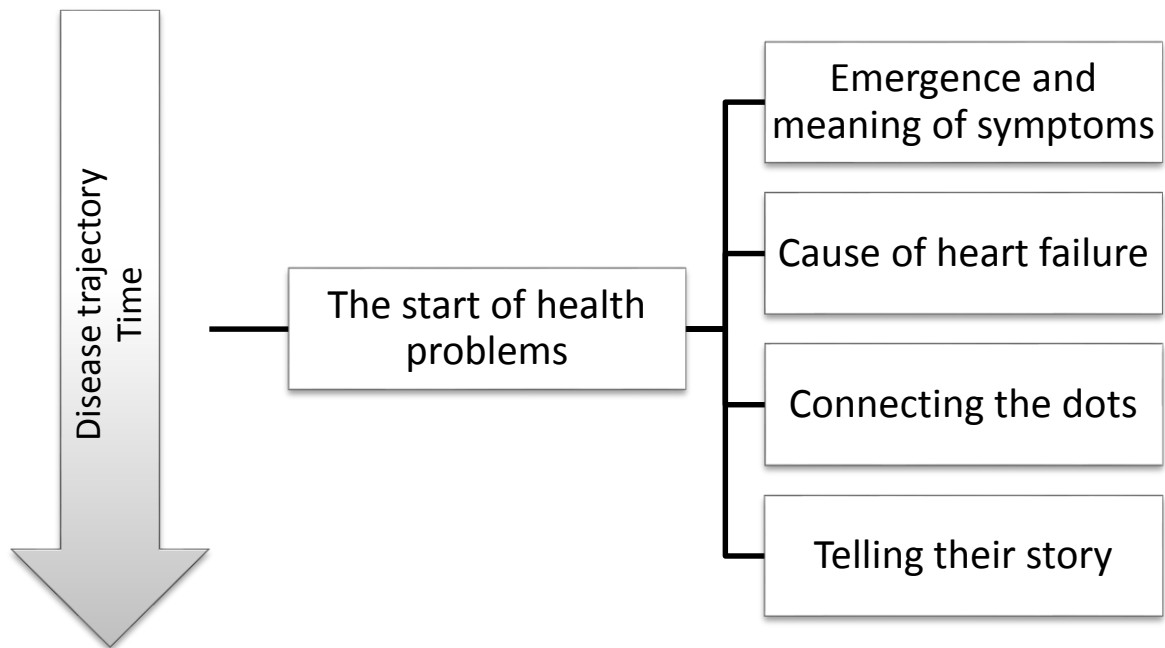


Figure 15 First core category: the start of health problems

All patients and carers were asked about the moment they were diagnosed with heart failure, and how they felt about the diagnosis. For most participants, this elicited detailed stories about the very moment they started experiencing symptoms (not necessarily heart failure, many explanations about the diagnosis point of heart failure were actually about the first instance of a heart attack). Four categories of these detailed stories were identified; emergence of symptoms, searching for the event or part of their body ‘responsible’ for developing heart failure, connecting the dots between their symptoms, their body, and their subsequent understanding of heart failure, and a general sense of wanting to ‘tell their story’ of their health and life as they saw it, integrated within their experience of developing heart failure.

### 5.1.1 Emergence and meaning of symptoms pre/post diagnosis

When asked about their heart failure experience, most patients described the emergence of symptoms related to their heart which often occurred many months or years prior to a formal heart failure diagnosis. Prior to formal diagnosis, symptoms were often attributed to indigestion or viewed as something natural that happens with aging.

*I didn't fully understand the implications of [the symptoms]. I thought maybe it was just as I was getting older. [PT14]*

These symptoms were reported to have become more and more unmanageable to the point where, especially in the case of breathlessness and pain, an ambulance was called or the patient attended their GP and after investigation, a diagnosis of heart failure was made. As such, participants spoke of coming to a realisation, post diagnosis, that the reason they had been feeling unwell for some time was due to developing heart failure.

*Last year I started with palpitations and hadn't been feeling well all over the summer, and I knew something wasn't right, I wasn't myself. [PT7]*

Past symptoms which were previously not understood, or misunderstood/misattributed to other causes, were explained by patients and carers as now being part of heart failure. These pre-diagnosis symptoms were viewed as important for participants to understand, so they could trace back to when symptoms first emerged.

*But I always knew, having had, I realised I had had problems for many years before I was diagnosed, and it was only when I was diagnosed when [clinician] said you've had a heart attack that I realised all those years ago, when I was having what I thought was indigestion, and it wasn't. [PT9]*

Prior to this the vast majority of participants did not suspect heart failure, possibly because many did not know what heart failure was. As such, patients and carers re-interpreted their initial symptoms as now being part of their heart failure, and assimilated them into their emerging heart failure experience.

### **5.1.2 Cause of heart failure**

Once the shock of the diagnosis became less raw, most patients and carers set out immediately to find out the cause of their development of heart failure. Participants reported that most clinicians volunteered the possible cause, which then prompted the patient or carer to seek directly from them information about whether or not it was their 'fault', if it was something they could have avoided, and to possibly have something they could place blame upon. Having this explanation (where possible) seemed to reassure patients and helped them to understand why they had become so ill. Some patients spoke of being told they had scarring on the heart which was possibly caused by a prior childhood illness, which they were unaware of;

*[the consultant] said that they'd found some scarring on the MRI. And they think it's been caused by a virus, Erm, she doesn't know when it happened or how, but that was the results of, of the MRI. [PT7]*

*According to [cardiologist], I've had rheumatic fever when I was little but I can't remember. [PT2]*

Some spoke of the unfairness of developing heart failure if they had not smoked in the past;

*She's never had a puff of a fag in all her life! She's never even touched a cigarette. [CR7]*

*I have never smoked and I don't drink very much. I try and eat healthily, tons of fruit and stuff. It's just one of those things isn't it, you do the right things but then it still creeps up on you. [PT14]*

However some patients and carers spoke of the development of heart failure as not connected with their health related behaviours. These patients tended not to speak about seeking an external cause for their heart failure. One patient in particular had both COPD and heart failure, but mentioned her prior smoking only once, in passing.

Most patients and carers expressed a wish to understand both the cause of their heart failure and the symptoms and internal circulatory/cardiac mechanisms underlying the condition. This led to the formation of the theme 'Connecting the dots'.

### **5.1.3 Connecting the dots**

When recounting the moment of a formal heart failure diagnosis, often patients and carers spoke of misunderstanding the term 'heart failure' – equating it with heart attack and thoughts of imminent death;

*I always connected heart failure with suddenly stopping, and you're dead. You know. [PT8]*

*Failure, the word failure is synonymous with things that fail. And if you, if something fails, then there's something wrong there has to be put right or it comes to the day where it fails, period. And you finish up in a box. [PT10]*

*I had to have it explained because I didn't know the difference between heart failure and a heart attack. I thought that, if you had heart attack your heart was a failure anyway by giving you a heart attack. It's, heart failure is more long-term than a heart attack. A heart attack, you can get over it. [PT12]*

Patient and carers also discussed their reaction to a perceived staged nature of diagnostic information. Many patients reported that they were not told they had been diagnosed with heart failure until subsequent appointments with their specialist heart failure nurse, who then

had the task of revealing the term 'heart failure' to the patient and carer. All patients and carers who reported finding out in this manner spoke of a shock when hearing the term.

*But it wasn't until [specialist heart failure nurse] came up to see me between Christmas and New Year, the heart failure was mentioned!... Well when she just said, she said you've got this heart failure, and I said what do you mean heart failure? And she said it's just the term that we use, the term, actually hearing it I sort of took a bit of a step back you know. [PT7]*

Despite this initial alarm, patients and carers reported feeling more optimistic about their diagnosis and prognosis once the nature of heart failure was explained to them, with strong reassurance being given from clinicians that it is seen as a chronic condition rather than a more serious, terminal condition;

*[participant re-counting their clinician's conversation with them]... And you will have permanent heart failure, and it's not something to panic about, it is because of what's happened, it doesn't mean it's going to stop working at any time now, it just means you can't do what used to be able to do because of the damage. [CR11]*

*Well, we were a bit taken aback of course, if somebody says you've got heart failure, you think, right I'm going to die because the heart is failing, you know? But of course once [specialist heart failure nurse] visited us, she was very good and answered all the questions that we had for her. So we just sort of accept it now, that that is what he has got. [CR10]*

Patients and carers felt that clear explanations were given by clinical staff and this was universally appreciated, helping them to understand the condition and feeling that this lessened any possible negative psychological impact;

*I think they do very well trying to make you understand, not to be frightened, you know. And it does help, definitely. Because if you don't understand a heart attack, you are very frightened. But once somebody begins to explain, you know, I mean why did I have a heart attack, I've never had any trouble. You know, and they explain that, and it's good. [PT11]*

However other patients struggled more significantly with the diagnosis, especially when they felt it had not been explained in the most sensitive manner. It seems that the manner and wording of the diagnosis is crucial for patients;

*I had never heard of heart failure. And if [the consultant] had just said, you know, you're going to have to be careful, don't try all of the things you've done in the past,*

*be much more careful, I could have coped with it, but he said heart failure and of course I had no idea what heart failure was...I think it would have been better if [the consultant] had said more at that time. He just said, you see the trouble is [name of patient], you've got serious heart failure. Well that meant nothing to me; it was just a death sentence almost. And I think, if he had explained that, you know, it's not quite as bad as it sounds, it needn't be as bad as it sounds, I think maybe it would have helped. [PT13]*

Some patients spoke of perceived discrepancies in their diagnosis and/or the information given to them by clinician, which often made them feel anxious but in most cases did not prompt the patient or carer to investigate further.

*[produces photocopied clinical notes] This is my cardiac history on the something of December when I was first admitted, they admitted me with a heart attack, you can see that on there. It says severe LVSD, reasonable RV function, mild TR. And they've ticked the heart failure. So I mean, for [the consultant] to write that, I couldn't understand it. And I still don't to be honest with you, not 100%. [PT12]*

Overall, most participants strove to understand why they developed heart failure and reflected often on past health issues and symptoms to see if they could be explained with the diagnosis.

#### **5.1.4 Telling their story**

In explaining the start of their health problems, patients would often speak at length about events leading up to their formal diagnosis of heart failure – often heart attacks rather than symptoms associated with heart failure. Details such as where they were at the time, what they were doing, and what other people said or did were included in their stories.

*I thought, when I was driving me car, and I had trouble, me pain. The big accident. I was down [village], and our lass says, you don't look well, she says sit in the car a bit. She said, what you gonna do? I said, I'll drive home. Five miles an hour, I'd just got out here, and she dashed over for the neighbours, she says look after [him], I'm sending for an ambulance, he doesn't look, he looks as though he's having a heart attack, and I had a one then. That was me big one [heart attack]. [PT3]*

Others pointed to life events as being a possible cause of heart failure, particularly stressful and (physically) painful times;

*You see a fortnight before [the heart failure diagnosis], her sister lives in Norfolk, down that way, and she had come up for some do. We couldn't put her up where we were, and I think the stress of all that, because we had to keep running her back, and I think*

*that didn't help, the stress and all that.. She's got trouble with, something to do with the bones now, you see. Osteoporosis. And I think it has stemmed from the operation that she had on her back. She shouldn't have had that, and it has put too much pressure on her. You see she can't walk, she struggles from here to the car. And of course that has put more pressure, I think on to the heart. That's what I think, you see, because she struggled when I don't think she had needed to struggle. [CR12]*

Most patients and carers communicated a fairly well-rehearsed 'story' of their first heart attack or heart trouble, bringing in elements of their lives at the time and how they felt. The details of these stories seemed important to get across, as patients and carers experienced their health problems in a holistic backdrop of the rest of their life as they saw it.

## 5.2 Living in the present

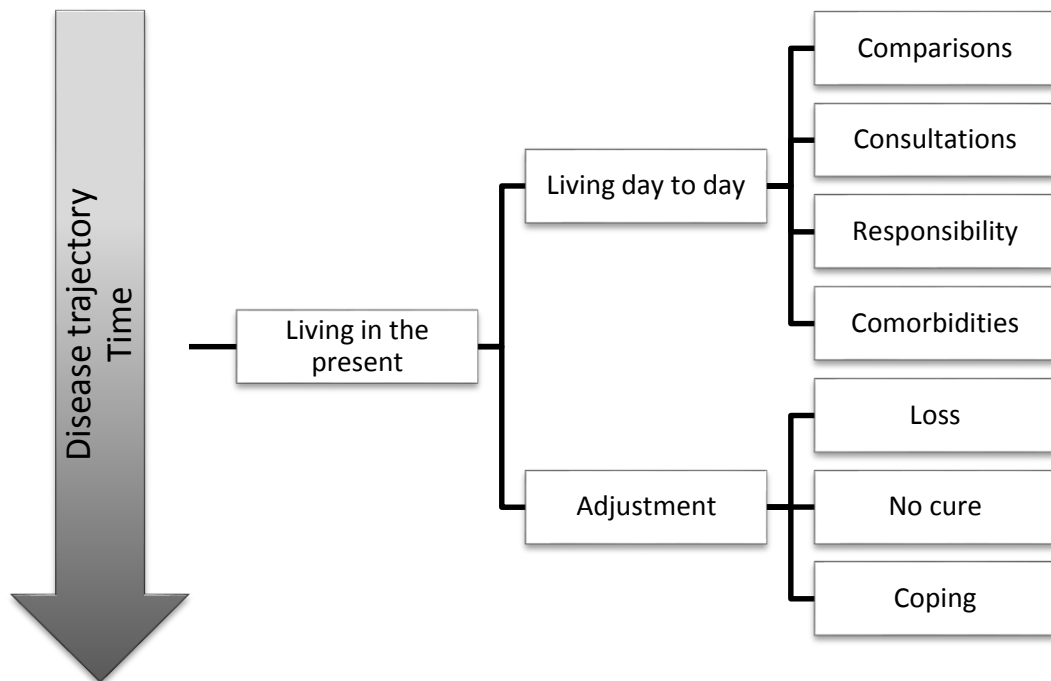


Figure 16 Second core category: living in the present

All patients and carers related the impact of living with heart failure, as it stood at the time of the observation and interview. Whilst the start of their health problems was seen as important to acknowledge and explain, the way in which they lived their life, day to day, was seen as essential to their experience of having heart failure. This included descriptions of clinical encounters, taking responsibility for their health, descriptions of comorbidities, and making comparisons between them and others such as other heart failure patients, and their own families and friends.

### 5.2.1 Living day to day

Day to day living was a strong theme running through most observations and interviews. Patients spoke of taking each day as it comes, trying to enjoy the present day and not thinking needlessly about the future. Thinking about the future too much was seen as unnecessary and akin to worrying, which participants were keen to avoid.

*It's just a day to day thing as far as I'm concerned. I'm quite happy to go down the allotment and come here, and maybe just go, a little bit of this and that roundabout. I'm not that bothered about anything, really. I just potter about. [PT13]*

*We are really just not thinking about [becoming more ill], we are going on day-to-day and so forth. [CR13]*

Living life in this way ensured a focus of making the most of one day whilst making few comparisons between functional abilities now and in the future.

#### 5.2.1.1 Comparisons

Both patients and carers would often make comparisons with others, specifically regarding their health. Often this would involve comparing themselves to siblings, parents, friends, and even death notices in the paper. Most of these comparisons led to the conclusion that they were doing well and indeed better than many others.

Whilst some participants spoke mostly of their current day to day difficulties with functional abilities, others made more comparisons with their life before they developed heart problems, and when they first felt unwell. Some spoke of how lucky they felt that they were able to recover from being very unwell from a heart attack or heart failure decompensation – and whilst they still struggled now, they were glad to be better than they were back then. Others mourned the loss of their life before their diagnosis of heart failure. Either way, almost every participant spoke of a change in their lives – both in relation to functional abilities and also in relation to their own personal identity – compared to before, and mostly negative.

##### 5.2.1.1.1 Negative comparisons

The majority of patients did not compare themselves negatively (health wise) with others, however some did – particularly comparing their progress;

*You know, lots of people who have had heart surgery were back to where they used to be, but I didn't. [PT9]*

The reaction to this when questioned was that whilst they would have preferred to have experienced better health than their peers if possible, it was merely bad luck or fate that they

had been so unwell. Participants spoke of drawing on the positives of their disease management where possible.

#### 5.2.1.1.2 Favourable comparisons

Favourable comparisons, on the other hand, seemed to be linked into a sense of maintaining hope. Often patients and carers spoke of their age and felt they had 'done well' considering age at death of others that they knew, in particular their parents and siblings.

*We get about all right, and I suppose, when you read through the obituaries, what a funny thing to say, and you look at their ages, we are doing all right. [CR2]*

*I've outlived both my mum and my dad, they were both in their 60s. [PT2]*

*I mean, I'm 76 this month. And I've always said when I hit 76 I'm going to look up, because my dad died at 76, and I want to know how many months I'm going to beat him by! [CR9]*

Age seemed to be a significant benchmark of a favourable comparison with others, and was a source of pride – in some sense – that they had managed to 'get to' their age – and so heart failure or some other serious illness was acknowledged as more or less inevitable or to be expected with such an advanced age.

#### 5.2.1.2 Consultations

Thirteen consultations were observed and conversations focused almost solely on pharmacological medical management of current symptoms. Living in the present involved appointments with health care staff – for individual participants, ranging from once every six months to multiple times a day – and these appointments quickly became part of the routine nature of life. Clinicians working in the heart failure service were, on the whole spoken of highly, in particular the specialist heart failure nurses. Praise centred both on feeling thoroughly 'checked out', in a medical sense, and how the nurses communicated during appointments, in relation to education, medication advice, and a general concern for the patient and carer's wellbeing.

*I think they are very easy to talk to, the heart failure nurses... Whereas when you go for a consultant's appointment, I tend to get a bit tongue tied. [PT7]*

#### 5.2.1.2.1 Team effort

Living with heart failure was not seen as a lone experience for those patients with carers in the study. Patients and carers had already negotiated between themselves regarding the



carer's attendance at the patient's appointments, sometimes to the finer detail of which one would listen to which parts of the consultation so that all of the information was remembered afterwards. Carers often spoke of wanting to attend appointments when they could, as part of their 'role'.

*I go everywhere with her to see all the doctors, I go to see all of them. Because I think, when we are talking to the doctors, what she misses I will remember and what I have missed she will remember. That's the way I think. Two is better than one. Team effort. [CR12]*

*Oh I always go [to patient's appointments], yes. In with [consultant], yeah. Same as when the two lads were born, I was there to see them on. You like to know, you'd like to be there, you know! [CR9]*

*You know, he always likes to do things on his own. Like yesterday, when he had to go to the hospital I said, I will come with you. He said there's no need. You know, so he lets do it on his own, he likes to go himself. [CR13]*

As such, these negotiations were seen as part and parcel of their (patient and carer) relationship.

#### 5.2.1.2.2 Time and resource pressures

Participants were very aware of pressures within the NHS to complete appointments on time and to discharge patients home once they had recovered from a heart related exacerbation. Often this led to unease and uncertainty that the specialist heart failure nurses could provide a high level of care compared to a consultant, specifically concerning medication monitoring and relatively higher level clinical knowledge which a specialist would be able to provide in comparison.

*I think the heart doctors at the hospital have too much to do, we don't see [consultant]. [PT8]*

*The doctors and nurses, they all did their very best to get me out of that bed as quickly as possible. Because there was always a queue of people wanting to get into the beds. The pressure on the beds especially in the [local hospital] is acute. [PT10]*

Patients and carers also alluded to limiting the discourse with clinicians at appointments due to the recognised time constrained nature of the interaction, particularly in clinic.

#### 5.2.1.2.3 Positive attitudes

The vast majority of participants spoke very highly of their clinical team, particularly the heart failure nurses. Often patients and carers would feel happy and reassured once an appointment had concluded, and reported using humour (on both sides) to chat with the clinician whilst discussing the relevant medical aspects for the appointment. This type of working was valued highly by participants and helped them feel that clinicians were there to help them maintain a certain level of health (if possible) with a friendly, approachable nature. Many of the older participants spoke of how times had changed, whereby clinicians (especially consultants) used to be difficult to speak to and far removed from the daily life of the patient, whereas now they felt that clinicians try and understand the holistic nature of the illness;

*To me, like, it's maybe the wrong word but it's jovial. I mean it's not like [consultant] and [patient] and you know, you are miles apart. I like [consultant]. I like him because he is just down to earth. Just like us, like. [CR9]*

*And [heart failure nurse] has an upbeat personality. So after [nurse] has been in, and she will say oh your stats are good, you know his blood pressure and his pulse, pulse is very good, and his valve is working very well, so you feel reassured after she has visited. [CR10]*

*We have a bit of banter which is good, and in between that banter the information comes over. [CR11]*

#### 5.2.1.2.4 Clinician-patient and carer relationship

Positive attitudes from clinicians, as described previously, also contributed significantly to the building of a relationship between clinician and patient. These relationships, usually specialist heart failure nurses, were valued highly by both patients and carers and many spoke of their nurse as being readily available and part of the family;

*I mean well [heart failure nurse] is just like part of the family nowadays. [CR2]*

*I don't know really, she's just like a sister, like a big sister, you just talk to her about anything you know? [PT2]*

*I think they are very easy to talk to, the heart failure nurses... Nothing seems to be too much trouble; it doesn't seem how many silly questions you ask them, it's not silly in their eyes. They try to understand how you're feeling. [PT7]*

However one patient spoke of having a better relationship with one of the specialists at the heart failure clinic, and commented that she was going to seek more information about her prognosis but as she unexpectedly (for her) saw a heart failure nurse instead she decided not to. Her reasoning behind this was that she did not have the same rapport with the nurse, whereas she felt she knew that the specialist she was hoping to see at that time would discuss her prognosis with her in a sensitive and empathetic manner and give her a sense of hope with a plan for the future – something she felt she would need when discussing prognosis issues.

*I actually, I thought I would be seeing [specialist] last week because I was going to asking [about prognosis], but then it was the nurse and I don't know I just didn't ask. When she said that the tablets were doing what they were supposed to do, and they are going to refer me to the heart clinic at the health centre where I go to, so I suppose I could ask somebody there. [PT14]*

#### 5.2.1.2.5 Follow-up and continuity of care

All participants felt that high levels of follow-up were very important to their continuing health. Poor experiences tended to occur at the level of the appointment making system or prescription paperwork, whereas better experiences occurred mostly with patients who had home visits, and therefore had one specialist heart failure nurse who visited them each time.

##### 5.2.1.2.5.1 Poor experiences

Carers were more likely to speak of poor care experiences with regards to following up care – possibly because in most situations, especially with an ailing patient, they would take on the role of arranging and coordinating care such as out of hours visits, picking up prescriptions, etc. Exacerbations were often dealt with by out of hours doctors in a routine, medical manner – only checking the patient was not in imminent danger – carers felt that there was little or no consideration of how this event might impact on their lives afterwards;

*[speaking about out of hours/locum doctors] Obviously they go through the same routine of checking the pulse, blood pressure, his back. But you don't feel any reassurance really from them, you feel they've gone and they haven't really done anything. He's feeling ill, they've come and checked his stats, and as long as his stats are okay according to them, he's okay! And off they trot. You know, whereas with [heart failure nurse], if there is anything, she follows it up. [CR10]*

Many carers also spoke of their frustrations with navigating the system of repeat prescriptions and changes to medications. They questioned the wisdom of endless repeated prescriptions

and felt that this repetition without clinical review (that they knew of) could be dangerous for the patient;

*Well sometimes we wonder, you know, because we just send in [the prescription] and get them and they come and then the next lot, you know, once a month we get a load of stuff, I go to the chemist and get a carrier full, and I wonder sometimes if it's necessary. Because the doctor hasn't sort of updated your health, has he really. [CR8]*

*The hospital changes the tablets, and they said oh you need to take two of these so consequently for a month's supply of tablets you needed two lots if you know what I mean. Then the doctor is sending one month's worth of tablets which only last a fortnight. Then [patient] has to go through the rigmarole of, they can't get through to the doctors, they said got to go on the computer and it doesn't, there's lots of things you know, it's difficult, and these situations don't help. And it seems to me as though the tail wags the dog in the surgeries. [CR7]*

One carer of a patient with advanced heart failure spoke at length of his perceived battle to ensure appropriate assistance (such as grab rails, stair lift, and monetary benefits) was provided. Upon discharge from hospital after a very serious exacerbation he reported receiving no help or information related to their situation, which made them both very anxious and the situation much more difficult to cope with;

*We weren't given any information about how to cope when she was discharged from hospital. Nobody sort of came forward and said, do you need any help? Which I would have thought was pretty obvious, when something like that is dumped on you, you wonder what can I do? [CR2]*

#### **5.2.1.2.5.2 Positive experiences**

Carers again related experiences of follow-up of care and spoke about positive experiences. Carers valued the thorough medical checks a patient has at their appointments and whilst small changes in prescriptions could be troublesome to coordinate, they recognised that these were in response to the best interests of the patient;

*They have [patient's] welfare at heart at the hospital, they seem to be concerned about her, they're getting her back on a regular basis, they're monitoring her, keeping her right, they've adjusted her medication, and I don't know if it is [helping] or isn't but they must know what they're doing. I think that they are managing the situation as best that they can at the moment. [CR7]*

*I mean, they are very good because they test his blood pressure, and once a year he gives blood... for tests. So they are keeping tabs, you know. [CR8]*

### 5.2.1.3 Responsibility

Many patients spoke of feeling a personal responsibility for keeping well and delaying any sickness or deterioration. Being 'sensible' about their diet and not doing too much to tire themselves out was seen as protective of possible future deterioration. Having this personal responsibility helped patients to take on the disease themselves and, in a way, feel that they could exert some control over it.

*[consultant] says, he can't tell me [a prognosis], it's up to me really, to try and fight it... It's just up to myself. It's how I look after myself and what I do and everything. Which I try to do. [PT2]*

*Actually with heart failure, providing you are careful, you can be all right for quite a long time... Yes, I realised that my life is dependent on me not doing too much more than what I can do. [PT13]*

### 5.2.1.4 Comorbidities

Some patients spoke of the impact of comorbidities on their health, in addition to their heart failure. This was very difficult to cope with especially if the patient was in advanced heart failure.

*I'm not ready for any other problems. And after the [heart operation], the legs went, then I had pneumonia, and then the gout started. And now I've got this bowel problem, which is, one can say it is just one damn thing after another. [PT10]*

*I mean, I have always been very restricted because of this nerve damage that I've got in my legs. I had a stenosis of my spine 15 years ago which was operated on. So there is scar tissue around the nerves now, and I have got neuropathy in both my legs. [PT14]*

However whilst comorbidities clearly had an adverse effect on some participant's health, they reported rarely discussing it with their clinicians. Patients with fewer comorbidities spoke of simply dealing with heart failure and its restrictions in line with the way that they have dealt with/deal with other illnesses they have – whereas patients with more comorbidities found them more overwhelming on their daily lives, with no end seemingly in sight. Differing levels of comorbidity did not appear to influence patient's likelihood of prompting a prognostic or end of life discussion with clinicians.

## 5.2.2 Adjustment

Adjustment to having heart failure was described as occurring even before a diagnosis of heart failure was received. Patients would often describe feeling tired and breathless and attributing

it to old age or another illness, before becoming overwhelmed with their symptom burden, eventually seeing their doctor at some stage – which ranged from a few months to a decade for the patients in this study – and eventually being diagnosed. Loss was a strong theme and participants spoke of losing their independence and confidence as a knock on effect from their loss of functional ability. Some participants spoke of the fact that there is no cure for heart failure (but did not necessarily equate this to a terminal or life limiting illness). Finally, most participants had found ways of coping with the competing pressures of depression, supporting each other (for those who had a carer), feeling a burden on their family, and making lifestyle adjustments to accommodate.

### 5.2.2.1 Loss

All patients and carers spoke of losses. Losses included losing functional ability (such as the ability to perform certain tasks), losing independence, and losing confidence – as a result of losing this functional ability. As such, loss was a strong theme through all interviews and all spoke of having to negotiate these losses.

#### 5.2.2.1.1 Loss of functional ability

Most patients spoke of losing the ability to do hobbies and tasks such as shopping and gardening. This was upsetting to many, and many carers reported taking on extra duties such as housework in order to alleviate this.

*I can't do no gardening. I can't do nothing. Just walk around, my heart's too weak [PT3]*

Often this was compared to activities performed before the diagnosis of heart failure, and patients reflected on their loss of functional ability since then;

*And I had no energy, nothing, I just couldn't do things. Now when you think just a few years earlier I was doing the gardening and everything, I used to be in the shed, greenhouse. I used to cook the meals, everything. [PT8]*

#### 5.2.2.1.2 Loss of independence

The effect of functional deterioration meant that many patients, particularly advanced heart failure patients, had lost a lot of their independence and had to rely on carers (where possible), nurses, and various home equipment such as stair lifts to try and maintain everyday life. This often hit carers hard as they had to take on more domestic tasks.

*I can't do anything, I can't walk, I've got a scooter and I've got the stairlift. And I know that it's getting worse, you know. I can't, I haven't gone into town on my own for years. And it's more and more difficult to walk, it's getting a lot more difficult. [PT9]*

#### 5.2.2.1.3 Loss of confidence

Losing functional ability and independence often resulted in a significant loss of confidence for patients. This was often very difficult, and carers in particular had to take on the burden of helping or 'chivvying along' the patient when they could. Some patients became emotional when speaking of losing their confidence in performing day to day tasks.

*So it's just sometimes, I've lost a lot of confidence in what I had. Sometimes if I turn around quickly I sort of feel off-balance. And when [carer] was on about falling, I've fallen down the stairs. It was only down the garden as well, just my foot, it was just the last step coming down. But I try to do a lot myself, you know. [PT2]*

*I'm sure I'll get there, I have faith in the doctors. But I just, I haven't got very much faith in me to be honest, you know, with all the [health problems] that have happened. [tears] [PT12]*

#### 5.2.2.2 No cure

Adjusting to being told that there is no cure for heart failure was described as sometimes difficult, but 'one of those things' that can't be helped. Some patients equated it to hope, and ensured that they did not expect what they perceived to be inordinately high hopes from their treatment. Others acknowledged the situation as a technicality – accepting it whilst hoping and striving for improvements in the shorter term.

*I know that there's not much hope. [PT2]*

Once participants had found out there is no cure, the thought of 'accepting' it seemed to be a significant point – however in most cases this did not then lead onto a consideration of end of life issues, more of an acceptance that their physical functional ability would be limited and that they would have to take tablets for the rest of their life. The aspect of 'no cure' did not translate into death, dying, or even deterioration for most.

#### 5.2.2.3 Coping

Day to day living was sometimes difficult, with symptoms precluding certain activities or serving as a timely reminder of the presence of their condition. Even routine activities would bring on an exacerbation of symptoms;

*But it's just, when I go out, you know, if it's, especially if it is a cold day, and especially if I've had something to eat as well and it comes on as like, very tight across my chest it's like I've got an elephant sat on my chest. [PT7]*

One patient spoke of having good days and bad days, but simultaneously rejecting the notion of being an 'ill person'. She made sure her life was busy enough, with various commitments

and hobbies, to distract or prevent herself from thinking about feeling ill and maintaining an outward healthy appearance. This is how she coped with having heart failure, and many other patients also spoke of ensuring they continued to meet as many commitments and tasks as normal;

*Having to take pills all the time makes you feel ill, it's as though, I don't want to feel ill, I don't think that I am ill. I don't think that I am ill, I know there are days when I've got to go and sit on a chair and I don't get any further than the chair, in there (points). Those are the bad days. But overall I don't think that I am ill, it's how I deal with it. I've got all these jobs that I've got to do. [PT9]*

*I try and lead a full life, I do go out most days, I have got lots of nice friends and we meet up. But yes, I do as much as I can. [PT14]*

#### 5.2.2.3.1 Frustration and depression

Many participants spoke of feeling frustrated and upset with the impact heart failure had on their lives. Often this was in the form of comparing their current situation with the past, and being unable to do things they were once able to do without much prior thought or preparation.

*I've become much slower. Trying to adjust myself to doing things slow. But I've always been a person, very quick. So it's very hard... I mean, yesterday I had a very bad day. I felt unwell, I felt very down. Why, I don't know, it's just these things, you feel down, you feel depressed. And other days are worse than others. [PT11]*

This depression was also experienced by carers, who often were living with their own health problems in addition to caring;

*I mean I know that sometimes I've said, you know, what's the point, I've had enough and all this sort of thing! As you do. And I was always out, I was always at meetings, always going here and there and now I don't you see. I've given it all up. So sometimes I get up in the morning and I think, you know, what's the point? And I say to him, have we come to the end of the, you know! But we don't talk about it very much. [CR8]*

Meanwhile a minority of patients consciously and vehemently rejected the idea of feeling burdened, depressed or otherwise unhappy about their condition. This was easier to do when they perceived their heart failure to be minor.

*I haven't been upset by it or worried by it. Because it's just mild. Perhaps if it had gone on for longer and if things had got really bad, you know, I might have been upset about*



*it but at the moment the only thing I am suffering from is shortness of breath and it's not really that bad, I can cope with it. [PT15]*

#### 5.2.2.3.2 Supporting each other

Most participants with spouses spoke of the support they received from each other. Often, a spousal carer had health issues of their own and as such, participants supported each other throughout times of crisis and periods of ill health.

*We prop each other up (referring to wife). [PT6]*

Whilst most participants were retired, some still worked – particularly carers. This often posed a problem for the level of support the carer could offer the patient, in particular being unable to attend medical appointments with them and ensuring the patient felt well through working hours;

*There's my wife, we would like a bit of help, so maybe, I would like to be able to be off work so that I could go to the hospital, to visit the hospital with her, see all the appointment she goes to. I would like to be able to be there for her all the time to help do the shopping. And if anything happened. But we can't, I have bills to pay, we've got to go to work. I'd rather be at home looking after my wife but I can't, we can't, it's just not possible. [CR7]*

#### 5.2.2.3.3 Being a burden

Some patients, particularly advanced heart failure patients, spoke of being a burden to their family. This burden consisted both of emotional pressure and practical pressure, such as the carer being unable to leave the house for longer than a short time. Stable patients spoke of the possibility of becoming a burden however this consisted more of a decision that they would not unduly encroach on their children and feeling it would not be the right thing to do.

*I am well aware of the pressures I am putting on this lot here, my two daughters and my wife, and the worry that I am causing them. When I was in the hospital, the adjustments that everybody had to make to their lives in order to make sure that I was the centre of attention. I will be forever grateful [tears]. [PT10]*

*This is the awkward bit; it's not leaving her too long on her own. She is a little bit unsteady so she could fall. It's a problem at the moment. She carries a mobile phone all the time, but if she is at the bottom of the stairs she can't get to the phone, so. I only leave her for a very limited amount of time. [CR2]*

*I've always been of the opinion that I don't want to encroach on family. I mean I looked after my mother after she had had a stroke and it was hell. Because they've got their own families and their own lives, I don't want to be like that. [PT8]*

#### 5.2.2.3.4 Making lifestyle adjustments

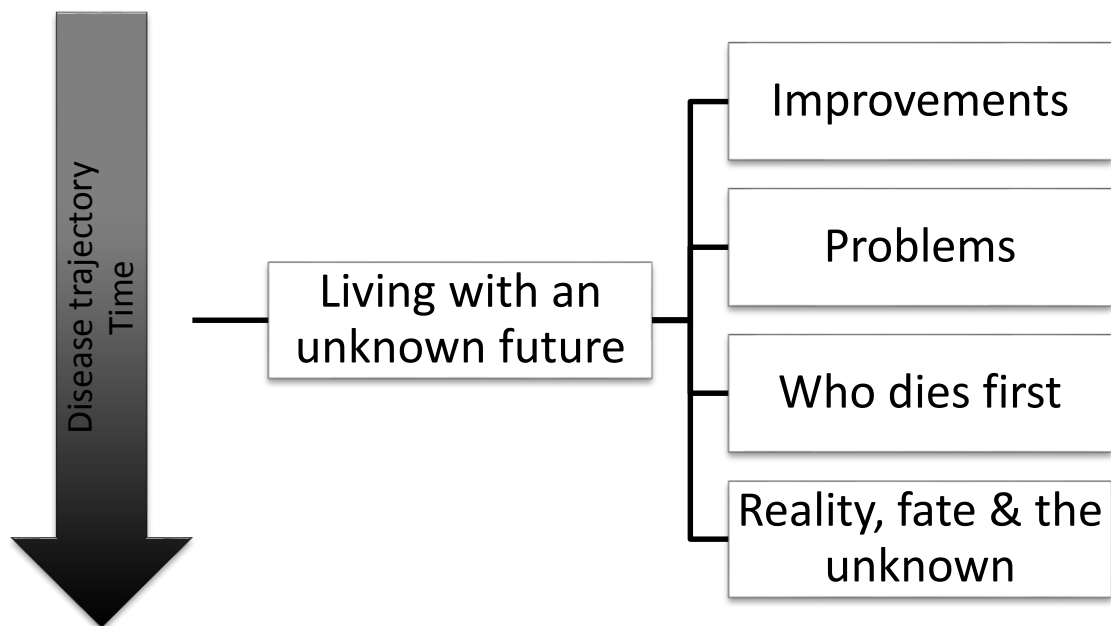
Most patients and carers spoke of having to make lifestyle adjustments. These were often in response to decreased functional ability, and re-negotiating household roles (cooking, cleaning). The prevailing attitude towards making these adjustments was one of 'make do and mend' – it was seen as something which cannot be helped.

*Well I understand that yes she has heart failure, she will get tired quickly because the heart isn't functioning as it should, but that is something we've got to learn to live with, sort of cut our cloth accordingly. [CR11]*

Some participants spoke of recognising patterns in their functional ability and attempting to negotiate the limits of the illness with a reassurance that if they stick to the limits, they will be rewarded with the ability to do more the next day.

*He does get tired if he does too much one day, he is finished the next. He just has to, you know, just rest or go to bed. And then the next day he gets up and he has got renewed strength. [CR13]*

### 5.3 Living with an unknown future



#### Figure 17 Third core category: living with an unknown future

The final category identified was how patients and carers acknowledge, and feel about, living with an unknown future. Comparisons were often made between knowing, in some way or another that the disease would progress – with the shorter term hope that the future would hold some improvements. As such, death and dying was spoken about openly – in a general way (i.e. without specific relation to their heart failure), by almost all patients and carers. Many participants spoke of ‘who dies first’ (themselves or their spouse). Finally, much of the discussion in this category surrounded the futility of trying to predict what will happen in life (in a general sense as well as a disease progression sense), and the perceived influence of fate upon the future and death.

Looking towards the future was often fraught with uncertainty and limited hope;

*We just want some future, which at the moment we don't seem to have one. You just don't know what's going to happen next. He gets over one thing and then he will develop something else. So it's this, just unsure where, we are just unsure of the future.*  
[CR10]

*She wants her life back you see, she wants her life back. So she can go to the shop for things, at the moment if she wants to go to the shop she has have somebody with her.*  
[CR12]

#### 5.3.1 Improvements

Many participants hoped for, and envisaged, improvements in their future. Clinical encounters gave them hope for future improvements and this was held on to.

Some patients had specific instructions for when they started to improve;

*And I've got to get weighed, and as soon as I start putting weight on I've got to get in touch with [heart failure nurse] and she will change my water tablets.* [PT2]

Others set the benchmark of future improvements (or the maintenance of a fairly decent quality of life) by the frequency of outpatient appointments;

*Well, I know I'm jumping the gun here but every time [consultant] says come back in two months' time, I think oh well you are okay for another two months! I feel a lot*

*better when he says come back in three months, you tend to think well you've got three months to go! At least! [CR9]*

One patient had been given a specific prognosis (after asking directly) of two years which she had exceeded – giving her the feeling that she had ‘cheated death’;

*[the consultant] said, he showed me some graphs he had done and at the time he reckons that I had about two years to live. He didn't tell me, I asked him. He said two years. He was wrong! Yes, he gave me two years, and the funny thing was, two years, the first year you think oh well I've got another year after this so it doesn't bother me. And when you get into that second year I started thinking oh, I don't need to buy clothes for Christmas, I've got enough clothes to last me out. And then when I got past that two years, and I'm still going on, I realised what a load of rubbish this was. After that, I mean this is about five years ago so I'm still three years into having cheated death by that. [PT9]*

Other participants reported no talk (from clinicians) about long term future at all, focussing fully on short term future and hoped-for improvements;

*The future, I haven't heard anything about that. All I know is that they are hoping that [ICD operation] is going to solve her breathing and her heart failure problem. That's what I understand. [CR12]*

*I just hope and wish that he can recover sufficiently to lead what I would call a normal life, and we are able to go out and about as we used to do. [CR10]*

### **5.3.2 Problems**

Many participants spoke of possible problems in the future. Interestingly, much of the discourse was abstracted, in a sense of there was an acknowledgement of the *possibility* – technically/statistically speaking – of dying from heart failure, however participants did not seem to apply this to their own personal situation and chance of becoming seriously ill. Broadly speaking, the sicker a patient was the more likely the problems would be spoken of in a more personal manner – however this was not universal at all, and in fact many advanced heart failure patients in the study rejected the notion of death and dying.

One participant described an unspoken understanding between themselves and their carer, and themselves and their clinical team, of the progressive nature of heart failure. When probed further on their understanding of prognosis, they replied;

*I think, it's a mutual understanding that it will gradually get worse as the years go on, and we've just got to accept that. Well what the outcome of that would be, I don't know. [PT8]*

### **5.3.2.1 Dying and death**

Whilst the majority of discussion about death and dying was framed in a general manner, some participants spoke directly about death with specific regard to heart failure with their clinicians. More often than not, these questions and concerns were reported as not being answered directly. Sometimes this caused anxiety for patients;

*Well, this is going to sound really strange but the last time I went to see them, I said is this a serious condition? She said it is a chronic condition. I asked am I going to drop down dead? She said not while we're here to look after you, you won't! And it's always in the back of my mind that something might happen but they've assured me that nothing will happen. But it's strange, you know when you get this it's hard to see that nothing will happen, can you understand what I mean? It doesn't feel right. [PT7]*

Others spoke of the shock at hearing about end of life in relation to heart failure, and reassurances from the clinical team that it did not necessarily apply to her;

*The only, the time when it was really brought home to me, was at one of the heart failure meetings. I think it might have been the first one that I went to because I've only been to four or five. And I don't know who was that was talking, but suddenly I heard the words "end of life care" were said, and I was absolutely taken aback. And [heart failure nurse] came over and asked me if I was all right! Because I thought, oh my God, you know, it kind of hit me like a sledgehammer because I hadn't thought that far ahead. She just sat beside me and said, you know it's not going to happen next week or next year, you know, you've got a long time to go yet. But it was just sort of, it was the first time that I'd ever sort of experienced those words in connection with my own situation. [PT15]*

Finally, one patient thought the whole thing quite ridiculous, feeling it did not apply to her at all as she did not feel unwell;

*I just want to drop down dead! I have decided! I'm not going to be any bother. [I expect to] just peg it and that's it! Without too much bother. I don't feel, well... I am so well that it doesn't come into the equation even. I don't think about it. [PT16]*

### **5.3.2.2 Getting things in order**

Some discussion about the future concerned 'getting things in order', mostly financially. On the whole this was framed in a way that participants felt obligated to deal with financial

considerations (in a general manner, not prompted by their diagnosis of heart failure) eventually, however it was seen as laborious and put off for the future.

#### 5.3.2.2.1 Financial arrangements

Some participants had all of their financial arrangements, such as a will and power of attorney in order.

*I've also spoken to [son] about things if [carer] died first, you know. And, [son] is aware that he would have to support [carer] if I died first. Because I look after all of our money side of it, and he says, he has said that that isn't worried to him. Even though he knows, [son] has already taken over, we've made our wills, we've also made our power of attorney. [Son] can now take over all of our money. We've done that, because you've got to do it now while you are corpus mentis. [PT9]*

However many others did not, and this caused concern amongst some carers who worried about what might happen if it was not resolved;

*Well I would like [patient] to get his papers in order. The finances. I would like him to sort that out. Because even if I went first, you know, my daughter would have to, it would all land on my daughter. So this is why I say to him, [patient], we need to have everything right just in case. [CR13]*

#### 5.3.2.2.2 Advance directives

Advance directives had only been considered by a few advanced heart failure patients and their carers. Mostly this was precipitated by their heart failure nurse bringing the topic up.

One participant (with advanced heart failure) spoke of being reluctant to have a Do Not Attempt Resuscitation order recorded formally as she did not feel she was at the stage of 'giving up' on the possibility of being revived, and indicating that it would depend on the specific nuances of the clinical situation;

*I'm a little bit sort of, one thing I'm a bit hesitant to have recorded anywhere is that, the bit about I don't want to be resuscitated, because I damn well do want to be resuscitated! Because I don't know what I'm going to be like, I mean I know that there's going to be a time where I've had enough. [PT9]*

One participant had brought up place of death with their heart failure nurse, however this was the exception rather than the rule;

*[heart failure nurse] said, I'm glad you broached that [place of death]. You know, because obviously it's a tender situation to discuss, end of life, that type of thing. And [patient] says straight out, I want to die at home if I am going to die. I mean everybody would like that as well, wouldn't they. But, [heart failure nurse] says, oh I'm glad you*

*broached that because she was, it'd be she been in the back of her mind that she was going to try and broach at some point. I guess we helped her along with it. [CR2]*

Some advanced patients and carers had not considered advance directives at all, feeling that there was little need as their wishes were not unduly specific or unusual, and so they were happy with leaving the situation and decision up to their family and their medical team;

*No. No, we haven't [spoken about advance directives]. We haven't, but the thing is, we know each other so well, I mean we've been married 63 years this year. Really, he knows that whatever I did would be alright and I know that whatever he did would be alright. We skirt around these things, really. [CR8]*

### **5.3.3 Who dies first**

When asked about death and dying, and what they think they might be able to expect in the future, some participants interpreted this as a question about who (i.e. which spouse) would die first. It seemed that amongst elderly participants in particular, this was an element of death that had been spoken about more fully than most other death related considerations.

*Yes. Well I always wanted to kick the bucket first. Since I haven't been so well. [PT6]*

Participants spoke about how they thought their spouse would cope if they died first, and vice versa.

### **5.3.4 Reality, fate & the unknown**

Whilst very little thought and planning had gone into the future, particularly with specific regard to how heart failure in particular might cause problems further down the line, patients and carers spoke quite openly of a 'reality' of death and their lack of ability to be able to control exactly what happens to them when they die.

*Yeah, well I know it's going to happen [death] so there's no use in putting it back is there. No use putting it into the back of your head, it's going to come, so. [PT2]*

Despite this general view of death, some desired further knowledge of what they could specifically expect in the future;

*I think I would like to know what is going on, and what's going to happen in the future. [PT7]*

Some participants relayed their clinical experiences of being given a philosophical based answer to a prognostic question, and feeling as if the clinician gave this sort of answer as an excuse;

*As [consultant] said, [patient], you've got to die sometime, nobody lives forever. That will stick with me for a long, long time! That was stating the obvious, but coming from a consultant I felt was a bit below the belt. [PT10]*

#### **5.3.4.1 Prognosis seeking**

When interviewed, all patients and carers were asked if they knew what they could expect to happen (with regards to their heart failure) in the future. The majority of participants said that they did not understand, or did not want to know (or both) their prognosis. Indications were given of their increasing age in relation to death in general, however most participants did not speak of a direct connection between heart failure and a decrease in life expectancy. Younger participants spoke of wanting to know what to expect in the future, whereas older participants were more dismissive of the possibility of seeking a more direct prognosis;

*I wouldn't want to know [about prognosis]. It's something that is unsaid. Yes. I don't think people would like to know. Well, some people do. There might be a few, but I think the majority of them are prepared to live on in ignorance of the end result, which has already been pointed out, is inevitable. [PT10]*

One patient spoke of her difficulties with hearing and memory, and the impact this has had on her ability to retain prognostic information;

*I don't know if I really understand [my prognosis] you know. So-so. I have asked quite a few questions, they have helped a great deal but unfortunately I forget some. And that's me. But it makes you angry when you have been a person who has been busy and always had to remember things. [PT11]*

Some patients, particularly newly diagnosed, had not 'got round' to thinking about the future;

*I haven't really done anything with that [discuss future with heart failure nurse]. I just thought in my own mind, I haven't had any confirmation, that I will live till I'm 100 years old, so to speak. [PT12]*

Some participants spoke of the 'red book', supplied by the British Heart Foundation as a guide to heart failure, and of the prognostic/future outlook section 'in the back'. Most who spoke of the book knew of the section but many purposefully avoided it;

*I could read that [book] more thoroughly and find out where I go from here, but I'm, I think because there's been so many problems I think I just want to push it onto the back of my mind and take each day as it comes. I don't dwell on it. [PT14]*



Again, focus was on day to day living and maintaining stability rather than the future;

*Well I mean, we haven't really thought about asking that question. But, as far as I know about longevity of life is, just the way they monitor it and keep her on the medication, and look after itself better, the better it will be. I don't know whether she has another 30 years, 20, or 10 years. I don't know. It's not very nice, is it. [CR7]*

#### 5.3.4.1.1 Place of death

Most patients and carers did not report speaking about where they would prefer to die. Conversations focused more on what they would prefer not to do (e.g. go into a nursing home). Most patients and carers had an opinion on this, formed either prior to interview or at the interview itself. This held true for even the most ill patients.

*I've just said that I want to die at home. That's all, you know. Yes, well I know it's going to happen sometime, and I just want to be at home. [PT2]*

One carer spoke of the futility of trying to plan a place of death when the very nature of becoming ill and close to death would probably mean an acute admission to hospital;

*But as for myself, I don't worry about where I'm going to end up, me. I mean, if you're nearer to a hospital or a hospice when you actually have a pain, you might end up where was quickest for the ambulance. Fate? [CR9]*

#### 5.3.4.2 Futility

Often, participants spoke of feeling futile when asked about their hopes and wishes for the future. Their age was seen as a limitation on how far they could control the future; consequently they had no ability or desire to influence it. This was based on the acute limitations many faced on a day to day basis, and knowing that they were getting older and therefore less likely to be in a better state of health in the future.

*Well, decisions, well, what can you wish for the future, in my state? You know, I never go away now, we don't. I wouldn't care, we can go on the train for nothing. [PT3]*

*Well when you get to our age, what is there to discuss about the future? [PT6]*

One carer felt cynical about the clinician's role when thinking about the future;

*Well... If I was in [the clinician's] position, and I wanted to help somebody, I would say [positive prognostic] things like that to help people. That's what I would do. But I'm cynical myself, the way, the experience I've had. [CR7]*

Either way, some participants felt that their lives were so restricted now that being artificially kept alive with a low quality of life would be both futile and unwanted.

*I would prefer active care if it was going to prolong life that was worth living. But not if, I mean to me, I mean I wouldn't want to be prolonged because I don't think my life could be the way it was, you know, before. All these things change your life so much that you think, oh, what's the point of it? [CR8]*

## **5.4 Chapter summary**

This chapter has presented patient and carer interviews undertaken as part of the current study. Patients and carers spoke of symptoms, often coming to a realisation that they had a heart condition and seeking a diagnosis, and the process of receiving a diagnosis. Focus was often placed on living their lives day-to-day rather than looking towards the future which they felt unnecessary, with priority placed on adjusting to the diagnosis and the resulting functional restrictions stemming from their heart failure. When patients and carers spoke of the future, including death and dying, it was in a general manner, not necessary applicable to them – or provoked further – with a diagnosis of heart failure. This was reportedly backed up by their clinicians even when specific concerns about the progression of the illness were aired. Hope and positivity were important to hold on to and death was simply viewed as a generalised concept, something everyone has to face at some point, mostly as an uncontrollable unknown.

# Chapter 6 Patient and Carer Vignettes

Whilst undertaking patient and carer interviews, observations, and subsequent analysis, it became clear that there was very little discussion of palliative or end of life issues either between themselves, or between themselves and their clinicians. It seemed that patients and carers felt that living their lives as fully as possible, reflecting on the past and looking (intentionally, in most cases) towards an unknown future was more important, and took precedence over issues surrounding death which, in actuality, they did not want to discuss anyway. The resulting modified constructivist grounded theory analysis depicts and explicates elements of every participant's story, and their interrelationships. Nonetheless I felt that as participants felt so much more of their lives were more relevant than dying and death, it would do the data more justice if selected stories were represented as whole units as well as integrated into the modified constructivist grounded theory. As such, vignettes have been constructed from interviews and observations to supplement the modified constructivist grounded theory analysis. These vignettes are intended to help bring patient and carer stories to life, describing a clear flow of events and context for an individual participant which may not be easily followed when integrated into the overall theory. Consequently these vignettes are intended to enhance the resulting modified constructivist grounded theory model, and provide an insight into patient and carer voices as they were presented within the research context. All participants have been given a pseudonym for the purpose of the following vignettes.

## 6.1 Vignette 1: patient with advanced heart failure

Mr Edwards is an 82-year old gentleman who lives in the North East of England with his wife of 62 years. He was first diagnosed with angina symptoms twenty years ago and subsequently underwent two bypass operations. A diagnosis of heart failure was made around two years ago. He underwent a pioneering cardiac surgical procedure shortly afterwards. Mr Edwards is currently categorised as having NYHA Class III heart failure.

At the first interview and observation Mr Edwards was very poorly. At that time he had grade IV heart failure, and was suffering or recovering from other comorbidities and illnesses such as undiagnosed (at the time) gastrointestinal issues, pneumonia, debilitating gout, and suspected pancreatic cancer. At that time he was essentially housebound, with his wife caring for him (who was, as a consequence, effectively housebound also).

Mr Edwards: *It's something which they say is monitored and treated and, well, once you've got it, you've got it. The treatments, the monitoring, and the advice and the medication, the whole package is basically to prolong my life. And this is the stage we are at now. But I am getting all these side issues which is got nothing to do with the heart, I hope, I don't think it has. But it's holding me back from getting, feeling well. I would love to be able to get up in the morning and go about my business, what little business there is, feeling well. And that just is not happening because of all these side issues that are hitting me, with the gout, fluid on the lungs, having to take the water tablets to keep things running, the restrictions it has on you, this is part of living. And living as well as you possibly can, this is what I'm striving for.*

Both he and his wife tried hard to keep their spirits high and preferred strongly not to speak of death – it was “*not a topic of conversation in this household!*”.

Mr Edwards: *[heart failure nurse]'s aim in life is to keep me alive as long as nature says. When my time is up, [heart failure nurse], I am sure we will have done everything possible to lengthen that time to its maximum. I have faith in her. She is very good.*

Interviewer: *Has she ever given you an indication of how long?*

Mr Edwards: *No.*

Interviewer: *Or anything like that?*

Mr Edwards: *No, and I wouldn't want to know.*

Interviewer: *Okay, have you told her that or is it something unsaid?*

Mr Edwards: *It's something that is unsaid. Yes. I don't think people would like to know. Well, some people do. There might be a few, but I think the majority of them are prepared to live on in ignorance of the end result, which has already been pointed out, is inevitable. ... I hope there's a few years ahead of me, and I am sure that [heart failure nurse] or whoever else takes over the reins at any time, will do their utmost to make life as long as possible, and as decent quality.*

The future was unknown, and whilst Mr Edwards and his wife tried to find enjoyment in what they could, when asked about the future they saw it as rather bleak despite efforts from all sides to improve Mr Edwards' health.

At the second, 6 month follow-up interview Mr Edwards' health had improved significantly. His gastrointestinal infections and gout had been resolved, and his heart failure had improved so much – from grade IV to III – that he was attending cardiac rehabilitation sessions regularly as well as getting out and about using a stick to socialise. Death and dying was even more so seen as an unwelcome topic especially as it now seemed much less applicable to their situation. Life continued, as normal as it could be, with further improvements hoped for and a brighter future not so unachievable as it first appeared.

## **6.2 Vignette 2: patient with stable heart failure**

Mrs Brown is a lady in her 60s who lives with her husband. She has a fairly long history of health issues, including chronic obstructive pulmonary disease, osteoporosis, and cancer. She had been diagnosed with heart failure for around one year at the beginning of the study and requires oxygen most of the day and night to support her breathing. She is unable to bathe/shower herself alone or wash her hair, and often struggles to dress herself. She is able to prepare meals, eat, or toilet without assistance. She is unable to complete any housework or go shopping. At the time of the first interview and observation she was scheduled to have a pacemaker and left ventricular assist device fitted, and had had her pre-operative assessment. She understood there to be an 80% chance she would feel some benefit (specifically a reduction in breathlessness) from the operation, the specialist heart failure nurse had relayed a figure to Mrs Brown of 60% during the observed home visit appointment. Mrs Brown believed that the device would stave off any worsening of her heart failure and prevent a 'premature death' from arrhythmia, and help her to "get her life back" as she was effectively housebound at that time.

Mrs Brown: *Well, at the moment I can't do my shopping on my own, I can't go shopping, on my own at all. But hopefully we will get there. I'm sure I'll get there, I have faith in the doctors. But I just, I haven't got very much faith in me to be honest, you know, with all the things that have happened. (tears)*

Interviewer: *I can imagine it's quite, piling on top of you a little bit.*

Mrs Brown: *Yes it is. It is rather.*

Interviewer: *I can imagine. Okay. So you've mentioned about the complications, and that it will prolong your life, is that something which has been spoken to you before about?*

Mrs Brown: *No, not really, no. I mean my mother had a pacemaker put in. But it was just a small one, you know, because she kept sort of passing out and going dizzy and that sort of thing. So she had one put in at the age of 80, and she lived until she was 100... My heart isn't going to stop, my heart doesn't stop, it just hasn't got the oomph to push the blood around the body and into the lungs. So this is what, it needs sort of recharging. And it recharges the heart to do what it's supposed to do. I think that's what it is anyway, something like that.*

Interviewer: *What would happen if you didn't have it?*

Mrs Brown: *Well, my quality of life would be like it is now, it is zero really. You know, I can't go shopping on my own, I can't change a bed, you know, I have a cleaner that comes in. I can't do what I want to do. (tears)*

At the six month follow-up interview Mrs Brown had been living with her new pacemaker and LVAD for around four months. She did not feel any benefit in the hoped for reduction in breathlessness from the operation but she felt reassured; *"I don't feel any better because of the breathlessness but my mind is more at rest now that I know my heart is alright, or my heart is being looked after, if you know what I mean."* Her activities of daily living remained unchanged after the operation. Mrs Brown excitedly showed me a device connected to her phone line which could *"read what is going on with my heart"* and transmit the information down the line to the hospital. She still struggled with mobility but felt a little better knowing that the LVAD, pacemaker, and phone line device were all there to monitor her constantly and correct any abnormal rhythms if necessary.

### 6.3 Vignette 3: patient with stable heart failure, now discharged

Ms Wright is a lady in her mid-60s who was diagnosed with mild heart failure in 2008. Prior to being diagnosed with heart failure she had a suspected heart attack and received treatment for angina. She has a long history of other restrictive illnesses including spinal damage and neuropathy which she has learned to live with, and described her heart failure as just another restriction she has to manage. She is able to complete the majority of daily living tasks such as showering/bathing, dressing, feeding, and preparing meals. She sometimes struggles with shopping and housework. Ms Wright lives alone in a small town and has quite an active life with regular social events and visiting family. She was discharged at the clinic appointment (observed for this study), as she was stable and in fact showed improvements in her heart function at her most recent scan. Ms Wright was pleased to have been discharged due to improvements and indeed had planned on asking the specialist heart failure nurse about her prognosis and what she could expect for the future at that appointment; however she felt there was no need once she was told she was being discharged, especially as she had been expecting to see another clinician at the clinic who she had built more of a relationship with.

At the six month follow up interview she described feeling worse than before, and worrying that she should be seen by her GP.

*Ms Wright: I've been discharged from the hospital. You sort of feel as though you're just left to get on with it... I am more breathless, I am aware of that.*

*Interviewer: Do you think that you're still as good as you were [six months ago]?*

*Ms Wright: No, I don't think so. I've been intending to ring and make an appointment to see the GP... but I've been quite busy... you put it off. I don't want to know really, I just plod on.*

Ms Wright preferred not to know the finer details about her prognosis, especially as she had a good general idea of what she could expect anyway – of a slow, progressive decline. One particular worry was that she might develop dementia due to her heart failure.

*Ms Wright: I worry about the future, you know about it deteriorating and maybe needing oxygen and things like that.*

*Interviewer: Did they tell you that that would happen?*

*Ms Wright: No, but I got a book on heart failure that was given to me by the consultant and I haven't read it in depth, I got so far and I thought I don't really want to know this. The thought*

*of that happening is quite frightening yes, especially when you live on your own and I don't want to be a burden. I think my biggest fear is developing Alzheimer's, which is my biggest worry. You know, thinking that my heart's not pumping the blood around, and if the oxygen is not getting to my brain properly I'm thinking, oh God, is that in my future? I've told [her children] they've got to put a bottle of tablets on the table in front of me and make sure I take them.*

Despite preferring not to know too much about her prognosis she was certain about what she wanted in case she deteriorated significantly. She had especially thought about it more since her divorce and living on her own.

Interviewer: *And have you given any thought to what if the worst might happen, at all, what you might want?*

Ms Wright: *Oh yes. I have. Yes! But I have thought about this quite often anyway, I think being on my own. My friend knows what I want, we have been friends for over 50 years. I just want to be cremated, and I want Elvis! Yes I have [thought about it] actually. Because I'm a big firm believer in euthanasia. And I have told my children, if I start with dementia, they have got to send me to Dignitas. I have the address.*

Mrs Wright continues to take her heart failure medication and is currently undergoing investigations for other health issues. She also continues to maintain an active social life.

#### **6.4 Vignette 4: carer of patient with advanced heart failure**

Mr Dant is a middle aged man, who at the time of the first interview and observation lived with and cared for his elderly mother, who had a diagnosis of heart failure alongside other comorbidities including chronic obstructive pulmonary disease, arthritis, and breast cancer. He described a very good relationship with his mother, Mrs Dant, characterised by humour and mutual respect. Mr Dant did almost everything in the house as his mother was too frail – being unable to complete any housework, go shopping, or bathe/shower independently and requiring a stick or walking frame to walk both indoors and outdoors. Any discussion of getting worse and death from heart failure (or anything else) was met with an acknowledgement of the inevitable progressive nature of the disease coupled with a strong hope that the sum of their efforts to keep her well would work for a long time to come.



Very sadly Mrs Dant died around two months after the initial interview and observation. Mr Dant was kind enough to agree to participate in the follow-up interview as scheduled at six months, and speak about his mother.

Mr Dant: *Well, she was a fragile, frail old lady which happened since her heart attack and unfortunately as time progressed she got more and more frail... [my son and I] both came into the house, couldn't find her downstairs, he was having a look downstairs so I shot upstairs and went into her bedroom and she just looked like she was fast asleep so me being a total nutcase I am, I swanned in there, shouted wake up you silly old bugger, you can't go to sleep this time of day, and I grabbed her arm and gave her a good shake and she didn't respond. I then felt the carotid artery and there was no pulse and that's when I screamed to my son ring 999 now. There was nothing that could be done, she passed away, I hope in my heart of hearts, she just literally went upstairs to have a sleep and just gently passed away and that's how I want to remember it.*

Prior to her death Mrs Dant had been visiting the local hospice – at the initial interview and observation it was one afternoon a week, however as she worsened she was admitted to the hospice for a week's rest, both for herself and for her son. I asked Mr Dant if her death had been a shock. He responded that it was a shock in some ways, but not in others.

Mr Dant: *I mean at the end again, at [the hospice], to get her from the car to the day room, we had to get the wheelchair and push her in, she couldn't walk any distance. From sitting down here to go upstairs, she'd have to take a break halfway to get up the stairs so she had gone, deteriorated, you know. The brain was as sharp as a tack and she used to give me some wonderful tongue lashings, but the body was failing and that's all you can say... I mean I was having to do more and more for her and that obviously upset her... but I think common sense told you that, and I'm not being cruel and nasty when I say this, but you could see that the end was coming.*

At the time of her admission to the hospice for a week Mrs Dant was asked if she would want to be resuscitated should 'anything untoward' happen to her whilst she was there. At the time she said yes, however when Mr Dant found her with no pulse he made the decision to refrain from attempting to revive her.

Mr Dant: *When we [called 999] on the day she passed away, the question was asked are you going to do CPR, do you want instructions on how to do it... I'm sorry to say my thought to myself was no. I'm not going to start beating her up. If it hadn't been successful, beating myself*

*up because I didn't do it, so I made that conscious decision then not to do CPR... It was just that she looked very peaceful, there was no pulse... Being quite selfish, I didn't want to upset myself anymore... I thought it was the best thing for her. So did you want to put her through anything more. I mean she had the full house [of illnesses], and she kept on going through it all. I thought now the time to say enough is enough.*

Mr Dant then expressed regret at not pursuing conversations with his mother about death and dying.

*Mr Dant: Our conversations were, and this is a funny thing, oh we must get the paperwork sorted out, which was up in the office upstairs. I'll have to go through it with you one of these days because I'm getting old and I haven't got much time left, and it would be oh shut up mother, you've got bags of time left, you're indestructible, we'll do it another day. Then I would say to her have we got time to go through the paperwork, you know, oh son, I can't be bothered today, we'll do it another day. Ok, Mum. We knew it was there but we put it to the back of our minds, I think like anybody would do if you don't want to discuss it. I wish we had done because by God it was an absolute nightmare sorting everything out.*

Mr Dant continues to live in the family home.

## **6.5 Chapter summary**

This chapter has presented short vignettes of patient and carer stories of their lives with heart failure. This was intended to bring together and re-contextualise potentially fractured narratives of experiences described throughout interviews and observations. The vignettes presented here illuminate the stories of a selection of participants in the study and illustrate several different experiences of heart failure, including stable and advanced, and the experience of the primary carer of a participant with advanced heart failure who died during the study period.

The vignettes presented here illustrate a feeling of 'limbo', or being in a liminal state, with many patients very poorly for a significant amount of time, but focussing on living day to day rather than thinking about or planning for the future. These findings are explored further within the theoretical framework in Chapter 7 Discussion and Conclusions.

# Chapter 7 Discussion and Conclusions

This chapter synthesises results from clinicians, patients and carers presented in Chapters 4, 5 and 6. The concept of knowing, telling, and acting upon a prognosis in heart failure on the part of clinicians is presented and discussed. The patient and carer experience of prognosis and their views of the future are discussed within the context of liminality, and the identities of suffering and the heart. Comparisons with other research are made and clinical and policy implications are considered. Finally, a discussion of whether or not heart failure should be classed as a terminal illness is presented.

## 7.1 The purpose of the study

The purpose of the current research study was to explore and examine patient, carer, and clinician experiences of prognostication and the transition point from active to palliative care in heart failure. Specific research questions were:

1. How was the process of prognosis giving experienced by patients, carers, and clinicians?
2. What factors do clinicians take into account when deciding when the transition from active to palliative care should occur, and how do they communicate this?
3. What is the experience of the consultation interaction between patient, carer and clinician?
4. How do patients and carers understand information given about their condition (during appointments and from any other source), and how do they construct meaning from this information?

In the preceding chapters research findings have been presented. The purpose of the current chapter is to:

- Summarise and synthesise the primary findings from patient, carer and clinician participants
- Discuss how the findings relate to the wider body of literature including the conceptualisation of the end of life care for heart failure paradigm
- Consider clinical, practical and policy implications of this paradigm construct, and
- Critically analyse the overall paradigm and usefulness of classifying heart failure as a terminal illness in light of these findings.

## 7.2 Synthesis of results

### 7.2.1 Summary of results

*“It is uniquely human to believe that mortality happens to other people[212].”* Dr Sharona Sachs, “Planning For The End: Talking About Death Often Stands In The Way”.

In the preceding results chapters, clinician interviews and patient and carer interviews and observations were analysed separately using modified constructivist grounded theory. In order to present a unified synthesis of results, clinician and patient/carer analyses will be brought together and integrated as a whole in this chapter. This will allow comparisons and distinctions to be made between these groups in order to develop an understanding of the

theoretical and practical implications of findings to patients, clinicians and the wider National Health Service.

The core category emerging from clinician findings was 'prognostic ambivalence'. This category was so named as clinicians described several conflicting feelings such as uncertainty, and feeling the weight of what they perceived to be a moral imperative about making a prognosis in heart failure. This ambivalence often led to avoidance of prognostication altogether, or procrastination. Within this, the process of prognostication can generally be described as having three parts; knowing the prognosis, telling the prognosis, and acting on it.

#### *7.2.1.1 Knowing, telling, and acting upon a prognosis*

Clinicians from all professional groups attempted to articulate the process of decision making surrounding making a prognosis, and how that translated from knowing (personally, and privately) that the patient had a poor prognosis, to telling that prognosis to the patient, carer, and/or the heart failure team, and finally acting upon the prognosis. Some clinicians did not specify a clear line between knowing and telling, demonstrating unclear lines of thought and difficulties in articulating how they would transition from simply knowing, to telling. Others spoke of coming to a realisation by linking together poor prognostic indicators (such as NYHA class IV symptoms, weight loss, depression), assessing the benefits of relaying this information to the patient and/or carer, and finally telling a prognosis if they deemed it necessary or valuable. Sometimes clinicians would skip from the later stages of knowing a prognosis (i.e. coming to a realisation) directly to acting upon the prognosis, by making referrals to palliative care services, without necessarily going through the second step of telling the patient and carer. When coming to tell a prognosis, this was often described as 'trickling down' or 'staging' information to the patient, although full disclosure was an unusual endpoint. There were no significant differences between clinician groups found with regards to knowing and telling. Prognostic indicators identified by clinicians are explored further in section 7.2.1.2. Overall, the process of prognostication for heart failure loosely fit with the below flow chart (Figure 18).

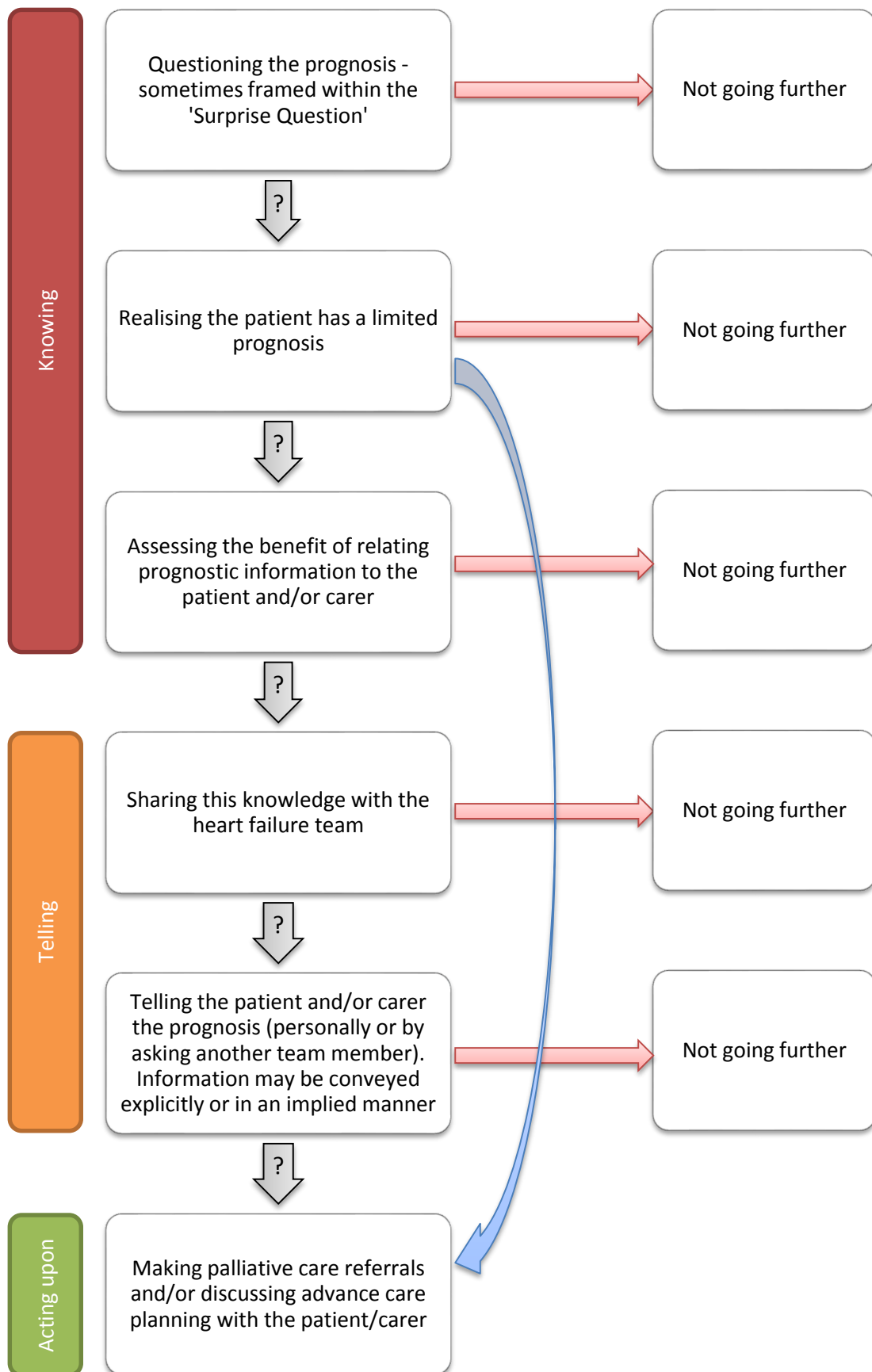


Figure 18 The process of knowing, telling, and acting upon a prognosis

Figure 18 shows the process of prognostication as described by clinicians. Once a diagnosis is made, the initial stage of prognostication is to privately question the prognosis of the individual patient. This may provoke the second stage of a realisation that the patient has a poor prognosis, and thirdly, an assessment of the benefits of revealing the prognosis to the patient and/or carer. These three stages are the stages of 'knowing' a prognosis. Two stages then comprise the 'telling' a prognosis: sharing the knowledge with the heart failure team, then telling the patient and/or carer directly (or employing a colleague to do so). Finally, the clinician may 'act upon' the prognosis by making referrals to palliative care and formally recording advance care planning decisions made by the patient.

At all stages the clinician may decide to go no further with the process of prognostication (or simply leave the next stage undecided, or have it 'slip off their radar' whilst focusing on active care). Deciding to go no further may be a result of feeling that the stage of 'telling' or 'acting upon' could not be reached due to feeling under-skilled, or that there are no appropriate service responses available such as hospice bed availability. Furthermore, there is the possibility of skipping the 'telling' stage by going straight from 'knowing' to 'acting upon', whereby the clinician does not explicitly reveal the poor prognosis to the patient or carer (often to avoid psychological distress for either party), but makes appropriate palliative care referrals and prescriptions for palliative medication.

Clinicians spoke of several influences to telling a prognosis. Often, prognostic conversations were delayed, with the subsequent transition from active to palliative care also delayed in line with this. Observations did not reveal any detailed prognostic conversations at all. Clinicians felt the lack of prognostic tools at their disposal jeopardised their ability to broach prognosis with the patient/carer, and flag up a perceived lack of palliative/supportive/end of life care resources and support for the patient even if they were to make a prognosis or consider palliative care anyway. Clinicians, particularly specialists and GPs, then went on to question the overall classification of heart failure as a terminal illness. Most felt that heart failure is not a terminal illness at the early or stable stages, and that the concept of a terminal illness should only be considered – but not necessarily accepted even then – when the patient is in advanced heart failure. Blurred boundaries of terminal illnesses were discussed, and patients were often not seen as having a terminal illness even if they were in NYHA grade IV heart failure, or had several hospital admissions.

Patients and carers also delayed prognostic conversations. Several participants spoke of 'meaning to' ask about prognosis and/or supportive care but felt that the time was not right,

or simply preferring not to think about death. Heart failure was not considered to limit lifespan significantly, and patients and carers prioritised getting on with their lives as 'normal', accordingly. They certainly did not feel that they had a terminal illness. Instead, they viewed heart failure as simply something they had contracted mostly due to bad luck or 'just one of those things', to be expected with advanced years. Most of the patients and carers in this study did not want a formal prognosis regardless of stage, with a few exceptions being the younger patients in the study who questioned both the diagnosis and prognosis more, feeling it was unfair to get what they perceived to be an older person's disease, especially if they had previously led a fairly healthy lifestyle. These patients reported asking their clinicians (mostly specialist heart failure nurses) in an offhand way, such as "am I going to drop down dead of this?" to which reassurance was given that they would not. The remainder of patients and carers did not feel strongly enough about having a prognosis to approach clinicians themselves, a finding supported by observation data collected for the study.

Whilst clinicians described the clinical differences between a newly diagnosed, stable, and advanced heart failure patient, they found it difficult to draw out many examples or commentaries of when a patient had 'crossed the line' from one category to another (e.g. from stable to advanced). This fit with unclear lines as to if, and when, a patient with heart failure becomes terminally ill. Comparisons were drawn with cancer and several clinicians said they would not routinely consider palliative and end of life models of care with their heart failure patients even though they were aware heart failure has a very similar mortality rate – acknowledging themselves that this situation did not seem 'right', but that was the way it was.

When a patient was recognised to be in advanced heart failure, on the whole only specialist heart failure nurses spoke of starting to involve palliative care services such as the local hospice, or prescribe palliative drugs such as oramorph. The decision making process surrounding palliative care involvement was not made in a systematic manner, rather nurses, and a small proportion of specialists and GPs, spoke of having a 'feeling' that the patient and/or carer was struggling. They then chose to communicate this by outlining the benefits of hospice care and underlined the supportive nature of palliative care (rather than using the word palliative).

Patient and carer findings were described within an overall journey over time from pre-diagnosis onwards. Three categories emerged – reflecting on the start of their health problems, living in the present, and living with an unknown future. In general participants spoke of all elements of their journey within these categories, regardless of how advanced



their heart failure was. Nevertheless, some differences between newly diagnosed, stable, and advanced heart failure were evident in patient and carer interviews and observations. Newly diagnosed patients and their carers spoke more of coming to terms with the diagnosis and looking for reasons why they had developed the illness. Often links were made between prior illnesses and unexplained symptoms which helped them to bring together their understanding of heart failure and how it fit in their life pre-diagnosis as well as post-diagnosis. On the whole, patients and carers were more likely to speak about the latter part of the journey (living in the present and living with an unknown future) if they had been diagnosed for longer and/or were more restricted by their heart failure.

Most patient and carer participants spoke of the future only in a philosophical manner, reflecting the way in which they saw the start of and development of their illness – as something which cannot be stopped or otherwise controlled other than ensuring a fairly healthy lifestyle and negotiating day to day restrictions in functional ability. The sicker patients (NYHA grade III/IV) tended to have more regular interactions with clinicians, such as home visits from their specialist heart failure nurse, which reassured them that their condition was being reviewed regularly. However the more stable or less sick (NYHA II) patients only tended to see the heart failure team once every six months which was seen as too infrequent by some patients, sometimes provoking anxiety in the patient and/or carer especially upon onset of symptoms. More stable patients also spoke less about their relationship with their heart failure team and this was raised as a reason why they did not ask about their prognosis (i.e. feeling they needed to have a better relationship with their clinician before the topic was broached by either person), however sicker patients did not seek a prognosis either – possibly as the existing dynamic of their relationship with heart failure clinicians did not include thinking about the future other than an immediate future, usually between appointments.

When questioned about indicators to transition from active to palliative care in heart failure, clinicians described several biomedical and holistic indicators which may prompt a consideration of either a transition to palliative care or involving palliative care services concurrently with active care. Several barriers to transition were also described:

### 7.2.1.2 Clinician suggested indicators of transition from active to palliative care in heart failure

Biomedical	Holistic
<ul style="list-style-type: none"> <li>• Acute hospital admission</li> <li>• Blood test results</li> <li>• NYHA class IV symptoms</li> <li>• Weight loss</li> <li>• Increase in breathlessness</li> </ul>	<ul style="list-style-type: none"> <li>• Depression</li> <li>• Struggling to cope</li> <li>• Patient asking for more support</li> <li>• Active care holds no more answers</li> </ul>

### 7.2.1.3 Clinician and patient identified barriers to transition

Biomedical	Holistic
<ul style="list-style-type: none"> <li>• NYHA class IV symptoms</li> <li>• Mild heart failure on echocardiogram</li> <li>• Effective drug treatments</li> <li>• No cure from the beginning (diagnosis)</li> <li>• Feeling fairly functionally unrestricted by heart failure</li> <li>• Improvements shown in blood tests</li> </ul>	<ul style="list-style-type: none"> <li>• It's not my job (specialists)</li> <li>• Lack of space/availability for patients dying of non-cancerous illnesses in hospices</li> <li>• Poor palliative skills training</li> <li>• Poor communication skills (breaking bad news) training</li> <li>• Focus on active care</li> <li>• Questioning overall terminal illness paradigm for heart failure</li> <li>• Patient slowly declines with no significant exacerbations to prompt palliative care consideration</li> <li>• Maintaining hope (partially) in order to lessen patient and carer psychological distress</li> <li>• Prefer not to discuss death and dying</li> <li>• Seeing heart failure as part of natural ageing</li> <li>• Viewing hospice as a place to die rather than symptom control</li> <li>• Focusing on small improvements in function rather than the overall picture of decline</li> <li>• Frightened of what may happen if active care lessens or ends</li> <li>• Preferring to wait until a good clinician/patient relationship was built up before broaching the topic</li> </ul>

Throughout clinician interviews it seemed that participants could speak about death very easily in an abstract, technical way – but when thinking about prognosis and death of an individual, particularly their own patients, death was not recognised as important or relevant enough to be spoken about – only in a technical sense, whereas the ‘practical reality’ of heart

failure was seen as a chronic, progressive illness. This was supplemented by a general consensus that patients did not want to know their prognosis anyway, and that was more important (in line with maintaining hope) as this was deemed to be the patient's wishes. This was borne out by observations of clinical encounters in which the focus was almost entirely on clinical/medical/physical issues which no discussion of prognosis. Patients and carers also displayed this reaction to interview questions surrounding prognosis and the possibility of death. When asked about prognosis some participants spoke of their 'heart failure book' which they had been given upon diagnosis and indicated they knew of a section about prognosis 'in the back'. However the prevailing attitude was that this section did not apply to them so they chose not to read it as it would scare them unnecessarily and that prognosis in general (or at least the part about death and dying) did not apply to them.

Most patients did not recognise the possibility of early death and even if they were aware of prognosis in heart failure (which was limited), they did not feel, or did not wish to think that it applied to them. This held true for all patients including those in advanced heart failure. The 'theory' (rather than reality) of death and dying from heart failure was viewed as a recognisable yet abstract concept by clinicians which did not fit their patients especially well, which was mirrored by patient and carer findings. Patients made reference to how well they were doing (health wise), but they did not feel heart failure was particularly serious especially when they felt little restriction from it. Whilst they knew others may be more seriously affected by heart failure with regards to their lifespan, this was not their own personal situation. As such, death was not viewed as an important or timely reality for those with heart failure by the vast majority of patients, carers, and clinicians. Death was indeed spoken about by patients and carers, with several speaking about the general aspects of death surrounding making a will, and a philosophical stance of 'death happens to everyone'. However death was almost never spoken about specifically in relation to heart failure, and the diagnosis of heart failure did not appear to provoke thoughts of death and dying – and if they were, they were reportedly minimised by the clinical team. There were very few clinical conversations witnessed during observations or reported during interviews about specific clinical aspects of heart failure with a view to how this might have an influence on their death (and subsequent advance care planning conversations. This was particularly evident when clinicians described speaking (or not) about prognosis with their patients, and borne out in observations where prognostic conversations were almost never observed. A lack of communication skills training was often described by clinicians as a reason why prognosis was not discussed, particularly in

difficult settings such as a fast paced clinic. However no efforts to change this issue were mentioned.

Through this study access has been gained to patient and carer perspectives of the trajectory of heart failure over six months. The disease trajectory experiences of the patients and carers involved in this study did not change significantly from the initial interview and observation to the six month interview. The classification of most patients, as specified by their heart failure nurse, stayed the same with only four out of thirteen changing classification. Two of these patients progressed from newly diagnosed to stable, one died, and one improved from advanced to stable. All changes in classification are shown in Table 5. (note: patient codes are not sequential as patients who declined to participate were still given a code in chronological order from the time they were approached, the table only contains patients who participated);

Patient code (n=13)	Status at initial interview and observation	Status at six month follow-up interview
PT2	Advanced	Advanced
PT3	Advanced	Advanced
PT6	Stable	Stable
PT7	Newly diagnosed	Newly diagnosed
PT8	Stable	Stable
PT9	Stable	Stable
PT10	Advanced	Stable
PT11	Newly diagnosed	(deceased)
PT12	Newly diagnosed	Stable
PT13	Stable	Stable
PT14	Stable	Stable
PT15	Newly diagnosed	Stable
PT16	Advanced	Advanced

Table 5 Patient disease status at each interview

Most patients described living with comorbidities and separate illnesses as part of their illness experience of heart failure. Comorbidities/separate illnesses included chronic obstructive pulmonary disease, angina, cancer, and arthritis. Overall patients felt restricted to one extent or another and they did not always attribute it specifically to their heart failure. On some occasions patients and carers would start to speak about restrictions or problems caused by their other illnesses, then stop themselves and say that it 'isn't anything to do with their heart so they'll stop talking about it'. In these situations the participant was encouraged to speak about how they felt restricted even if they felt it wasn't directly related to their heart failure. This illustrates the usual nature of heart failure being one of often several illnesses experienced by the patient, and suggests that patients do not necessarily separate out their 'heart failure' experiences with their experiences stemming from other illnesses. Again this is in line with a more holistic point of view, with patients feeling restricted regardless of what they felt the particular biological cause was.

#### *7.2.1.4 Results from 'Assessing the uptake of the Liverpool Care Pathway for the dying patient: a systematic review'*

When asked about the current state of end of life care for heart failure patients during interviews, some clinicians spoke of the Liverpool Care Pathway as the primary care plan used

(mostly by other health care professionals such as district nurses). Whilst there was a good awareness of the existence of this pathway, and other generic end of life care pathways, on the whole clinicians were unsure as to when a patient would reach the stage to prompt a consideration of entering a patient onto such a pathway. This was borne out by the systematic review, which found very little information of the uptake of the Liverpool Care Pathway for any diagnosis. Nevertheless, seventeen studies provided data which showed the Liverpool Care Pathway was used for 47.4% of dying patients. Findings also suggested that eligibility criteria were skewed towards those dying of cancer, for unknown reasons, and many studies did not include diagnosis which may be due to multiple contributory factors in each death (which is often the case with heart failure amongst other diseases). Reasons for uptake and non-uptake overall remain unknown, and the impression given by clinicians participating in interviews was that end of life care was somebody else's job to think about and put into place.

### **7.2.2 Comparisons with other research**

Several findings of the current study support prior research, and highlight either a lack of research for certain areas or challenge other findings.

GroupThink refers to the way members of a group distort their thinking to become overly supportive of suggestions made within the group, and dismissive of challenges made from outside it[213]. GroupThink can be a 'peril of group cohesiveness'[214], particularly in multidisciplinary teams where dialogue and shared decision making is regarded as important and useful for patient care[214]. Throughout clinician interviews elements of GroupThink were evident, with phrases such as "even though we like to think we treat people holistically, GPs, we are still medical, we think curative, we think medicines." and "it's not something we do [talk about prognosis]". The signalling of a lack of communication skills but nothing undertaken to do anything about it also suggests clinicians may not wish to 'rock the boat' and discuss prognosis, especially if they feel other members of the multidisciplinary heart failure team would provide different information to the patient and carer. Despite this, some heart failure nurses spoke of regularly having to correct or embellish knowledge provided by one specialist as they felt what the patient had been told about their diagnosis and/or prognosis was disingenuous or insufficient.

Several GPs felt that some of their colleagues working in primary care were unaware of the disease trajectory of heart failure and the possibility of either sudden death or that palliative care may be appropriate when the patient is close to death. Some alluded to the fact that they had not thought about the role of palliative and end of life care in heart failure much before,

and consequently it was not on their 'radar' to assess or bring up at any point during the disease trajectory. Evidence shows that patients gain health and illness information from a variety of sources (GP, specialist, specialist nurses) and cognitive appraisal literature postulates that patients consider healthcare workers to be credible sources of information in order to help them understand and appraise their illness[215]. As such, patients and carers may have several sources which they view to be appropriate and accurate to consult with about their prognosis. However healthcare professionals themselves may demonstrate misconceptions/misunderstandings about cardiac care – which are then passed on to patients, particularly in nurses and allied health professionals compared to medical staff, even when accounting for variations in length of service[216]. These differences may be explained by the types of patients different healthcare professionals see – heart failure nurses see ill, yet stable patients more often and in their own home, therefore have the ability to assess the long-term holistic impact of heart failure on their patient compared to a specialist who may only see heart failure patients when they are first diagnosed after an acute hospital admission.

Patients and carers who participated in the study were on the whole complimentary of clinicians, and reticent of directly providing any feedback which could be construed as negative of their heart failure team. Surveys of patient satisfaction routinely report high levels, particularly in older patients[217], which are not necessarily a reflection of their care experiences[218]. Some patients did speak of unhappiness with their specialist, feeling s/he did not give them accurate information at diagnosis and being shocked when their heart failure nurse had to 'break' the diagnosis later on. Unclear diagnosis communication, particularly between primary and secondary care has also been found in several heart failure specific prior studies[78]. Primary care clinicians have been found to use euphemisms when disclosing diagnosis to a patient with heart failure[42], in the current study both primary and secondary care clinicians demonstrated the use of euphemisms in their prognostic practice. Unclear communication of this sort can lead to confusion or resentment[42] which some of the patients in the current study demonstrated, which had an impact on the level of trust they placed in the clinician in question. Either way, patient and carer analysis supported prior research findings that many patients prefer not to speak about prognosis[78], especially if they believe they have a longer life expectancy[81]. Patients and carers in this study were on the whole optimistic – possibly overly optimistic – (with one patient believing, having reportedly been told by a clinician, that she would live for at least another twenty years) – about their prognosis which again supports prior findings[81], and clinicians (particularly specialists) also described a 'sense of failure'[70] when considering (if they did in fact consider)

palliative and end of life care for their patients, feeling reluctant to end active care until the patient is very close to death, which often led to clinicians delaying conversations with their patients, and subsequent care transitions.

While a formal assessment of quality of life or depression was not conducted for this study, many patients and carers spoke of having a poor quality of life and feeling low mood due to the restrictions stemming from their condition, which supports prior research[16, 17]. Increasing weakness and dependency was a common theme in the current study and others[219], which again made a significant contribution to low quality of life levels. Poor coordination of care has often been reported by patients, carers, and clinicians[32, 70] and this was mentioned several times by participants in this study particularly with regards to poor communication between primary and secondary care.

Several patients experienced a change in their understanding of symptoms prior to and after formal diagnosis. Symptoms which they attributed to other conditions or seemingly innocuous causes such as indigestion were now understood to be part of their heart failure and much discourse surrounded the change in understanding of this. Suspicion surrounding their symptoms prior to formal diagnosis and shock at receiving a diagnosis was commonly found in patient and carer interviews and observations which supports prior qualitative research of the diagnosis 'journey'[219], which has been studied extensively in cancer particularly with regard to subsequent delays in help seeking behaviour[220]. Whilst illness narrative research show other patients with HF considering how to cope with the unpredictability of dying suddenly[219], few patients in the current study spoke of this possibility and indeed some did not feel anything of that nature would happen to them.

### **7.2.3 Clinical and policy implications**

The results of the current study have several implications for clinical guidance and UK policy. Palliative care is recognised in policy literature as being appropriate for use in heart failure, and recommendations are specific that palliative needs should be assessed early in the disease trajectory and managed at the appropriate time. With regard to clinical indicators, Boyd and Murray[105] published supportive and palliative care indicators to transition in a 2010 special issue of the BMJ 'Spotlight: Palliative Care beyond Cancer'. With regard to heart failure, supportive and palliative care assessment was only included automatically at NYHA class IV. I would argue that this is at odds with their previous work and much of the wider research and policy literature which recommends supportive and palliative care much earlier in the disease trajectory. In light of the current study which showed uncertainty and anxiety amongst



patients and carers, and many unaware of prognosis even at advanced heart failure, clinical indicators for palliative care assessment should include patients with NYHA grade III heart failure. Evidence shows sudden death occurs in around half of those with heart failure, with sudden death more likely to occur in the earlier stages (NYHA II/III) of the illness[49] – however some studies show the incidence of sudden death to be lower in the new ‘therapeutic era’ (mid 2000s) than the historic therapeutic era (mid 1990s), and a concomitant increase in both the proportion of deaths from progressive heart failure and from non-cardiovascular causes[50]. Regardless, a significant proportion of patients with heart failure die suddenly (around one third to two thirds of patients[49]) and European Society of Cardiology (ESC) guidance quotes ‘approximately half[7]’. Regardless of mode of death it is clear that heart failure is a life limiting illness, and the received wisdom contained in ESC guidance of the distinct possibility of sudden death is not taken into account by the clinical community. Prognostic ambivalence, the core category identified in clinician interviews, should not lead to ‘prognostic paralysis[221]’. However the current study shows palliative care is left unconsidered until very late in the disease trajectory, if at all, confounded by several clinicians believing there to be no distinction between active and palliative care, and questioning whether or not heart failure is a terminal illness.

The results of the current study point to a significant care gap for those with heart failure who are categorised as ‘unwell’ but not ‘terminal’. Few resources are available for stable patients and indeed for patients with advanced heart failure if neither they, nor their clinicians, feel that advanced heart failure is concurrent with a terminal condition. It seems that having a ‘label’ of heart failure may preclude access to appropriate supportive resources for these patients despite clinical need.

Clinical guidelines for chronic heart failure[10] also stipulate that patients and carers should have the opportunity to discuss issues of sudden death and living with uncertainty. The current study shows that whilst patients and carers are uncertain of their future particularly towards the later stages of their illness, most are unaware that sudden death is a common experience for patients with heart failure. This would suggest that patients and carers perhaps do not take the opportunity to discuss sudden death due to a preference not to, poor prior communication between themselves and clinicians, or poor receptivity of prognostic information. Most patients reported little to no prognostic communication from their clinicians, and clinician analyses revealed a general sense of preferring to discuss active treatment and delaying conversations until the ‘bitter end’, if they occurred at all. During

interviews and observations, patients with advanced heart failure in this study often spoke of, and demonstrated, difficulties with remembering information provided at appointments which illustrates some of the problems associated with delaying prognostic conversations, judged as necessary by the clinician at that point, until very near the end of life.

At the time of writing, the primary end of life care pathway used in the UK – the Liverpool Care Pathway (LCP) – was in the process of withdrawal due to the independent review of the pathway published in July 2013 which criticised its implementation as often a tick box exercise, with many experiences of poor care under the Pathway. There is no specific alternative currently specified for structured end of life care in the UK. The review panel criticised poor communication standards often when using the LCP and argued that this is a result of poor skills training and a general lack of public discourse surrounding death. However supporters of the LCP have criticised what they perceive to be a knee jerk reaction by the review panel to recommend withdrawal of the Pathway, stating;

*“The LCP has become the ‘whipping boy’ for a failure of implementation of good end of life care practice, marked by a lack of investment in staff education and a lack of development of supportive interventions to improve the wider palliative and end of life care of patients that are effective in ‘real life’ resource-constrained contexts[222]”.*

The current study highlights poor communication in heart failure at all stages of the disease trajectory and a general reticence to speak about palliative and end of life issues as they are inherently linked with death and dying, which supports the review panel’s findings. However time constraints, large caseloads, clinical uncertainty, and a lack of communication skills training make it very difficult for clinicians to effectively consider palliative and end of life care, at the appropriate time.

#### **7.2.4 Commentary**

Most clinicians separated active and palliative modes of care, and did not subscribe to the concept of introducing palliative care in some form from the point of diagnosis. Active care was described as being provided right to the end of life and this was not modified to reflect a more palliative stance as the disease progressed. In other words, the two options available to the clinician were asserted as active OR palliative care – nothing in between.

When patients are in advanced heart failure they are seen more often by their heart failure nurse – often once a week. Whilst regular contact is recommended[7] for responsive disease management, it may be more difficult to accurately assess when a patient is so sick that they require supportive care. Consultations often focus on assessing how the patient is on that day

and in the immediate past (from appointment to appointment), mostly so that symptoms of significance can be recognised and coded by the clinician, rather than taking a step back and comparing the patient's health with their health six months, or a year ago. As such it is difficult for patients themselves to see how they are objectively, and regular clinician contact such as this may foster a routine of only comparing health from one week to the next, disassociating the components of the disease trajectory, and accepting small increases in restriction (over a shorter period of time) rather than objectively comparing restriction over a longer period which may prove to have increased significantly, and prompt a discussion of palliative care.

Some participants used the interview to think through their views and decisions on prognostication, with some views changing during the interview itself. This suggests that some patients had not thought about the topic prior to their participation in the study, a finding mirrored by several clinician participants saying that the issue was "not on their radar". This was borne out in observations where prognostic conversations were almost never observed. Clinicians also reported reluctance to break bad news to patients when they felt under skilled. One argument used against open communication of end of life issues is simply, if patients want to know, they will ask. This argument reflects the doctor-patient dyad change in clinical practice, where historically the patient was a passive recipient of knowledge bestowed by the doctor who controlled the conversation, asked the questions, and made the decisions[223] – to a model of care which privileges shared decision making, acknowledging the patient as the 'expert' in their own condition and ultimately an equal role in their care. Meanwhile some patients, particularly the current elderly generation, may feel that professionals should raise the matter, allowing them to judge whether or not it is clinically serious enough to warrant an open discussion[224]. In his role as an oncologist, Berry[225] wrote about clinicians using words or phrases to communicate – vaguely – to the patient that they are dying, without actually using the word 'dying' or 'death'. I would suggest that this avoidance, as demonstrated in the current study, is even more apparent in heart failure.

#### ***7.2.4.1 The identity of suffering and the heart***

The current study shows that everybody involved in heart failure – clinicians, patients and carers – all seem to be colluding to minimise the implications of a heart failure diagnosis, and do everything *except* privately come to accept the prognostic meaning. During the majority of patient and carer interviews and observations I was struck by the tenacity and sheer will to continue on with life as 'normal' despite often severe functional restriction brought on by heart failure. This was particularly apparent in patients with advanced heart failure. There was a real sense of refusing to allow the illness to 'beat them'. Suffering in this way has been

written about in several contexts, including chronic illness, and those who experienced war-related imprisonments.

*"Is this to say that suffering is indispensable to the discovery of meaning? In no way. I only insist meaning is available in spite of--nay, even through suffering, provided... that the suffering is unavoidable... If one cannot change a situation that causes his suffering, he can still choose his attitude. Long [a severely disabled, paralysed young man who is quoted elsewhere in the book] had not chosen to break his neck, but he did decide not to let himself be broken by what had happened to him[226]." Man's Search for Meaning, Viktor Frankl (1946).*

Some patients and carers made reference to cancer, comparing their heart failure to cancer both in positive and negative ways. One patient commented *"[heart failure is] in a way, worse than cancer, because at least you know cancer is eating you up"*. Perhaps cancer is, in a way, easier to conceptualise and accept. A tumour is visible in the mind's eye and can be focused upon to mount a fight or attack against this 'foreign invader'. Some patients even name their tumours;

*"His name is Boris. He is trying to kill me. I won't let him. [...] Boris. Foreign. Evil. Pint-sized. If I can picture my enemy I can fight him; at the very least I can write about him[227]." Greetings from Cancerland, Alysa Cummings (2012).*

It may be easier to accept the possibility of death from cancer when one can externalise the threat more easily, compared with heart failure where the threat emanates from one's own heart – which has, up to now, probably served them well and of course is a vital, innate part of the body. The heart holds significant personal and group connotations which permeate large swathes of societal knowledge and norms. Hearts are manifested socially and culturally as one of the most important parts of the body, central not only to maintaining circulation and life, but also as the source of love.

*"A good heart is worth gold"* – Shakespeare's Henry IV, Act 2, Scene 4 (circa. 1597)

The heart is used in everyday language to illustrate a multitude of emotions, concepts and idioms – e.g. "heartbroken", "warm-hearted", "know by heart", "faint hearted". Similar terms are used for describing the centre of something, like the "heart of the city", "get to the heart of it". Using the heart as a term in this way has been the case for several centuries, with the first references to the heart and emotion dating back to 800 BC[228] in Greek and Roman mythology and the Bible. By the early modern period (c. 1450 – c. 1750) the heart had come to mean several things in literature and society –

*“The center[sic] of all vital functions, the source of one’s inmost thoughts and secret feelings or one’s inmost being, the seat of courage and the emotions generally, the essential, innermost, or central part of anything, the source of desire, volition, truth, understanding, intellect, ethics, spirit. It was the single most important word referring both to the body and to the mind[228]”.*(pg 11)

Indeed, the word “heart” is used, in some form, 858 times in the Authorised Version of the Bible, far more than the word “spirit”[228].

*“Let not your heart be troubled”* – John 14:1

It is possible to suggest that, for these reasons, communication of a poor prognosis stemming from a failing heart is more difficult for clinicians to achieve, particularly in comparison with cancer, and for patients to seek out and receive. Another argument could be that patients simply wanted to get on with their lives, preferring not to conceptualise themselves as a suffering or dying person – with clinicians supporting that by way of focusing on improvements rather than a poor prognosis.

#### **7.2.4.2 Liminality and liminal states**

The concept of liminality is an interesting theory which may be applied to the findings of the current study. The word liminal comes from the Latin ‘limina’, meaning ‘threshold’. In turn, liminality, according to Victor Turner – an anthropologist and sociologist – “is a movement between fixed points and is essentially ambiguous, unsettled, and unsettling[229] (pg 274)”. A simpler way of describing the liminal space is the space between transitions. Those in a liminal state, ‘liminars’ or ‘liminal persons’, “are betwixt and between the positions assigned and arrayed by law, custom, convention and ceremonial[230] (pg 95).” There are several ways in which individuals can be in a liminal state, including the liminal space between living and actively dying. This is not a naturally occurring phenomenon; rather it is something individuals impose on naturally occurring phenomena, or on changes in status within a community[231]. The social situation of those in a liminal state is characterised by ambiguity and paradox[232], a ‘frightening no-man’s land[233]’.

Data analysis in the current study revealed uncertainty, ambiguity, and paradox for all participants. As demonstrated in vignettes 1-4 (pg 156), patients and carers could be described as being in a sustained liminal state – not well, but not seriously ill and dying. Another facet of this state is the extent to which a prognosis is ‘known’. As detailed above, most patients did not wish to know their full prognosis, despite in most cases knowing their illness was fairly serious especially when combined with advancing age. It seems patients and

carers are effectively sitting in a doorway – a doorway which leads to knowing a full prognosis – that no one wants to open. Indeed all individuals in this liminal state seem to be colluding to stay in the doorway, or not to come close to the door. Once a prognosis is known, it cannot be un-known – and once that door is opened, there is no going back. Clinicians are in a similar liminal space themselves, knowing that heart failure has a poor prognosis but not necessarily joining up the general poor prognostic signs to come to the knowledge that the patient sitting in front of them actually has that poor prognosis. Either way, clinicians sit in that doorway with patients and carers, knowing (to some extent) but rarely telling and acting upon the poor prognosis, accepting the patient and carer’s liminal state and staying there with them until either a serious hospitalisation (where it is very clear the patient is close to death) – forced through the doorway, or if the patient asks themselves and indicates he/she wants a straight answer. This clinical liminal state impacts on if and when the clinician starts acting upon a poor prognosis to involve palliative care.

This concept, of a doorway between not knowing and knowing a prognosis, can be seen as blended with what clinicians felt was a dichotomy between active and palliative care. Once the patient and/or clinician stepped through the doorway to knowing (and telling), palliative and end of life care considerations often followed. Prior to that, these considerations were not seen as relevant. So what is a way forward? We need to prepare clinicians so that they are willing to stay either in the liminal space with patients, or accompany the patient and carer through that ‘doorway’ to knowing a prognosis. There needs to be structures in place to help clinicians, patients and carers over the threshold should patients want, or need, to be helped over it. The data show no one seemingly wants to step over this threshold, or at least not completely or seriously, but there *are* patients who do want this, and when it comes to the very end of life, patients and carers often *need* to be helped over this threshold in order to ensure a ‘good death’. Either way, clinicians must be prepared to stay in the liminal space with patients and carers with the threshold of prognostic communication firmly on their radar, looking out for discourse from the patient or carer that they want to know more, and being prepared to discuss prognosis when it is needed.

### 7.3 Study strengths

There are several strengths to the current study. This is the first known study which has used a qualitative, longitudinal approach to explore prognostic communication from the viewpoint of patients with heart failure, their carers, and clinicians which has allowed comparisons between groups over a period of time, with the deliberate inclusion of a cross section of

patients in different stages of heart failure. The data collected and the subsequent analyses have the potential to inform health care policy on how the disease trajectory should be managed with specific regard to communication at each point of the illness, with a realistic perspective of the challenges of heart failure and how clinicians can manage uncertainty without denying patients and carers vital prognostic information. This has the potential to improve patient care and potentially facilitate links between primary care, secondary care, and hospices/specialist palliative care teams.

Despite the restrictive and emotive nature of heart failure, especially advanced heart failure, I was able to recruit several elderly and very elderly patients, including some near to the end of life. Historically this has been a challenging patient cohort to recruit. The current study illustrates that, with sensitive and thoughtful research procedures, there is no reason why very ill and/or elderly patients should not be given the opportunity to participate in research.

#### **7.4 Study limitations**

When embarking on the study I identified that it would be very difficult to arrange observations of clinic/home visit appointments where I, or the clinician, knew in advance that prognosis would be discussed. Prognostic discussion is often a staged event and several clinician participants spoke of ‘trickling’ information down to the patient and carer, feeling that this gives them more of an opportunity to digest and accept this sort of emotive information. Restricting clinic observations of the first or second appointment after diagnosis may have been useful to assess communication at this early stage, however the aim of the study was to illustrate communication at all stages of the illness. A longer term study using regular interviews and observations with patients and carers, from diagnosis to death, may have been useful to assess prognostic communication especially if their particular treating clinician was also involved to discuss their communication during appointments afterwards. Unfortunately this was prohibited by the time restricted nature of a PhD study.

Whilst observation data (of clinic and home visit appointments) were collected to inform subsequent patient and carer interviews, data were not analysed line by line. This was again prohibited by the time restricted nature of a PhD study with in-depth modified constructivist grounded theory analysis on 53 interviews, with most of them also transcribed by myself. However all observations were audio recorded and listened to afterwards, with themes/incidents of prognostic communication sought. Very little prognostic communication was found, and where it was found, it was brought up during the following interview and analysed, as described earlier. If thematic analysis of observations had revealed specific

conversations about prognosis, then time would have been re-allocated to conduct line by line analysis. However consultations almost always focused on pharmacological, medical problems thus it was inappropriate to invest time analysing prognostic content that simply did not exist.

Lastly, it is of course possible that patients and carers had considered their views about death and dying but could not, or would not, share these with me. One patient and carer dyad were un-contactable for the follow up interview and it is a possibility that this was due to feeling uneasy about the subject matter. The longitudinal nature of the study, my prior training in qualitative interviewing, and the semi structured nature of interviews were designed, in part, to allow a rapport between myself and participants to be built which could foster an open dialogue about such an emotive subject. Furthermore as the bulk of participants agreed to participate in the second interview, six months later, this signals that they were bought into the idea of engaging in, and discussing, prognosis and the future.

## **7.5 What is a terminal illness?**

The definition of a terminal illness differs somewhat between dictionaries, clinical guidance, and definitions for the purposes of insurance and financial matters.

According to the UK Department for Work and Pensions (DWP), specifically regulations provided for Disability Living Allowance/Attendance Allowance, a terminal illness is something which is 'more likely than not to cause death in the next six months'. The DWP note that clinicians use a different definition of a terminal illness, namely 'any illness that will end in death'. As such, a person may be terminally ill from a clinician's definition but not be terminally ill according to DWP regulations because they are expected to live longer than six months.

Insurance providers have similar definitions of a terminal illness. Legal and General will pay out on their Terminal Illness Cover if the patient is diagnosed with a terminal illness and is not expected to live longer than twelve months in the opinion of both the hospital consultant and the insurer's medical officer.

With the clinical definition of a terminal illness being broader than insurance and social security working definitions, clinicians may adopt their own personal definition for their practice and for different diseases and disease stages.



## 7.6 Is heart failure a terminal illness?

One of the core questions emerging from the study was whether or not heart failure is, or should be, classed as a terminal illness. It appears that heart failure meets the terms of the 'official' clinical definition of a terminal illness described above, in that it is an illness which will result in death. However when questioned on this issue opinions differed both within clinician groups and within patient and carer groups. Most clinicians pointed to the significant advances in treatments for heart failure and the improvements in life expectancy they had seen through their work. They felt that whilst in a technical sense heart failure could be described as a terminal illness, the more appropriate description would be of a chronic progressive illness and that is what they chose to communicate to their patients and carers. Whilst the mostly incurable nature of heart failure was expressed to their patients, clinicians stopped short of equating it with a cause of death, even when (in many cases) their patient was in advanced heart failure. This leaves clinicians in a pragmatic conundrum of whether to classify patients as for active care or palliative care – being that they mostly expressed a polarised view of the two types of care, with no gradual blending of palliative care into active care as the disease progresses.

It is perhaps unsurprising therefore that no patient or carer saw heart failure as a terminal illness. Heart failure was instead seen as a chronic illness with a progressive nature, however as the vast majority of heart failure patients are elderly, the worsening of their illness was seen as part and parcel of the general, natural experience of getting older and frailer. Death was acknowledged in an abstract, theoretical sense but was rarely applied to participant's own personal situations, either in a general manner or as a direct result of heart failure.

## 7.7 Should heart failure be classed as a terminal illness?

There are advantages and disadvantages to classifying heart failure as a terminal illness for the purposes of care, communication with patients, and delivering appropriate palliative and end of life care. The arguments are summarised below.

### 7.7.1 The ethics for classifying heart failure as a terminal illness

Certain arguments of accepted clinical knowledge surrounding the definition of a terminal illness, the clinical nuances of heart failure, and the end of life ethical paradigm would suggest that heart failure should be classed as a terminal illness. Heart failure *will* cause death unless another illness causes death first (which is often the case, and a confounding influence in prognostication). Arguably, heart failure is certainly terminal in the advanced stages, particularly at NYHA class IV. Furthermore 50% of heart failure patients die suddenly, and are

more likely to die suddenly in the earlier stages of the illness. Consequently death is, on paper, a reality for those with heart failure at *any* stage of the disease trajectory.

Looking to the use of ‘terminal illness’ to describe certain cancers, and other cancers in the advanced stages, the accepted definition of terminal cancer is when the illness is past the point of no return. We know there is no cure for heart failure (other than the rare, reversible versions caused by drug/alcohol misuse amongst others). Whilst it is difficult to predict the course to death in heart failure, it is relatively straightforward to predict when a patient will NOT recover – i.e. past the point of no return, as in terminal cancer.

Lastly, taking the above arguments into account, the end of life ‘ethos’ stipulates that all individuals and their families have a right to put their affairs in order. Policy guidance recognises this and recommends open, clear communication from the point of diagnosis or soon afterwards. There may be patients who are unaware, or in a liminal state, that they can make advance directives including do not attempt resuscitation orders. Unaware patients may be keen to make their wishes known if/when they become too ill to think about or communicate their wishes effectively. Heart failure often causes confusion, depression and anxiety (particularly in the later stages) which can impact on an individual’s ability to think clearly. Classifying heart failure as a terminal illness and evoking preferences regarding decision making soon after the point of diagnosis would go a significant way to prompting discussion and documenting those wishes, further ensuring they are adhered to when practicable rather than denied due to a lack of forethought and/or the denial of the indisputable nature of heart failure causing death.

### **7.7.2 The ethics against classifying heart failure as a terminal illness**

In contrast, there are several arguments against classifying heart failure as a terminal illness. Heart failure in itself may not be the cause of death, especially as patients can be kept stable for many years, and there can be many comorbidities that may cause death. This is reflected by the fact that cause of death as reported on death certificates for those with heart failure is often listed as a comorbidity, rather than heart failure itself. Like other illnesses such as diabetes, heart failure can be seen as a chronic illness rather than a specific cause of death.

Whilst it can be identified when a patient will not recover from heart failure, it is very difficult to predict how long a patient has left of their life. Some patients may live for several years and there are many cases of patients living over ten years with heart failure. Some definitions of a terminal illness, including the Department for Work and Pensions, specify it is to be used for an illness which is more likely than not to cause death in the next six months. In the majority

of cases it is clinically very difficult to make that prediction, suggesting that heart failure does not meet the terms of that definition.

Some arguments are made for the classification of heart failure as a terminal illness to be concurrent with NYHA classification – the more functionally restricted a patient is, the poorer their prognosis (particularly in NYHA grade IV). However NYHA classification does not often accord with precise prognosis. Some patients can be very ill/restricted yet classed as a lower grade, whereas some grade IV patients can appear fairly well and live for many years stable at that grade. Part of the argument is confounded by the variable speed of progression of the illness (through the disease trajectory). Some patients may progress to advanced heart failure, and die, within a couple of years of diagnosis. Some may die within a few months of diagnosis. Some may stay stable for several years without too much restriction, and some may even remain stable for several years in advanced heart failure. All of the above possibilities occurred in the cohort of patients for the current study.

Finally, many patients with heart failure are (were) not eligible for the Liverpool Care Pathway due to the inherently unpredictable nature of the illness, confounding the already difficult task of predicting death. As a result, end of life care in its current form may be inappropriate for heart failure, which suggests it may not consequently be classed as a terminal illness.

### **7.7.3 Is prognosis a helpful concept in heart failure?**

The findings from this study indicate that the concept of prognosis, and prognostication, in heart failure is not helpful from the perspective of patients, clinicians or carers. In particular, the concept of the end of life phase being 12 months – reflected in various policy documentation including the Department of Health End of Life Care Strategy 2008 – appears to be particularly unhelpful when considering palliative care, and advance care planning for patients with heart failure. Findings from this study demonstrate that the concept of prognosis means different things to different groups of people. In practical terms for clinicians, it may mean putting anticipatory care plans into place, or discussing advance care wishes with patients. However the concept of 12 months in policy terms did not emerge from the data as being a useful or an important concept or definition. Certainly it was viewed as not a working definition, rather a theoretical definition which was not useful in clinical practice. There is a lack of a clear operational, working definition of the end of life that could actually be helpful for patients, carers, and clinicians. From the perspective of patients and carers, the current study shows that the concept of prognosis may mean a general planning for the future whilst

living day to day, having their symptoms and needs addressed and holding on to hope – not necessarily connected with length (timescale) of life.

## 7.8 Sociological perspectives of death and dying

The factors that contribute to society's provision and experience of palliative care are complex and varied. It is clear, both from the results of the current study and the existing body of literature, that death and dying is a difficult subject to discuss. This is an issue rooted in the manner of which death is culturally constructed in the Western world. Many researchers identify the competing interests of dichotomy/discordance between holistic palliative care and the constant drive to provide and improve active, curative care to have an impact on the way in which death and dying is culturally constructed. Many Western cultures, including the United Kingdom and the United States may be seen as a death-avoidant society. This is a result of fighting against death with advanced medical science and technology – which has been successful in eliminating former 'death sentences' such as smallpox and polio – whilst of course never being able to conquer the inevitability of death. Many diseases such as heart failure, chronic obstructive pulmonary disease, and diabetes mellitus are now viewed as long-term chronic illnesses, as mortality rates have plummeted since treatments have improved. The success of medical science in 'conquering' some infectious diseases may lead to the societal belief in many instances that medical professionals can put off and indeed conquer death. Indeed the current study indicated the vast majority of clinicians prefer to communicate a focus on stability in heart failure over and above any issues to do with prognostication or palliative/end of life care. Health care could be seen as a victim of its own success, allowing illness to become chronic and permanent rather than an imminent or short term cause of death - impacting on the provision of prognostication skill training which several clinicians indicated they lacked (both in a clinical sense and a communication skill sense).

As a society we face many fewer instances of death at a 'young' age, with a constant strive to circumvent death if it is deemed untimely. This lack of visible death experience in society may result in misunderstanding, lack of acknowledgement, and avoidance of the subject. Heart failure is not colloquially seen as a serious illness or cause of death (or even as a cause of death for those who have the disease), whereas cancer is often equated with death and dying. However every one of us must face death, and when we do, many experience an existential struggle and negotiation of the tension between attempts to cure or control disease and the unavoidable nature of humanity.

## 7.9 Critique of palliative care

As the hospice model of care near the end of life has grown and evolved, encompassing palliative and supportive care earlier in the disease trajectory, some authors have put their heads above the parapet to discuss what one author terms “palliative care triumphalism[234]”. This concept refers to the fact that death is, by its very nature, uncontrollable and the result of multiple components of the body failing in an inherently undignified and overwhelming manner. Death is what it is; an unknown, an existential reality, a process, a suffering. To attempt to control it with carefully managed clinical efforts by dedicated palliative care professionals may run the risk of ignoring this fundamental aspect and process of life which is, eventually, to die[235]. Is a “good death”, seen from the eyes and expectations of clinicians, carers and the dying person, ever fully achievable? The current model of palliative care for those with heart failure may not be fit for purpose, evidenced further by the results of the current study showing the liminal state clinicians, patients and carers occupy with clinician reluctance to progress further into, and between, the states of ‘knowing’, ‘telling’, and ultimately ‘acting upon’ a prognosis.

## 7.10 What I learnt

When I began the current PhD study I, admittedly, did not know very much about heart failure. My initial research on the topic prior to formal enrolment demonstrated that it was a serious chronic condition, and that patients live their lives with heart failure to the best of their ability without unnecessary thought to prognosis and the future. Meanwhile I was aware that the term ‘heart failure’, informed further by my subsequent readings into the aetiology and mortality of the disease, demonstrated a condition which would ultimately result in death, probably within six or seven years of diagnosis. I went on to read many journal articles which illuminated a lack of clear communication surrounding prognosis both in heart failure and cancer, and whilst significant steps had been made to improve prognostic communication in cancer, heart failure seemed to be left behind. This seemed like a clear injustice to me. Added to this was the usual reaction I seemed to be getting when describing my study to others – a grimace, sucking-in of air through the teeth and comments of “that must be a very difficult topic to study”. I imagined myself having heart failure (or any serious chronic illness) and asked myself the question of, if I was that ill, would I want to know if I had a limited life expectancy? In my easily conjured up scenario, in my healthy body and identity, as a health researcher, I thought *yes, definitely*. I went forward and spoke to anyone who asked about my research about heart failure, and conveyed my feelings that it was an injustice for patients to be more or less universally denied clear and honest communication at every stage of their illness,

particularly prognostic information. As I come to the end of my PhD, having interviewed many patients, carers and clinicians who deal with heart failure on a daily basis, it now seems to me that my personal identity of having a more or less healthy body and an imperative to objectively probe prognostication in heart failure significantly influenced my thoughts and feelings around prognosis communication. Heart failure *is* an inescapably terminal illness, from the very basic definition of terminal illness as being something which will eventually cause death. However I have learned that heart failure is increasingly seen by clinicians as a chronic illness, and the notion of 'terminal' with reference to this disease has been rejected by many working in the field. The ethical issues surrounding this are difficult and complex, and it has been a long and difficult task for me to separate my personal opinion with what is evidenced in the data. One of the core issues here is that it is both a chronic and terminal illness, and our health service is seemingly ill equipped to deal with this dichotomy (or at least, what clinicians perceive to be a dichotomy). As such, the semantics of each term and a lack of communication skills training amongst clinicians significantly confound the issue to such an extent that patients end up slipping through the gaps of getting care right at every transition point.

The ethical argument of open, honest communication and giving the patient and their family a chance to prepare, emotionally and practically, for the future is strong. This argument is enhanced by the chance of dying suddenly from heart failure being 50%. I still believe that more effort should be made by clinicians to advise patients and carers about the life limiting nature of heart failure, and relate this to the patient in the most effective way possible so that they understand it applies to them and not for other faceless statistics of heart failure. However the majority of clinicians, patients and carers rejected this argument. In the current study, the few instances where patients reported asking about their prognosis, patients were told that nothing untoward was likely to happen and the major focus was to ensure stability, which was seen as having a very good chance of success with no particular end to that disclosed. Personally, it is worrying that whilst the prevailing model of communication about heart failure being a chronic progressive illness (rather than terminal) works for many, there are some who are being denied a fuller disclosure of prognosis when they muster up the courage to ask. Several clinicians spoke of making a judgement of prognosis disclosure based on what the patient asked, however did not then describe subsequent open conversations with the small group of patients seemingly demonstrating an appetite to know what to expect in the future, including lifespan.

The fact that death and dying was spoken about in general terms by patients and carers may indicate that there is a willingness in principle to speak about death and dying, which could be built upon by clinicians to then extend the conversation to death and dying with specific relation to heart failure and the implications of heart failure on death and dying. This is not to say that prognostic communication should be 'forced' onto a patient and their family – rather that extra care and awareness should be taken during appointments, to carefully listen out for questions being raised about prognosis from the patient and to discuss this openly, taking cues from the patient to assess exactly which nuances of prognosis they wish to know.

Clinicians in this study are mostly of the opinion that their patients and carers do not want to know if they have a terminal illness, demonstrating this by not asking about their prognosis (therefore not ready to hear the answer), and that current poor societal knowledge of the nature of heart failure makes the task of breaking bad news even more difficult, to the extent that all too often communication of prognosis, palliative and end of life issues does not occur at all. However I feel the medical community should not necessarily be led by popular societal opinions of which illnesses kill whom (e.g. cancer), and stereotypes of what the 'average' patient wants to hear about their prognosis. A small body of patients, as demonstrated by this study, wish to know their personalised prognosis. The literature also shows patients tend to view heart failure as less serious than it actually, objectively is, and clinician communication often backs this up by delaying, or avoiding, discussions of what care might look like when it progresses to advanced heart failure. Perhaps it is unsurprising, therefore, that most of the patients in this study did not wish to know their prognosis as the concept had not been introduced to them, and notions of progressing to the end of life from heart failure were left unexplored, minimised, or even denied when questioned. Nevertheless, arguably patients and carers have the opportunity to read in other sources (such as the internet and British Heart Foundation publications) what they might expect, in general, their prognosis to be. A few patients alluded to this and spoke of a desire not to read 'the back of the book' as they were too afraid to. These patients had an idea of the progressive nature of the illness but preferred not to read it. The same patients did report asking their clinicians what they could expect in the future ("Am I going to drop down dead with this?"). I got the impression from patients that this was asked when their clinician had been reassuring them about the nature and implications of the disease – i.e. during a positive interaction, where they might hope the positivity would continue for the answer to the question about prognosis, rather than during a more negative clinical interaction. Furthermore these patients spoke of making the decision to ask their clinician in person about their prognosis, rather than read it in the book, as they

were afraid to read something that may scare or confuse them (especially as the written information is not personalised to their particular situation), then have no opportunity to discuss it further until their next appointment. Clinicians also spoke of the British Heart Foundation book as part of, and supplemented to a theoretical staged discussion of prognosis in heart failure – but then several of these clinicians reported not speaking of a prognosis with patients, effectively making the book the only source of prognostic information (rather than supplementary information).

The small body of patients who would like to know their prognosis may grow if open and clear communication about the seriousness of the illness – without needlessly stamping out hope, as pharmacological treatments have seen huge improvements in providing stability and improving mortality in recent years – was given from early on in the disease trajectory. But does the prevailing patient assessment of the seriousness of heart failure actually matter, either in day to day life or near the end of life? Certainly it would be unhealthy for patients and carers to dwell on a poor prognosis, becoming anxious, depressed, and ultimately denying themselves the chance to live their life – whether long or short. The difficulty with this lies within the competing pressures of end of life ethics, and the pragmatic nature of communication and maintaining hope (and psychosocial quality of life) within a time limited clinical consultation. I am unsure if one ultimately ‘trumps’ the other, particularly when treating the ‘average’ patient – who may prefer to wait for their clinician to deliver what they professionally deem to be relevant disease related information. Furthermore, it should not be ignored that the majority of patients demonstrated that they do not wish to explicitly know their prognosis. The one clear conclusion I can make is that very little effort was reported (by all groups – clinicians, patients, and carers) to assess communication preferences, ask about patient expectations for the future, their worries and concerns for future care, their preferences (if any) for care when very serious illness may occur. These ‘feelers’ for information were not on most clinician’s radar at all, and when patients took it upon themselves to ask, an accurate answer was most often not provided and no indications of progression of the illness, personalised to the patient, were given.

### **7.11 Future research**

A larger, longitudinal study which involves regular observations of clinic and home visit appointments from diagnosis, right through the disease trajectory would be useful to illustrate the qualitative aspects of the trajectory from start to finish, and assess communication of



prognosis objectively in a clinic setting. This would also further illuminate barriers to early prognostication in heart failure.

Equally, the inclusion criteria of the current study were patients with an echocardiogram confirmed diagnosis of heart failure. There is a body of patients, of unknown proportion, without a formal heart failure diagnosis or without an echocardiogram confirmed diagnosis (especially if they are managed solely by their GP). These patients may also be excluded from other heart failure related studies due to a lack of formal or echo-confirmed diagnosis. As the 'gold standard' of heart failure diagnosis includes an echocardiogram assessment, more effort should be made to confirm the diagnosis in this manner, and recruitment should be expanded to those with suspected heart failure.

With regard to the evidence for sudden death in heart failure, more research is needed quantifying the likelihood and proportion of this mode of death in more differentiated populations including in the elderly and very elderly, between genders, and in different places of residence.

Further, in light of the current study, future research should focus on promoting discourse in the community surrounding end of life care, particularly for those with heart failure and other non-cancerous, progressive illnesses. In addition, as heart failure is so poorly understood by the public, more work should be embarked upon which educates the general public as to the nature of heart failure so that they may be less fearful and further informed should they, or a member of their family become the one in fifteen (if aged between 75 and 84) who receive a heart failure diagnosis.

## **7.12 Conclusion**

The current research study has demonstrated that despite the overall disease trajectory, heart failure is seen as a chronic illness rather than a terminal illness by the majority of patients, carers, and clinicians – and treated as such in practice. Several patients and carers described concerns over maintaining stability but did not equate this to a limited life expectancy, focussing more on the everyday difficulties in negotiating functional restrictions. Most clinicians felt under-skilled with regard to breaking bad news, and felt it was unnecessary – pointing to new evidence based treatments which have benefited mortality in heart failure. A number of cardiology specialists felt that prognosis communication was 'not their job', choosing instead to leave these discussions to the heart failure nurse. Heart failure nurses in turn did feel better placed to discuss prognosis but felt it was often inappropriate to discuss it

in a clinic setting, preferring to delay these conversations until the patient was receiving home visits (which would mean they were more sick, and further along in the disease trajectory). None of the patients and carers in this study seemed to be aware of the significant risk of dying suddenly despite evidence showing around 50% of heart failure patients do die suddenly, and are more likely to die in this manner earlier on in the trajectory. Transitions from newly diagnosed to stable heart failure were evident and exemplified by achieving a balance of medication and lifestyle adjustments, however other transitions such as from active to palliative care were not demonstrated in clinician data as a cogent, considered, and applicable event for patients with heart failure.

Throughout this PhD research study I have been attempting to decide for myself, and subsequently create an academic argument, around whether or not heart failure should be seen as a terminal, or chronic illness. I have come to believe that there are elements of both and the situation is not as dichotomous as illustrated. The literature on this topic, and the current study, underline the imperative of sensitive communication at each stage of the illness. The medical community should forge its own path of improvement, based on evidence provided by this and other studies – especially in this case where there is an imperative to provide some form of advanced care planning for the good of the patient, and future shaping of appropriate services. The current study shows clinicians feel there is a lack of skill and resources, which supports a status quo based on assumptions of what their patient and carer don't want (i.e. they don't want to/can't talk about death and dying), rather than an assessment of what they might actually want to know, which ultimately denies patients and carers the opportunity to know and plan for poor health and death. This stance, by its nature, will never encourage policymakers and commissioners to improve services. Prognostication is currently tied in with the commencement of considering palliative care, which as shown in the current study occurs often too late to be beneficial. Ultimately a package of care which is able to cope with the complexity of the disease trajectory and the often oscillating symptoms and functional restriction with heart failure would address many of the issues of prognostic paralysis. This package would address heart failure as a life limiting illness, but with an active care plan (beginning at the point of diagnosis) that improves quality of life, and is capable of fluctuating between traditional 'modes' of care (active/palliative) – delivering palliative care earlier as appropriate to achieve quality of life improvements, and active care to stabilise and improve symptoms, individualised to the patient and their needs for the duration of life. The following chapter develops these themes into specific recommendations for practice.

# Chapter 8 Recommendations for Practice

## 8.1 Commentary with recommendations

The results from the current study indicate that (accurate) prognostication is very difficult to achieve for patients with heart failure. These difficulties are likely to increase over time, with an increasingly ageing population and a higher rate of comorbidity and polypharmacy which confound prognostication further. Prognostication, in itself, is often viewed in relation to the constricted definition of time (i.e. death is likely to occur within a certain timeframe); this and other studies demonstrate this definition, in heart failure and other illnesses with an uncertain trajectory, is unworkable in practical terms. This may be one of the large reasons behind 'prognostic paralysis[221]', which ultimately denies patients and carers appropriate access to palliative care when necessary. Thus a key recommendation from this study is that notions of prognosis become unattached to, and ultimately rejected, in heart failure. A problem based approach to care - active AND palliative care from the point of diagnosis onwards – in heart failure may be more appropriate, taking each day and each issue as it presents itself as well as looking ahead to the future, treating as appropriate under an active care paradigm, a palliative care paradigm, or both as necessary. The process of a problem based, rather than prognostication based approach in heart failure is shown in Figure 19, which depicts the cyclical nature of knowing information about the present and future, sharing this with patients and carers and the wider multidisciplinary team ('telling'), and acting upon this information collaboratively and proactively.

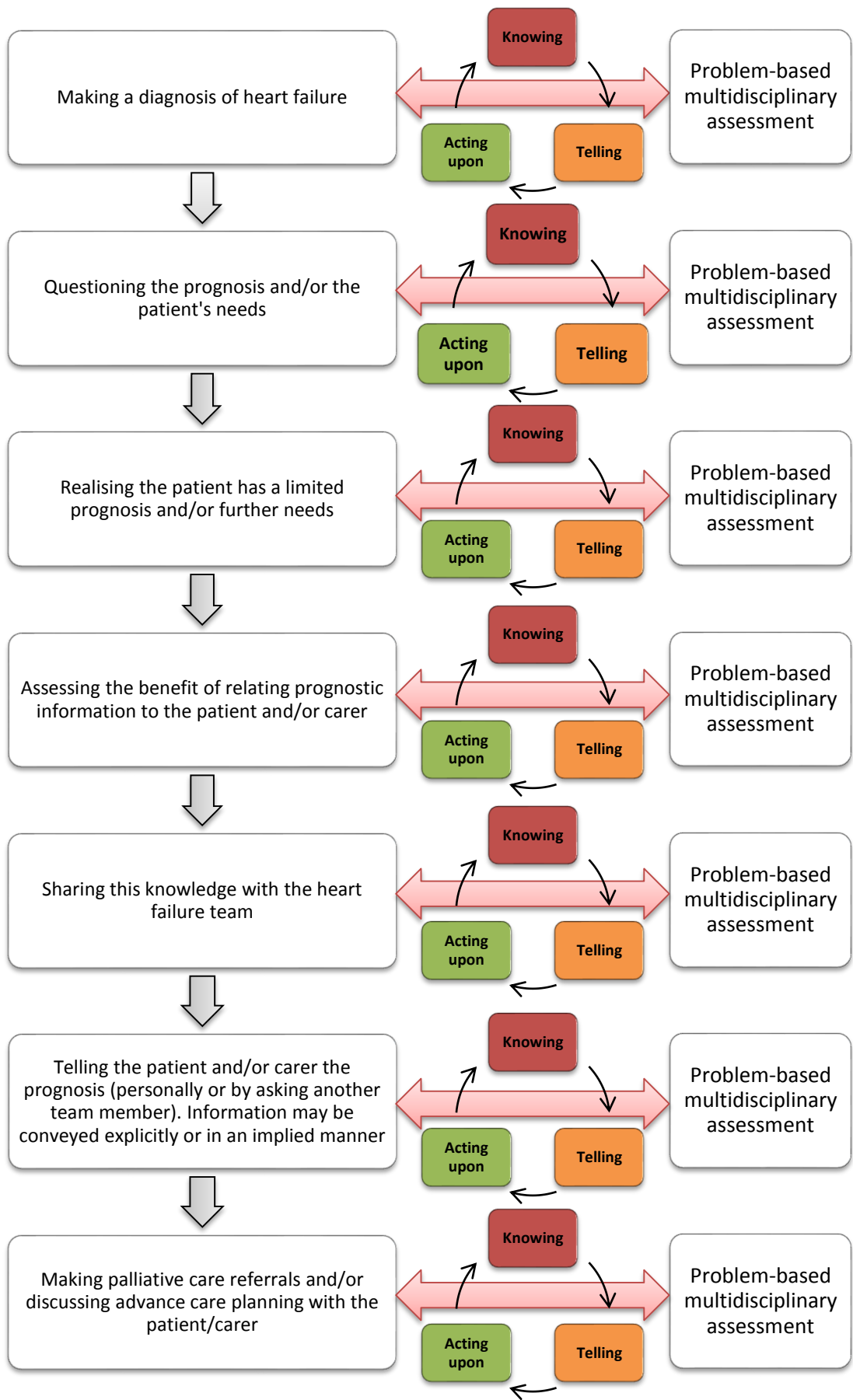


Figure 19 A problem-based approach to patient care

This problem based approach, with integrated problem based multidisciplinary assessment at all stages of the disease trajectory and all phases of disease management is likely to avoid the negative impact of prognostic paralysis in heart failure, with regard to patients with symptoms who would benefit from a palliative care approach to their care – and may ensure patients receive the most appropriate care as and when they require it.

With regard to communication in heart failure, this approach would require an assessment of to what extent patients and carers would prefer to engage in conversations and planning about the future. As this study demonstrates, patients and carers may wish to discuss the future without necessarily discussing ‘how long they have left’ (a too-constrictive paradigm). Active care and communication through this mode of care should be maintained, as hope is extremely important to hold on to, both for the clinician and the patient and their family – evidenced further by this study. Indeed this may not be misplaced hope as many patients live for several years with a reasonable quality of life. Regular assessments of NYHA class should be undertaken by clinicians and when a patient enters advanced heart failure, this should trigger a further assessment of patient and carer individual communication preferences, shared with their multidisciplinary team, with full and frank discussion of prognosis and the future when appropriate – or, indeed, when the clinician feels it imperative to communicate in the best interests for the patient and their family – and the relevant clinical decisions such as DNAR, place of preferred care, Gold Standards Framework entry. Suggestions as to how to go about assessing communication preferences with patients are included in a recent BMJ advance care planning article by Mullick, Martin & Sallnow[236], reproduced in the Appendix, item 8, page 266 (reproduced with permission from BMJ Publishing Group Ltd).

Discussions of death and dying, and relevant clinical considerations, give patients and their families the chance to discuss their future care preferences with each other, and give clinicians the opportunity to record these preferences (with the ability to amend them if and when these feelings change) formally, in order to ensure the patient has the best possible chance of receiving the type of care they would most prefer, when they may no longer be able to communicate or have the time to consider these issues at length and with their families. The current study shows that most patients and carers were happy to speak about death and dying openly, and as such, clinicians have a positive, concrete opportunity to build upon this foundation of openness to then frame a discussion about future care preferences – again, without necessarily a discussion about time-related prognosis.

This study has demonstrated that future care discussions and decisions are either not occurring at all, or occurring too late to benefit the patient and their family. Certainly in advanced heart failure, it is difficult to see how this could not be viewed as an illness which should provoke advance care planning preference discussions. This research illustrates the urgent need to consider a new, individualised package of care for those with heart failure – which delivers elements of palliative care alongside active care as needed earlier in the disease trajectory, under a problem-based approach, with appropriate, patient led communication. This will require palliative and end of life care services, and policies which support these services, to fully embrace the idea of palliative care as a flexible, needs-based concept concurrent with active care where appropriate.

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**Experiences and perceptions of the role  
of palliative and end of life care in heart  
failure: A modified grounded theory  
study.**

**Volume 2 (of 2)**

**Rachel Stocker**

**Thesis submitted for the degree of Doctor of Philosophy, School of  
Medicine, Pharmacy and Health, Durham University.**

**2014**

# Appendix

## 1. Table 6 Uptake of the Liverpool Care Pathway study characteristics and data extraction

Study characteristics								
Study number (year)	Study design	Geographical setting	Clinical setting	Inclusion/exclusion criteria	Characteristics	Patients on LCP	Patients not on LCP	% Patients on LCP
[172] 2005 Somerville et al.	Audit	UK: Peterborough	Hospice	NP	n 47 Patient mean age NP Gender mix NP Diagnosis NP LCP or modified LCP? LCP with modified entry criteria halfway through study Period of time assessed 16 weeks Mean length of time on LCP - 2.75 days in first half of study, 3.2 days in second half Pathway facilitator No	35	12	74.5%
[176] 2006 Duffy et al.	Pre-post design	UK: Kent	Care home	Inclusion: All deaths in 6 month period.	n 19 Patient mean age NP Gender mix NP Diagnosis - Mixture of fracture, renal disease, chest pain, aspiration LCP or modified LCP? LCP Period of time assessed 6 months Mean length of time on LCP NP Pathway facilitator Yes	6	13	31.6%
[175] 2006 Veerbeek et al.	Audit	UK: Liverpool	Hospice	NP	n 294 Patient mean age NP Gender mix NP Diagnosis NP LCP or modified LCP? LCP Period of time assessed 15 months	250	44	85%

	Audit	Netherlands: Rotterdam	Palliative Care for oncology unit	NP	Mean length of time on LCP NP Pathway facilitator No  n 100 Patient mean age NP Gender mix NP Diagnosis - Cancer LCP or modified LCP? Modified LCP Period of time assessed 15 months Mean length of time on LCP NP Pathway facilitator No	50	50	50%
[178] 2007	Audit	UK: England	Secondary care	NP	n 29646 Patient mean age NP Gender mix NP Diagnosis - NP LCP or modified LCP? LCP Period of time assessed NP Mean length of time on LCP NP Pathway facilitator Yes	4303	25343	14.5%
Marie Curie Palliative Care Institute Liverpool								
[237] 2008	Pre- post design	Netherlands: Rotterdam	Hospital, nursing home, and home care	Exclusion: Patients who had expressed objections of the use of their records in this manner, and patients who could not provide informed consent.	n 255 Patient mean age 75 years Gender mix 58.1% female Diagnosis - Cancer and other LCP or modified LCP? Translated LCP Period of time assessed 12 months (intervention period) Mean length of time on LCP NP (median 63 hours) Pathway facilitator No	197	58	77.3%
Veerbeek et al.								
[238] 2008	Audit	UK: Liverpool	Specialist PC team in secondary care	Inclusion: Patients with 'renal' as a primary diagnosis	n 44 Patient mean age NP Gender mix NP Diagnosis - Renal failure LCP or modified LCP? LCP Period of time assessed 24 months	22	22	50%
McKeown et al.								

					Mean length of time on LCP NP Pathway facilitator No			
[177] 2009 Jackson et al.	Pilot study: audit	Australia: Victoria	Secondary care - general medical wards	Inclusion: Anticipated deaths	n 28 Patient mean age 83 years Gender mix NP Diagnosis - Mostly non-malignant, including cardiovascular accident, dementia, pneumonia LCP or modified LCP? Modified LCP (PICD) Period of time assessed 2 months Mean length of time on LCP NP Pathway facilitator Yes	20	8	71.4%
[152] 2009  Marie Curie Palliative Care Institute Liverpool	Audit	UK: England	Secondary care	NP	n NP Patient mean age NP Gender mix NP Diagnosis - NP LCP or modified LCP? LCP Period of time assessed NP Mean length of time on LCP NP Pathway facilitator Yes	NP	NP	21%
[72] 2010  Pugh et al.	Audit	UK: Teesside	Secondary care	NP	n 407 Patient mean age NP Gender mix NP Diagnosis - Any LCP or modified LCP? LCP Period of time assessed 3 months Mean length of time on LCP NP Pathway facilitator No	157	250	38.6%
[239] 2010  Rolls et al.	Audit	UK: Wirral	Hospice	NP	n 65 Patient mean age NP Gender mix NP Diagnosis NP LCP or modified LCP? LCP	58	7	89.2%

					Period of time assessed 6 months	Mean length of time on LCP NP	Pathway facilitator No	
[174] 2010 Hockley et al.	Pre- post design	UK: Edinburgh	Private care homes	Inclusion: Deaths occurring after implementation of care tools	n 133 Patient mean age NP (age range 66-103) Gender mix NP Diagnosis - Dementia and other diagnoses LCP or modified LCP? LCP Period of time assessed 18 months Mean length of time on LCP NP Pathway facilitator Yes	44	184	33%
[240] 2010 Halfdanardottir et al.	Pre- post design	Iceland: Kópavogur	General PC unit, geriatric PC unit, oncology unit.	NP	n 227 Patient mean age NP Gender mix NP Diagnosis - Cancer and other, undefined LCP or modified LCP? LCP Period of time assessed 6 months Mean length of time on LCP 26 hours Pathway facilitator No	167	60	73.6%
[241] 2010 Laird et al.	Audit	UK: Leicester	Secondary care (2 hospitals)	NP	n 100 Patient mean age NP Gender mix NP Diagnosis NP LCP or modified LCP? LCP Period of time assessed 3 months Mean length of time on LCP NP Pathway facilitator No	26	74	26%
[242] 2010 Magee et al.	Audit	UK: Wolverhampton	Hospice	NP	n 40 Patient mean age NP Gender mix NP Diagnosis NP LCP or modified LCP? LCP Period of time assessed NP	9	31	22.5%

	Audit	UK: Wolverhampton	Secondary care	NP	Mean length of time on LCP NP Pathway facilitator No n 30 Patient mean age NP Gender mix NP Diagnosis NP LCP or modified LCP? LCP Period of time assessed NP Mean length of time on LCP NP Pathway facilitator No	6	24	20%
[243] 2011 Hamour et al.	Audit	UK: Belfast	Secondary care (geriatric medicine wards)	Inclusion: Recently deceased patients	n 100 Patient mean age 83.4 years Gender mix 52.9% female Diagnosis NP LCP or modified LCP? Modified LCP (CPDP) Period of time assessed NP Mean length of time on LCP NP Pathway facilitator No	44	56	44%
[167] 2011 Marie Curie Palliative Care Institute Liverpool	Audit	UK: England	Secondary care	NP	n 44256 Patient mean age NP Gender mix NP Diagnosis - NP LCP or modified LCP? LCP Period of time assessed NP Mean length of time on LCP NP Pathway facilitator No	12647	31609	28.6%
[173] 2011 Hemington- Gorse et al.	Audit	UK: Chelmsford	Secondary care specialist burns unit	Inclusion: Burn injured patients	n 22 Patient mean age NP (range of 21-76 years) Gender mix NP Diagnosis - Burn injuries (primarily flame) LCP or modified LCP? Modified LCP	11	11	50%

(BM-LCP)  
Period of time assessed 24 months  
Mean length of time on LCP 11.41 hours  
Pathway facilitator No

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Mean

47.4%

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Acronyms: LCP = Liverpool Care Pathway; UK = United Kingdom; NP = Not Provided



## 2. Coding examples

### Open coding

Communicating prognosis can result in Y harm

SP7 27/04/2012 Rachel Stocker

Oh yeah. Erm, yes of course. I mean, some patients might, erm, (inaudible) because he says he's ok, the doctor says the prognosis is not good, it might affect them, it might not, but erm, I think more emotionally at the time, telling the patients or the relatives is not good for them.

And thinking about when a patient deteriorates. Erm, now I know you've been saying that you see patients in the outpatient clinic. Do you have any input as to when the decision needs to be taken to switch from active to palliative care?

Er, not really, because most of these patients come to hospital poorly and things, and that's when they reach the palliative care. Erm, as you know, we don't expect palliative care to come to the clinic, I don't think, no I haven't seen it.

Ok, so it's mainly stable?

It's mainly stable patients, yeah.

Ok. Have you ever had to have that conversation with a heart failure patient?

I mean, er, for example, this week, somebody admitted who has poor LV function before, been admitted with heart failure, he was diabetic and lots of comorbidities. Erm, came in the week before, this week, last week actually, and I know the decision has been made by some of the others, but I did involve, speaking with the family again because we, we decided that, erm, he's not for active treatment any more because of, he's not responding to treatment. And he came with pneumonia and things, so there's lots of other things going on, not just heart failure. And if you consider that heart failure, yes. And so for example, this week, I had to speak to the family maybe three or four times to explain to them why we're doing this.

Ok. And can you tell me about what kind of things you would say to the family in that instance?

Erm for example for such patient we say, erm, the patient is, he's ischaemic heart disease, had a few MIs in the past, we know he's got severe LV dysfunction from before, he's diabetic, he came a couple of weeks ago with collapse, brachycardia, with pacemaker. And then we admitted again with pneumonia. And then obviously because of his LV dysfunction and heart failure in the past so, he just deteriorated gradually, his kidney function shut off, so it's multiple organ failure not just the heart. And, and the decision was made, the er, week before that his prognosis is poor and (inaudible) He was tried on ibritamine and diuretics and he didn't respond, so we've reached a stage where it was

Separating clinic from PC

Recounting past pt experience

Involving family in prognosis discussion

Making a joint decision

Comorbidities exacerbating condition

Reasoning PC w/ family

Illustrating how poorly pt is

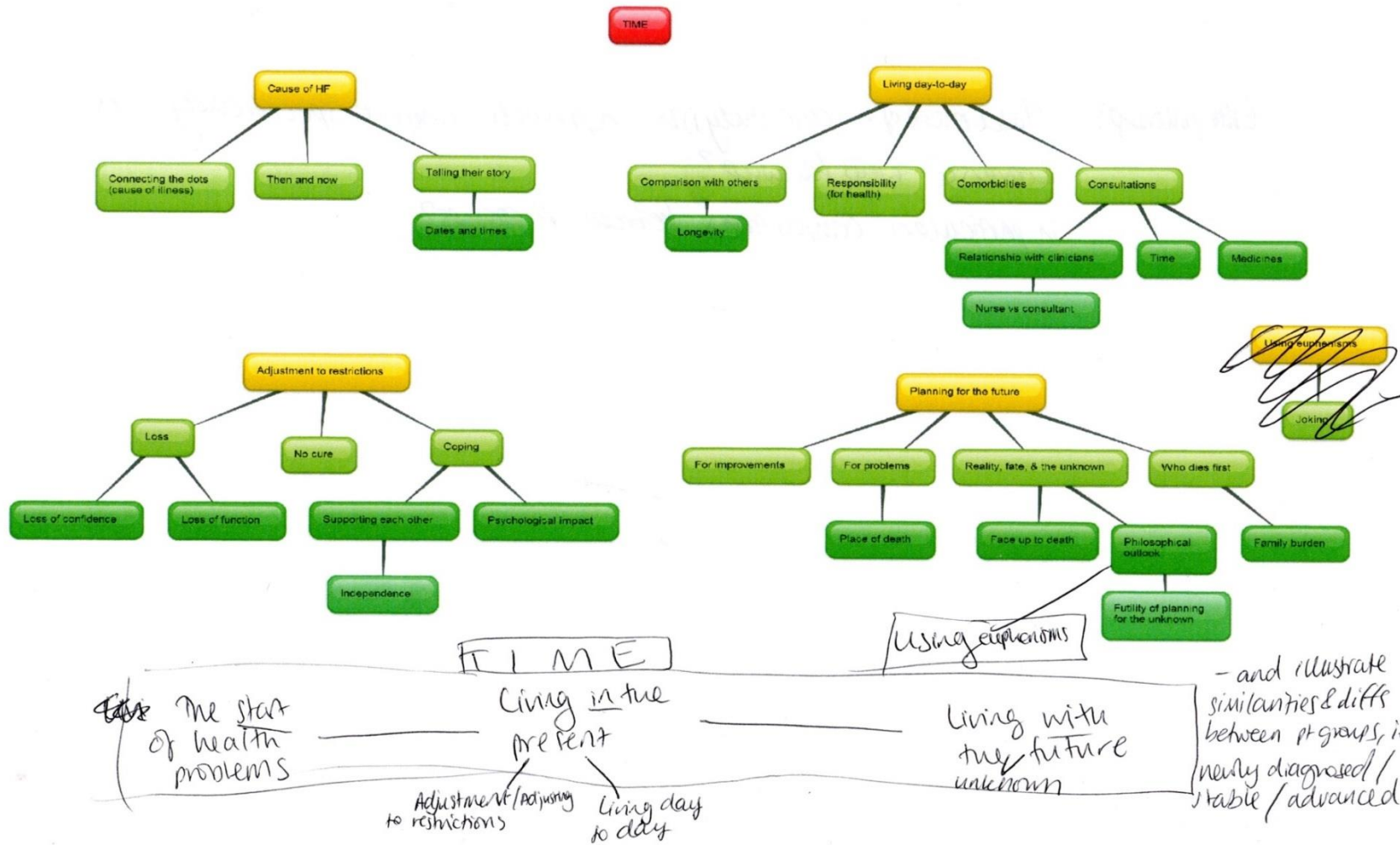
Bringing reality of prognosis indirectly home

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prognosis made when treatment becomes ineffective

Focused coding

Patient & Carer mind Map for analysis



### **3. Letters of Invitation to Participate**

## Patient and carer invitation to participate



County Durham and Darlington   
NHS Foundation Trust

Professor Jerry Murphy

Consultant Cardiologist & Professor of Cardiovascular Medicine  
Darlington Memorial Hospital  
Hollyhurst Road  
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DL3 6HX  
01325 380100

Dear Patient

We would like you to invite you and your carer to take part in a research study. It is important for you both to understand why the research is being done and what it involves. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Your participation is entirely voluntary and your decision to take part, or not, will not impact the care you receive.

The aim of the research study is to help doctors and researchers to understand further the perceptions and experiences of those who suffer from heart failure. As a patient with a diagnosis of heart failure, your experiences are very important to understanding how we can improve the care you, and other cardiology patients receive. To that end, a member of the research team would like to conduct an interview lasting around 30 minutes with yourself, and another interview lasting around 30 minutes with your carer. Interviews will be arranged at a time and venue convenient to you, such as your home. We would also like to observe one home visit from your heart nurse, and one visit you make to the Heart Clinic which I run at Darlington Memorial Hospital.

If you are interested, please read the enclosed participant information sheet.

Thank you for your anticipated participation.

## Research Team

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## GP and specialist invitation to participate



County Durham and Darlington **NHS**  
NHS Foundation Trust

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### End of Life Care in Heart Failure

Dear (insert GP or specialist's name):

This letter is an invitation to participate in a research study. As a Ph.D. student in the School of Medicine and Health at Durham University, I am currently conducting research under the supervision of Dr Helen Close and Professor Pali Hungin on end of life care in heart failure. Professor Jerry Murphy is also part of the research team.

As a clinician who treats patients with heart failure, we would like to conduct a 15 minute interview with you to explore your perceptions and experiences of communication surrounding diagnosis and prognosis in heart failure. We will also be interviewing heart failure nurses, patients with heart failure, and their carers. Interviews will be arranged at a time and venue convenient to you.

If you are interested, please read the enclosed participant information sheet.

Thank you for your anticipated participation.

### Research Team

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Version 3.0

10<sup>th</sup> February 2012

## Heart failure nurse invitation to participate

Rachel Stocker

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### End of Life Care in Heart Failure

Dear (insert heart failure nurse's name):

This letter is an invitation to participate in a research study. As a Ph.D. student in the School of Medicine and Health at Durham University, I am currently conducting research under the supervision of Dr Helen Close and Professor Pali Hungin on end of life care in heart failure. Professor Jerry Murphy is also part of the research team.

As a nurse with a specialist interest in heart failure, we would like to conduct a 15 minute interview with you to explore your perceptions and experiences of communication surrounding diagnosis and prognosis in heart failure, and also allow Rachel Stocker to shadow you on routine home visits to heart failure patients who have agreed to take part in the study. We will also be interviewing heart failure specialists, patients with heart failure, and their carers. Interviews will be arranged at a time and venue convenient to you.

If you are interested, please read the enclosed participant information sheet.

Thank you for your anticipated participation.

### Research Team

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## 4. Participant information sheets

### Patient and carer information sheet



Shaped by the past, creating the future

County Durham and Darlington   
NHS Foundation Trust

### Participant Information Sheet – Patients and Carers

#### What is the purpose of the study?

We are studying a condition affecting the heart known as heart failure, which occurs when the heart muscle doesn't pump as well as it should. Heart failure affects one million people in this country and is common in older people. It can go undiagnosed and we are unsure how common it is. This condition can sometimes cause severe breathlessness, tiredness and swelling of the ankles and feet, hinder normal daily activities, and reduce life expectancy. When heart failure is treated, symptoms and quality of life often improve.

Often, doctors find it difficult to accurately predict what type of care a patient needs at certain points in heart failure. This can be due to the unpredictable nature of this type of condition, and the effect of other illnesses a patient may have. Due to these difficulties, at times some patients report an undesirable experience of care, especially when thinking about the communication between themselves and their doctor. This project aims to explore the perceptions and experiences of communication between doctors and their patients, especially when speaking about a heart failure diagnosis and talking about how the patient may progress.

#### Your Involvement

Your doctor or heart failure nurse has selected your name because you have a diagnosis of heart failure. We now invite you and your carer (which may be your husband, wife, partner, relative, or friend) to consider taking part in a study to find out what information you have been given about your diagnosis and prognosis, and how you and your family feel about that information. As a separate part of the study, we will also be interviewing doctors and heart failure nurses to gain their



thoughts on the experience of communicating with patients. We would also like to accompany your heart failure nurse on one of the home visits he/she makes to you, and if you attend the heart failure clinic at Darlington Memorial Hospital, we would like to observe one of your appointments.

You may also have a diagnosis of another condition, such as diabetes or high blood pressure. This is very common and we would equally value your contribution to our research. There are no right or wrong, good or bad answers in the interview, it is not a test. We are more interested in your important story of how you and your carer live with heart failure.

Please be assured that your contribution will remain totally anonymous. Your name and your carer's name will not appear in any thesis or publication resulting from this study, and you both will remain completely anonymous in any published work as a result of this project. We will take necessary measures to protect both your identities and your information at every stage of the research. We will use direct quotes from your contribution in the write up of the study, but assign you a pseudonym (a different name) to refer to you so that you remain anonymous.

We expect that the study will commence in January 2012, starting with observations of clinic appointments and nurse home visits, followed shortly by an interview lasting around 30 minutes with both yourself and your principal carer (separately). This will involve open-ended questions surrounding your experience of health care for your heart failure, and for your carer, their experience of your health care. We would also like to conduct a second interview lasting around 30 minutes with yourself and your principal carer, 6 months after the initial interview. The interview will be conducted by the Chief Investigator (Rachel Stocker). Her academic supervisor (Dr. Helen Close) may also attend. The researchers involved in this project also understand that you may require a comfort/refreshment break during the interview. Please be assured that this would not pose any problem concerning your involvement in the research.

It is anticipated that the findings, greatly informed by your and your carer's contribution, will inform the development of an improved way in which doctors talk about prognosis in heart failure, and ultimately an improved experience for all those delivering and receiving heart failure care.

### **Why have I been chosen?**

You are being asked if you would like to participate because you have a diagnosis of heart failure. Your doctor or heart failure nurse will be giving this information sheet to all patients who have this condition. Only your clinical team has your details at this stage. Unless and until you agree to take part in this study, your personal details (including your name and address) will not be shared with any other member of the research team.

### **Do I have to take part?**

No, you don't have to take part. If you and your carer want to take part we will ask you both to sign a consent form. We would ask that both yourself and your carer take part, rather than one participating without the other. This will allow the research team to gain better information for the study. You would both be interviewed separately to each other (i.e. in a different room). You are both free to withdraw, up to 30<sup>th</sup> April 2012, simply by letting me know your decision and without giving a reason. This will not affect the care you receive, and any information you have given us will be securely destroyed. If you don't take part in the study all other care will continue as normal. You may decline to answer any of the questions you do not wish to answer. All information you provide will be considered confidential, and information collected will be kept in a secure location until 1<sup>st</sup> June 2016 where it will be disposed of.

### **What are the benefits of taking part?**

This study will help us to find the best way for doctors and nurses to communicate and manage the care of heart failure; this may assist doctors in working with patients to think about and plan ahead for future care options, and may help you and others to feel more supported by your medical team.

### **What are the possible disadvantages and risks of taking part?**

It is very unlikely that there will be any risk to you as a result of your taking part. We will pay careful attention to your emotional and physical needs when you are participating in the observations and interviews. If you become concerned about any aspect of this study, you can talk to us or your doctor.

The study has insurance and indemnity cover from Durham University.

If anything is disclosed that may lead the researcher to believe a child is at risk of harm, the researcher is obliged to pass this information on in line with safeguarding children policies.

**Who is organising and funding the study?**

The study is being organised by Durham University as part of a PhD project, and is funded by a Durham Doctoral Studentship. This study is insured by Durham University.

**Who has reviewed the study?**

This study has been reviewed independently and approved by the School of Medicine & Health Ethics Committee at Durham University, and through NHS REC Ethics Committee, to protect your safety, rights, wellbeing and dignity. However, the final decision to participate is yours.

**What do I do next?**

If you would like to take part, please fill out the consent form and contact details sheet included in this letter and post it back to us in the enclosed stamped addressed envelope. Once this information is received, the Chief Investigator (Rachel Stocker) will contact you by telephone. Please feel free to contact us before this if you would like to meet us, have a telephone conversation with us, or if you would like more information about the study. You can do so by post, email or telephone:

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By phone: (0191) 334 0689 By email: [rachel.stocker@durham.ac.uk](mailto:rachel.stocker@durham.ac.uk)

You can also contact the Chief Investigator's supervisor Dr Helen Close at 0191 3340369 or by email ([h.j.close@durham.ac.uk](mailto:h.j.close@durham.ac.uk)), or contact County Durham &

Darlington Patient Advice and Liaison Service on 0800 1957998 or by email ([cd-pct.pals@nhs.net](mailto:cd-pct.pals@nhs.net)).

Thank you in advance for your interest and assistance with this research.

Yours sincerely,

Professor Jerry Murphy, Consultant Cardiologist

## Participant Information Sheet – GP and Specialists

### End of Life Care in Heart Failure Study

#### Study Overview

Heart failure is a progressive, terminal illness with a mortality rate of 50% within four years. Patients diagnosed with this illness require palliative care at some stage. However it is difficult for doctors to accurately predict when a patient may deteriorate enough to reach this juncture, due to the disease being characterised by peaks and troughs, the impact of co-morbid conditions, and periods of significant decline followed by a recovery.

To that end, this project proposes to explore the perceptions and experiences of communication surrounding diagnosis and prognosis on the part of clinicians, patients with heart failure, and their carers.

As a clinician who treats patients with heart failure, you play an important role in communication surrounding end of life issues in heart failure, and your input would provide key information and opinions to this study. I would like to invite you to participate in a 15 minute interview, at a time and venue convenient to you.

It is anticipated that the findings will inform the development of an improved paradigm of end of life care in heart failure, and ultimately an improved experience for all those delivering and receiving heart failure care.

#### Your Involvement

The interview will include questions about end of life care in heart failure, specifically questions surrounding communication with patients and their carers, and the process of judgement when a patient requires a transition from active to palliative care. If you agree to participate, please complete the enclosed Consent Form including the contact details sheet, and forward on to the Chief Investigator (Rachel Stocker) in the stamped addressed envelope included. Once I receive your signed Consent Form, I will contact you again to arrange a 15-minute in-person interview with you. I will be scheduling in-person interviews commencing January 2012. I would ask your permission to audio record the interview.

Participation in the interview is entirely voluntary and there are no known or anticipated risks to participation in this study. You may decline to answer any of the questions you do not wish to answer. Further, you may decide to withdraw from this study up to 30<sup>th</sup> April 2012, without any negative consequences, simply by letting me know your decision. All information you provide will be considered confidential, and the data collected will be kept in a secure

location until 1<sup>st</sup> June 2016 where it will be disposed of. If you decide to withdraw from the study, your data will be disposed of securely.

Please be aware that the Chief Investigator has a duty to report any unethical behaviour revealed to them during the course of the study, to the relevant authority.

Your name and the name of your organization will not appear in any thesis or publication resulting from this study. After the data have been analyzed, you will receive a copy of the executive summary. If you would be interested in greater detail, an electronic copy (e.g., PDF) of the entire thesis can be made available to you.

### **Contact Information**

If you have any questions regarding this study, or would like additional information about participation, please contact me at 0191 3340689 or by email ([rachel.stocker@durham.ac.uk](mailto:rachel.stocker@durham.ac.uk)) . You can also contact my supervisor Dr Helen Close at 0191 3340369 or by email ([h.i.close@durham.ac.uk](mailto:h.i.close@durham.ac.uk)), or Professor Jerry Murphy at 01325 380100 or by email ([Jerry.Murphy@cddft.nhs.uk](mailto:Jerry.Murphy@cddft.nhs.uk)).

This study is being sponsored by County Durham & Darlington NHS Foundation Trust, and has been reviewed and received ethical clearance through the School of Medicine & Health Ethics Committee at Durham University, and through the NHS REC Ethics Committee. However, the final decision to participate is yours.

Thank you in advance for your interest and assistance with this research.

Yours sincerely,

Rachel Stocker

PhD Candidate

## Participant Information Sheet – Heart Failure Nurses

### End of Life Care in Heart Failure Study

#### Study Overview

Heart failure is a progressive, terminal illness with a mortality rate of 50% within four years. Patients diagnosed with this illness require palliative care at some stage. However it is difficult for doctors to accurately predict when a patient may deteriorate enough to reach this juncture, due to the disease being characterised by peaks and troughs, the impact of co-morbid conditions, and periods of significant decline followed by a recovery.

To that end, this project proposes to explore the perceptions and experiences of communication surrounding diagnosis and prognosis on the part of clinicians, patients with heart failure, and their carers.

As a heart failure nurse, you play an important role in communication surrounding end of life issues in heart failure, and your input would provide key information and opinions to this study. I would like to invite you to participate in a 15 minute interview conducted by the Chief Investigator (Rachel Stocker) to be arranged at a time and venue convenient to you, and also allow Rachel Stocker to shadow you on routine home visits to heart failure patients who have agreed to take part in the study.

It is anticipated that the findings will inform the development of an improved paradigm of end of life care in heart failure, and ultimately an improved experience for all those delivering and receiving heart failure care.

#### Your Involvement

The interview will include questions about end of life care in heart failure, specifically questions surrounding communication with patients and their carers, and the process of judgement when a patient requires a transition from active to palliative care. Shadowing home visits will involve the Chief Investigator (Rachel Stocker) accompanying you as an observer. Patient consent will be obtained for shadowing home visits.

If you agree to participate, please complete the enclosed Consent Form including the contact details sheet, and forward on to the Chief Investigator (Rachel Stocker) in the stamped addressed envelope included. Once I receive your signed Consent Form, I will contact you again to arrange times for shadowing your home visits, and a 15-minute in-person interview with you. I will be scheduling in-person interviews commencing January 2012. I would ask your permission to audio record the home visits and interview. Patient consent will also have been gained by this stage.

Participation in the interview is entirely voluntary and there are no known or anticipated risks to participation in this study. You may decline to answer any of the questions you do not wish to answer. Further, you may decide to withdraw from this study up to 30<sup>th</sup> April 2012, without any negative consequences, simply by letting me know your decision. All information you provide will be considered confidential, and the data collected will be kept in a secure location until 1<sup>st</sup> June 2016 where it will be disposed of. If you decide to withdraw from the study, your data will be disposed of securely.

Please be aware that the Chief Investigator has a duty to report any unethical behaviour revealed to them during the course of the study, to the relevant authority.

Your name and the name of your organization will not appear in any thesis or publication resulting from this study. After the data have been analyzed, you will receive a copy of the executive summary. If you would be interested in greater detail, an electronic copy (e.g., PDF) of the entire thesis can be made available to you.

### **Contact Information**

If you have any questions regarding this study, or would like additional information about participation, please contact me at 0191 3340689 or by email ([rachel.stocker@durham.ac.uk](mailto:rachel.stocker@durham.ac.uk)). You can also contact my supervisor Dr Helen Close at 0191 3340369 or by email ([h.j.close@durham.ac.uk](mailto:h.j.close@durham.ac.uk)), or Professor Jerry Murphy at 01325 380100 or by email ([Jerry.Murphy@cddft.nhs.uk](mailto:Jerry.Murphy@cddft.nhs.uk)).

This study is being sponsored by County Durham & Darlington NHS Foundation Trust, and has been reviewed and received ethical clearance through the School of Medicine & Health Ethics Committee at Durham University, and through the NHS REC Ethics Committee. However, the final decision to participate is yours.

Thank you in advance for your interest and assistance with this research.

Yours sincerely,

Rachel Stocker

PhD Candidate





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### **Useful contact details - Patients**

If you are concerned about heart failure or any other health related issues, seek advice from your GP or specialist. Alternatively please see below for general advice and support groups.

#### **British Heart Foundation**

The British Heart Foundation is the leading UK charity for people with heart and circulatory disease, providing a helpline for anything heart related.

Telephone: 0300 330 3311

#### **Darlington Coronary Heart Support Group**

This busy North East Heart Support Group has been running since 1992 and has a mixed membership of over 100 heart patients and carers. It promotes 5-6 meetings per month, the main meeting being held at 7.30pm on the 3<sup>rd</sup> Tuesday of every month at St Cuthbert's Church Hall.

Telephone: 01325 743 532

**Growing Old Living in Darlington (GOLD)**

GOLD works towards a bright, active and positive future for people over fifty, whether working or retired.

Telephone: 01325 388 845

**Samaritans**

Samaritans provides confidential non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair, including those which could lead to suicide

Telephone: 08457 90 90 90.



### **Useful contact details - Carers**

If you are concerned about heart failure or any other health related issues, seek advice from your GP or specialist. Alternatively please see below for general advice and support groups.

#### **British Heart Foundation**

The British Heart Foundation is the leading UK charity for people with heart and circulatory disease, providing a helpline for anything heart related.

Telephone: 0300 330 3311

#### **Darlington Coronary Heart Support Group**

This busy North East Heart Support Group has been running since 1992 and has a mixed membership of over 100 heart patients and carers. It promotes 5-6 meetings per month, the main meeting being held at 7.30pm on the 3<sup>rd</sup> Tuesday of every month at St Cuthbert's Church Hall.

Telephone: 01325 743 532

#### **Carers Direct**

Carers Direct provides information, advice, and support for carers.

Telephone: 0808 802 0202 (free from UK landlines)

**Growing Old Living in Darlington (GOLD)**

GOLD works towards a bright, active and positive future for people over fifty, whether working or retired.

Telephone: 01325 388 845

**Samaritans**

Samaritans provides confidential non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair, including those which could lead to suicide

Telephone: 08457 90 90 90.

## 5. Consent forms

### Patient consent form



School of Medicine and Health

County Durham and Darlington   
NHS Foundation Trust

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#### PATIENT CONSENT FORM

Research Team: Professor Jerry Murphy, Mrs Rachel Stocker, Dr Helen Close, Professor Pali Hungin.

*Please initial each box as appropriate*

1. I confirm that I have read, or had read to me, and understand the information sheet dated 4<sup>th</sup> November (version 3) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any point before 30<sup>th</sup> April 2012 without giving any reason, without my medical care or rights being affected. If I withdraw, the information I have provided up to that point will be destroyed securely.
3. I am 18 years of age or over
4. I am currently under the care of a cardiologist
5. I understand that I am agreeing to meet to talk about my experiences of heart care.
6. I am happy for Rachel Stocker and Helen Close to accompany me and my carer to one of my appointments at the Heart Clinic ran by Professor Murphy, and to accompany the heart specialist nurse on a routine visit to my home.
7. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the Medicines and Healthcare products Regulatory Agency, or from County Durham & Darlington NHS Foundation Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
8. I understand that ***the clinic observation, heart specialist home visit***, and interview will be voice recorded, and that direct quotes from myself will be used in the write up of this study, which will be given a pseudonym (different name) so that I remain anonymous.

P.T.O

9. I agree to take part in the above study.

\_\_\_\_\_  
Name of Patient

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Please complete and sign both copies of this form, and post one copy back to us with the contact details sheet completed, in the enclosed stamped addressed envelope.**

## Contact Details

Name: \_\_\_\_\_

My address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

My daytime telephone number: \_\_\_\_\_

Best time to telephone: \_\_\_\_\_

Carer consent form



School of Medicine and Health



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**CARER CONSENT FORM**

Research Team: Professor Jerry Murphy, Mrs Rachel Stocker, Dr Helen Close, Professor Pali Hungin.

*Please initial each box as appropriate*

1. I confirm that I have read, or had read to me, and understand the information sheet dated 4<sup>th</sup> November 2011 (version 3) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any point before 30<sup>th</sup> April 2012 without giving any reason. If I withdraw, the information I have provided up to that point will be destroyed securely.
3. I am 18 years of age or over.
4. I care for someone who is under the care of a cardiologist. The person who I care for is also participating in the study.
5. I am happy for Rachel Stocker and Helen Close to accompany me and the person I care for to an appointment at the Heart Clinic ran by Professor Murphy, and to accompany the heart specialist nurse on a routine home visit.
6. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the Medicines and Healthcare products Regulatory Agency, or from County Durham & Darlington NHS Foundation Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
7. I understand that the clinic observation, heart specialist home visit, and interview will be voice recorded, and that direct quotes from myself will be used in the write up of this study, which will be given a pseudonym (different name) so that I remain anonymous.

P.T.O.



8. I agree to take part in the above study.

\_\_\_\_\_  
Name of Carer

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Please complete and sign both copies of this form, and post one copy back to us with the contact details sheet completed, in the enclosed stamped addressed envelope.**

## Contact Details

Name: \_\_\_\_\_

Name of person I care for: \_\_\_\_\_

My address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

My daytime telephone number: \_\_\_\_\_

Best time to telephone: \_\_\_\_\_

## GP and specialist consent form



**Durham**  
University

School of Medicine and Health

County Durham and Darlington **NHS**  
NHS Foundation Trust

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### GP AND SPECIALIST CONSENT FORM

Research Team: Professor Jerry Murphy, Mrs Rachel Stocker, Dr Helen Close, Professor Pali Hungin.

*Please initial each box as appropriate*

1. I confirm that I have read and understand the information sheet dated 10<sup>th</sup> February 2012 (version 2) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any point before 30<sup>th</sup> April 2012 without giving any reason.
3. I am a GP or specialist who treats patients with heart failure
4. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the Medicines and Healthcare products Regulatory Agency, or from County Durham & Darlington NHS Foundation Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
5. I understand that the interview will be audio recorded, and direct quotes from myself will be used in the write up of this study, which will be given a pseudonym (different name) so that I remain anonymous.
6. I agree to take part in the above study.

\_\_\_\_\_  
Name of GP/Specialist

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Once completed: 1 copy for clinician; original for research site file;**

Heart failure nurse consent form



Durham University

School of Medicine and Health

County Durham and Darlington NHS Foundation Trust

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HEART FAILURE NURSE CONSENT FORM

Research Team: Professor Jerry Murphy, Mrs Rachel Stocker, Dr Helen Close, Professor Pali Hungin.

Please initial each box as appropriate

- 1. I confirm that I have read and understand the information sheet dated 24<sup>th</sup> August 2011 (version 1) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any point before 30<sup>th</sup> April 2012 without giving any reason.
- 3. I am a heart failure nurse
- 4. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the Medicines and Healthcare products Regulatory Agency, or from County Durham & Darlington NHS Foundation Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- 5. I understand that the interview and patient home visit will be audio recorded, and direct quotes from myself will be used in the write up of this study, which will be given a pseudonym (different name) so that I remain anonymous.
- 6. I agree to take part in the above study.

\_\_\_\_\_  
Name of Heart Failure Nurse

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Once completed: 1 copy for nurse; original for research site file;**

## 6. Ethical approvals

Favourable opinion letter – Durham University, School of Medicine, Pharmacy and Health  
(then School of Medicine and Health)



Wolfson Research Institute  
Improving health and well-being

**Rebecca Perrett**  
Research and Development Manager, Wolfson Research Institute  
Chair, School of Medicine and Health Ethics Sub-Committee

Tel: 0191 334 0425  
Email: [Rebecca.Perrett@durham.ac.uk](mailto:Rebecca.Perrett@durham.ac.uk)

**Rachel Stocker**  
School of Medicine and Health  
Durham University Queen's Campus  
Stockton-on-Tees  
TS17 6BH  
United Kingdom

5<sup>th</sup> September 2011

Dear Rachel,

**Re: Ethics Application ESC2/2011/16**  
**Perceptions, attitudes and experiences of end of life care for heart failure: Are current end of life paradigms appropriate and applicable for heart failure?**

Thank you for sending your revisions to the above application to the School of Medicine and Health ethics sub-committee. I am satisfied that all of the changes requested by the SMH ethics sub-committee at the meeting on 17<sup>th</sup> August have been made. I can therefore confirm Durham University ethical approval for you to conduct this project.

Please note that as custodian of the data generated for this study you will be responsible for ensuring it is maintained and destroyed as outlined in this proposal and in keeping with the Data Protection Act.

Please do not hesitate to contact me should you have any questions. Good luck, I hope that the NHS REC submission goes smoothly and that project goes well.

With best wishes

A handwritten signature in black ink that reads "R Perrett".

Rebecca Perrett



## Health Research Authority

### NRES Committee North East - Sunderland

Room 002  
TEDCO Business Centre  
Viking Business Park  
Jarrow  
Tyne & Wear  
NE32 3DT

Telephone: 0191 4283563  
Facsimile: 0191 4283432

07 December 2011

Mrs Rachel Stocker  
Durham University  
Room E113a  
Wolfson Research Institute  
Queen's Campus  
Stockton-on-Tees  
TS17 6BH

Dear Mrs Stocker

**Study title:** Perceptions, attitudes and experiences of end of life care for heart failure; are current end of life paradigms appropriate and applicable for heart failure care?  
**REC reference:** 11/NE/0313  
**Protocol number:** N/A

Thank you for your letter received 14 November 2011, responding to the Committee's request for further information on the above research [and submitting revised documentation].

The further information has been considered on behalf of the Committee by myself as Chair.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **favourable ethical opinion** for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

#### Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		
Evidence of insurance or indemnity	UMAL	06 July 2011
Investigator CV	Rachel Stocker	
Other: Investigator CV	Dr Helen Close	
Other: Investigator CV	Prof A Pali S Hungin	
Other: Useful contact details for patients	Version 1	29 July 2011
Other: Useful contact details for carers	Version 1	29 July 2011
Other: Letter of invitation - GP and Specialist	Version 2.0	29 July 2011
Other: Letter of invitation - Heart Failure Nurses	Version 2.0	29 July 2011
Other: Letter of invitation - Patients and Carers	Version 2.0	26 September 2011
Other: First Interview Guide - Heart Failure Patients	Version 3	26 September 2011
Other: First Interview Guide - Heart Failure Carers	Version 3	26 September 2011
Other: Second Interview Schedule - Heart Failure Patients	Version 2	26 September 2011
Other: Second Interview Schedule - Heart Failure Carers	Version 2	26 September 2011
Other: Interview Schedule - Heart Failure Clinicians	Version 1	29 July 2011
Other: Letter from Rebecca Perrett re ethics approval		05 September 2011
Other: Letter from Dr Helen Close		07 November 2011
Participant Consent Form: Patient	Version 3	04 November 2011
Participant Consent Form: Heart Failure Nurse	Version 2	04 November 2011
Participant Consent Form: GP & Specialist	Version 2	04 November 2011
Participant Consent Form: Carer	Version 3	04 November 2011
Participant Information Sheet: GP and Specialists	Version 1.0	24 August 2011
Participant Information Sheet: Heart Failure Nurses	Version 1.0	24 August 2011
Participant Information Sheet: Patients and Carers	Version 3.0	04 November 2011

Protocol	Version 6.0	04 October 2011
REC application	Version 3.2	04 October 2011
Response to Request for Further Information		

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

##### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

##### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

<b>11/NE/0313</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

With the Committee's best wishes for the success of this project.

Yours sincerely

  
**Mr Paddy Stevenson**  
**Chair**

Email: Helen.Wilson@suntpct.nhs.uk

*Enclosures:* "After ethical review – guidance for researchers"

Copy to: Simon Hackett, Durham University

Professor Jerry Murphy, County Durham & Darlington NHS Foundation Trust



Favourable opinion letter – County Durham & Darlington NHS Foundation Trust R&D department

County Durham and Darlington   
NHS Foundation Trust

Research and Development Department  
Darlington Memorial Hospital  
Pierremont Unit  
Hollyhurst Road  
Darlington  
DL3 6HX

Tel: 01325 743458

*All studies are subject to the requirements of the DoH's Research Governance Framework 2005 Second Edition and subsequent amendments. If you have not read this document, or are unfamiliar with its contents you are strongly advised to refer to it before commencing with any research or data collection. You may not commence data collection until you have written formal authorisation from the Chair of the Research Review Board and an appropriate ethics committee.*

23rd January 2012

Mrs R Stocker  
Durham University  
Room E113a  
Wolfson Research Institute  
Queen's Campus  
Stockton-On-Tees  
TS17 6BH

Dear Rachel

**STUDY TITLE:- Perceptions, attitudes and experiences of end of life care for heart failure; are current end of life paradigms appropriate and applicable for heart failure care?**

**R&D No: MED-176-2011**

I am writing to inform you that you have trust approval to proceed with the above-titled study. This notification allows you to begin recruitment and data collection and acknowledges that both ethical and trust approval procedures have been successfully completed.

**Approved documents**

Document Type	Version	Dated
R&D Form	87372/.../936	-
SSI Form	87372/271687/6/746/121169/229941	
REC approval letter	-	7 <sup>th</sup> Dec 2011
Investigator CV	Rachel Stocker	
Useful Contact Details for Patients	1	29/7/2011
Useful Contact Details for Carers	1	29/7/2011
Letter of invitation – GP and Specialist	2	29/7/2011
Letter of invitation – Heart Failure Nurses	2	29/7/2011
Letter of invitation – Patients and Carers	2	26/9/2011
First Interview Guide – Heart Failure Patients	3	26/9/2011
First Interview Guide – Heart Failure Carers	3	26/9/2011
Second Interview Schedule – Heart Failure Patients	2	26/9/2011

Approval letter (non CTIMP)

with you  
 all the way

Second Interview Schedule – Heart Failure Carers	3	26/9/2011
Interview Schedule – Heart Failure Clinicians	1	29/7/2011
Consent Form: Patient	3	4/11/2011
Consent Form: Heart Failure Nurses	2	4/11/2011
Consent Form: GP & Specialist	2	4/11/2011
Consent Form: Carer	3	4/11/2011
Patient Information Sheet: GP & Specialist	1	24/8/2011
Patient Information Sheet: Heart Failure Nurses	1	24/8/2011
Patient Information Sheet: Patients & Carers	3	4/11/2011
Protocol	6	4/10/2011

### Research Conduct, Management and Governance

It is the responsibility of the Chief Investigator/Principal Investigator to maintain robust management of the clinical trial and ensure that the trial is conducted in compliance with the Organisational Research Review Board and Independent Ethics Committee approved Protocol. You are reminded to refer to your SOPs File to ensure good Conduct, Management and Governance of this Study.

The R&D Department will monitor the progress of the study (SOPs 11&14)

You will receive:

- a Start-up Form 6 weeks from the date of this Approval Letter.  
(Upon indication on the study start up form that accrual has commenced you will be required to complete an Accrual Pro-forma on a monthly basis).
- A Monitoring From 6 monthly/yearly

You are required to complete and return the above documents within two weeks of receipt. (SOP 14)

The R&D Department must be notified within 90 days of the close down of the study and within 15 days if terminated early. On receipt of notification of study closure the R&D Department will send a study closed down form for completion . A member of the R&D Department will arrange to meet with a member of the Research Team to finalise the closure of the Study (SOP 11).

The NHS Retention and Disposal schedule (HSC 1999/053) states that clinical notes of patients entered into clinical trials of medicinal projects should be retained for 15 years after conclusion of treatment. Please find enclosed the procedure for the identification of patients in clinical trials of medicinal products and study labels to identify notes

On completion of your study I would be grateful if you could forward a copy of your final report and any publications as a result of the study to the R&D Office at the above address.

The R&D committee wishes you every success with the completion of your study.

Yours sincerely

Approval letter (non CTIMP)

with you  
all the way



**Dr Y Yiannakou**  
**Research Review Board Chair**

Copy to:-

**SPONSOR**  
Simon Hackett  
Durham University  
School of Applied Social Sciences  
32 Old Elvet  
Durham  
DH1 3HN

Approval letter (non CTIMP)

with you  all the way

Insurance forms

Hasilwood House  
60 Bishopsgate  
London EC2N 4AW  
Tel: 020 7847 8670  
Fax: 020 7847 8689



---

TO WHOM IT MAY CONCERN

6<sup>th</sup> July 2011

Dear Sir/Madam

**UNIVERSITY OF DURHAM  
AND ALL ITS SUBSIDIARY COMPANIES**

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following cover is currently in place:-

**PROFESSIONAL INDEMNITY**

Certificate of Entry No.	UM050/00
Period of Cover	1 August 2011 to 31 July 2012
Limit of Indemnity	£10,000,000 any one claim and in the aggregate except for Pollution where cover is limited to £1,000,000 in the aggregate.
Cover provided by	U.M. Association Limited and Excess Cover Providers led by CNA Insurance Company Limited

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

A handwritten signature in black ink, appearing to read 'Susan Wilkinson'.

Susan Wilkinson  
For U.M. Association Limited



U.M. Association Limited  
Registered Office: Hasilwood House, 60 Bishopsgate, London, EC2N 4AW  
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TO WHOM IT MAY CONCERN

6<sup>th</sup> July 2011

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A handwritten signature in black ink, appearing to read 'Susan Wilkinson'.

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For U.M. Association Limited



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## 7. Interview guides

### Patient interview guide

1. Can you tell me about when you were diagnosed with heart failure?
2. How would you describe the communication between yourself and your doctor?
3. Can you tell me about what you understand to be your prognosis with your heart condition?
4. Do you know anyone else with heart failure?
5. Could you tell me about your appointment at the clinic which I was present at, and what you understood of the discussion with the doctor?
6. What do you think the doctors and nurses do well?
7. What do you think the doctors and nurses don't do so well?
8. Have you had any discussions with your doctor about your decisions and wishes in the future?
9. Can you tell me about your hopes and wishes for the future?
  - About your care?
  - About your place of care?
  - About your place of death, including any Do Not Resuscitate Orders?
  - About any plans you have for death, e.g. for an undertaker, or a will?

### Carer interview guide

1. Can you tell me about when (name) was diagnosed with problems with their heart?
2. How would you describe the communication between (patient) and their doctor?
3. Can you tell me about what you understand to be (name's) prognosis with their heart condition?
4. Do you know anyone else with heart failure?
5. (if carer was present) Could you tell me about your and (name)'s appointment at the clinic which I was present at, and what you understood of the discussion with the doctor?
6. What do you think the doctors and nurses do well?
7. What do you think the doctors and nurses don't do so well?
8. Have you or (name) had any discussions with the doctor about (name's) decisions and wishes in the future?
9. Can you tell me about your hopes and wishes for the future?
  - About (name's) care?

- About (name's) place of care?
- About (name's) place of death, including any Do Not Resuscitate Orders?
- About any plans (name) has for death, e.g. for an undertaker, or a will?

#### Patient 6 month interview guide

1. Can you tell me about what has happened with your health since the last interview?
2. In the last interview you understood your prognosis to be [CI describes what patient said]. Has your understanding of this changed since the last interview?
3. Have you had any further discussions with your doctor about your decisions and wishes in the future?
4. How do you feel about the communication you have had between yourself and your doctor over the last six months?
5. What do you think the doctors and nurses have done well over the last six months?
6. What do you think the doctors and nurses haven't done so well over the last six months?
7. Has your perspective of your heart failure care changed within the past six months? How?

#### Carer 6 month interview guide

1. Can you tell me about what has happened with [name of patient's] health since the last interview?
2. In the last interview you understood [name of patient's] prognosis to be [CI describes what carer said]. Has your understanding of this changed since the last interview?
3. Have you had any further discussions with [name of patient's] doctor about [name of patient's] decisions and wishes in the future?
4. How would you describe the communication between [name of patient] and their doctor over the last six months?
5. What do you think the doctors and nurses have done well over the last six months?
6. What do you think the doctors and nurses haven't done so well over the last six months?
7. Has your perspective of [patient's] heart failure care changed within the past six months? How?

#### Clinician (GPs, specialists, and heart failure nurses) interview guide

1. Can you tell me about how you communicate with your patients with heart failure?

2. Can you tell me about how you decide when a patient should receive palliative care?
3. How do anticipatory care plans such as the Liverpool Care Pathway fit into your work?
4. How do you feel about the heart failure patient's general experience of palliative and end of life care?
5. Do you have any suggestions for how doctors can improve their treatment of heart failure patients nearing the end of life?



## 8. Advance care planning communication tips for clinicians

The following appeared on page 4 of article: Anjali Mullick, Jonathan Martin, and Libby Sallnow. "An introduction to advance care planning in practice." *BMJ: British Medical Journal*, 347 (2013). Reproduced with permission from BMJ Publishing Group Ltd.

### **Communication tips**

#### **Initiating the conversation**

*Start with general open questions, then be guided by the patient's cues and responses to know whether to explore further*

#### **Examples:**

*How have you been coping with your illness recently?*

*Do you like to think about or plan for the future?*

*When you think of the future, what do you hope for?*

*When you think about the future, what worries you the most?*

*Have you given any thought to what kinds of treatment you would want (and not want) if you became unable to speak for yourself?*

*What do you consider your quality of life to be like now?*

#### **During the conversation**

*Use language that patients can understand and any other communication aids you might need*

*Give patients enough information to make informed choices without overloading them*

*Clarify any ambiguous statements that patients make—for example:*

*Patient: "I don't want heroics"*

*Professional: "What do you mean by heroics?"*

#### **Ending the conversation**

*Summarise what has been discussed to check mutual understanding, or ask the patient to do so*

*Screen for any other problems—for example: "Is there anything else you would like to discuss?"*

*Arrange another time to continue, complete, or review the discussion if necessary—for example, if the patient would like help completing an advance decision to refuse treatment*

*Document the contents of the discussion in the patient record*

*Share the contents (with the patient's permission) with anyone else who needs to know, such as family, carers, the community team, and the general practitioner or specialists".*

## 9. Publications

Attached are three publications resulting from the PhD so far – one abstract and reference, one reproduced below (open access) and a pre-publication version of one as a chapter in Chapter 2 (press release for this publication found in the below section).

## End of Life Care in Heart Failure: Is it Time to Reinvent the Wheel?

Stocker, R., Close, H., & Hungin, A. P. S. (2013). End of Life Care in Heart Failure: Is it Time to Reinvent The Wheel? In Rose Richards and Jennifer Creek (Eds.), *Chronicity, Care and Complexity*. Oxford: The Inter-Disciplinary Press, pp. 169-179. ISBN: 978-1-84888-190-7 - EBSCO index.

Rachel Stocker, Helen Close and A Pali S Hungin

### Abstract

There are around one million adults in the UK suffering from heart failure, with this number set to rise as the population ages. It is increasingly argued that heart failure is a chronic yet essentially terminal condition which requires the provision of an interdisciplinary palliative care plan. Symptom profiles are often broadly similar to cancer and thus service developments increasingly draw upon cancer-specific models, including anticipatory care plans such as the Liverpool Care Pathway. These may ease physical symptoms in the final days and hours of life, but appear to do little to address the longer term burden of a disease characterised by unpredictable peaks and troughs, which can be interspersed by long periods of relatively good health. It is becoming ever more apparent that the experience of palliative and end of life care for heart failure is often inadequate for patients, carers and clinicians alike. The unsophisticated 'one-size-fits-all' application of cancer-based palliative care tenets fails to adequately account for the specific challenges of heart failure and may simply be an inappropriate foundation for care of a condition that might, more accurately, be regarded as life-limiting, not terminal. The relative lack of societal knowledge surrounding heart failure in comparison to cancer is considered to have an effect on how individuals with heart failure integrate their condition into their illness identity, precipitating a chasm in how patients view their illness and ultimately their death compared to the biomedical clinical reality. This paper argues that we urgently need a new paradigm for managing heart failure towards the end of life, recognising current societal knowledge and attitudes towards heart failure as a condition, and the taboo of communicating issues surrounding mortality, especially in a clinical setting.

**Key Words:** Communication, end of life care, heart failure, illness identity, narrative medicine, palliative care, patient knowledge, terminal illness.

## A Novel Method of Enhancing Grounded Theory Memos with Voice Recording

Stocker, R & Close, H (2013). A novel method of enhancing grounded theory memos with voice recording. *The Qualitative Report* **18**(T & L Art. 1): 1-4.

(Open Access)

Rachel Stocker and Helen Close

Durham University, Stockton-on-Tees, United Kingdom

In this article the authors present the recent discovery of a novel method of supplementing written grounded theory memos with voice recording, the combination of which may provide significant analytical advantages over solely the traditional written method. Memo writing is an essential component of a grounded theory study, however it is often difficult to capture thoughts, feelings, and emerging theorising using written methods after a research interview. I found that many of these potentially valuable ideas were lost or misunderstood upon reading my subsequent written memo, and the feelings and context which influenced the emerging theory were not always clear. I turned to voice recording to enhance my grounded theory memos and soon discovered substantial additional benefits upon listening back. This novel method, the cognitively different ways in which human brains process verbal and written information, and the ultimate benefits I have enjoyed by combining writing and voice recording memos are presented. Keywords: Grounded Theory, Memos, Voice Recording, Memory, Cognition, Research Context, Interpretivism

In this article the authors present research insights on extending the use of voice recording grounded theory based interviews, to supplement written memos with voice recording, and the additional layers of understanding and reflection that this method can provide.

Grounded theory (GT; Glaser & Strauss, 1967) provides a framework for structuring the collection and analysis of qualitative data, underpinned by different elements of philosophical research paradigms such as pragmatism and interpretivism. The GT research procedure of memo writing in particular is deemed by many authors to be vital to constructing a GT (Charmaz, 2006; Glaser & Strauss, 1967) and consists, quite literally, of writing a 'memo' to yourself about what you feel is happening in your data, reflections on your philosophical research position, issues, analytical decision making, and developing theory (amongst many other topics). In this way, memos can be a useful tool for exploring and challenging our underlying processes and assumptions embodied within our codes, in order to construct theory, raise theoretical sensitivity, and can be helpful to capture and illustrate the development of theory as data collection and analysis progresses. It is a "space and place for exploration and discovery"(Charmaz, 2006, p. 81). Memo writing can begin from the first conceptualisation of the study (Birks & Mills, 2011), between data collection and theory construction (Bryant & Charmaz, 2007) or solely during analysis (Strauss & Corbin, 2007). Other qualitative methods such as Interpretative Phenomenological Analysis utilise a similar, less prescribed way of reflecting on data by advising researchers to compile a reflective research diary which can be used in the same way to understand findings, construct themes and categories, and bring data together (Tenni, Smyth, & Boucher, 2003).

Whilst memo writing is traditionally positioned as the intermediate stage between coding and analysis (Charmaz, 2003), in my doctoral GT research, the concept and process of memo writing has been valuable even before formal data analysis began, and informed the iterative relationship between data collection, coding, and final stages of analysis. Charmaz (2006) advises the GT researcher to construct memos as quickly and clearly as possible, the speed element fostering the development and preservation of the researcher's natural voice; written by a thinking, feeling, human being. Reflecting on research in this way has greatly assisted me to develop categories and theory, firmly grounded using the most basic element of the data; the spoken word and resulting in vivo codes.

An Accidental Discovery

A discovery I (Rachel Stocker, RS) made whilst conducting my research was to use the voice recorder I had been using to record interviews, for recording my emerging, uninhibited thoughts and theorising which would provide further clarity to my later, written memo. The thought came to me when driving away from an interview, and realising that I had so much valuable information in my mind resulting from the interaction with my participant that I wanted to "let it out" and get it recorded in any way possible ("stop and analyse your ideas about the codes in any – and every – way that occurs to you during the moment" [Charmaz, 2006, p. 72]) – quickly. I felt that these initial, grounded impressions ("what is actually happening in the data?" [Glaser, 1978, p. 57]) would be vital to constructing the eventual theory. I parked up round the corner, turned on the voice recorder and articulated my feelings into the microphone. I wanted to capture my thoughts at that point, whilst fresh in my mind straight after the interview. The recording consisted of my personal feelings about the interview, including the main points outlined by my participant, their body language, what was 'said but unsaid', and the chat after the voice recorder had been switched off, which contained information that illuminated and gave further context to other elements of the interview.

I soon came to realise that this contained many elements of a GT memo which could be useful in informing parts of my later, written memos. The major benefit of using this method to record thoughts and subsequently develop written memos and theory was illustrated shortly afterwards. When listening to my recording later during supervision, hearing my own voice immediately brought me back to that moment, the feelings I was experiencing, and the strands of thought and theorising which were filling my head at that time which may otherwise have been lost, misunderstood upon later recall, or affected by other later events. I found that using the voice recorder, especially straight after the interview and during precious moments of clarity shining through the data overload, allowed me to record my gut feelings about what was "going on" in my research.

Whilst voice recording my initial thoughts on the research interview and data collection was inherently valuable, memo writing in full sentences forced me to come to (at least preliminary) terms with my analytic idea. Voice recording, therefore, cannot and should not replace the traditional method of writing a memo, with writing as a practice going some way to organize the thought process in a proper and (more often than not) non-idiosyncratic fashion. However, flexibility in memo writing is deemed by many to be essential to the process (Birks & Mills, 2011), and researchers “should not be constrained by the normal conventions of writing and documentation” (Birks & Mills, 2011, p. 43). Listening back to verbally recorded thoughts and theorising can spark recall of the situational aspects and overarching context which remain unsaid in the actual interview and perhaps could not be pinned down at that time by traditional written methods. At a basic level, the brain processes verbal information in a qualitatively different manner to written information. Listening to information has been shown, through functional Magnetic Resonance Imaging (fMRI), to activate a different part of the brain in comparison with reading the same information (Michael, Keller, Carpenter, & Just, 2001) even at the conceptual level of understanding the meaning of a sentence, harnessing increased semantic processing and working memory. Memory is most effective when details of the context (such as environmental cues) are available at retrieval (Tulving & Thomson, 1973). Recording elements of research memos verbally would thus serve as an acoustic retrieval cue when listening back to the recording, to be used to complement the construction of the traditional written memo. Recalling as many details as possible is particularly important in GT studies in which sometimes huge amounts of data are collected and the researcher is required to move iteratively between data collection and analysis.

## Conclusion

Whilst traditionally writing memos are the essential basis of memoing in a GT study, voice recording can provide grounded, ‘gut feeling’ insights to answer Glaser’s (1978) question of



what is actually happening in your data, with the spontaneity and creativity of certain elements that sometimes only a human voice can capture. Accordingly, it is suggested that researchers using GT and/or a reflective research diary, consider using voice recording equipment to record their thoughts, theories, and memos to supplement the process of memo writing. Through the use of this creative method, theorising and analysis could be enhanced by harnessing the phenomenon of acoustic cues to be 'transported', to an extent, back to the research context; something which would otherwise be unachievable, and of which we must hold on to as much as possible to stay grounded in the data. Further research is required, focussing on the extent of which recording, and other creative uses of voice recorders outside of the traditional interview/observation/focus group context, can assist the research process.

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Author Note

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**Press release from BMJ for Assessing the uptake of the Liverpool Care Pathway for the dying patient: a systematic review**

<http://spcare.bmj.com/content/early/2013/05/25/bmjspcare-2012-000406>

**ABSTRACT**

Improving the care of the dying is regarded as a national priority and current guidelines stipulate the need to provide holistic palliative care. Despite this, many dying patients and carers report low levels of comfort and satisfaction with care. Reasons include poor coordination of care, variability in communication and crisis-driven interventions. Integrated care pathways aim to support care coordination and open communication with patients and carers. One example is the Liverpool Care Pathway (LCP). Using the LCP entails assessment of eligibility criteria which requires skills, knowledge and clinical judgement about its timing. This can be problematic, and little is known about actual uptake, characteristics of assessed patients and reasons for inclusion/exclusion. A comprehensive systematic review was conducted for papers published between January 1990 and July 2012 providing information on LCP uptake. 17 papers met inclusion criteria. A total of 18 052 patients were placed on the LCP, in a variety of inpatient and primary care settings, and cancer and non-cancer diagnoses. 47.4% of dying patients identified were placed on the LCP. Although the LCP is widely recommended, it is only used for around half of dying patients. Reasons may include lack of knowledge, high staff turnover and concerns about applicability particularly for unpredictable dying trajectories. The proportion of patients who meet the eligibility criteria and the reasons surrounding low uptake remain unclear. Research is urgently required to further quantify the variable use of the LCP, and to investigate whether alternative approaches should be developed for non-cancer groups.

(Please see Chapter 3 for a pre-publication version.)

**BMJ SUPPORTIVE & PALLIATIVE CARE**

Less than half of dying patients are placed on a nationally recommended care pathway

Lack of knowledge and eligibility is stopping half of terminal patients from going on the Liverpool Care Pathway

[Assessing the uptake of the Liverpool Care Pathway for dying patients: a systematic review. Online First doi 10.1136/bmjspcare-2012-000406]

Less than half of terminally ill patients are placed on the Liverpool Care Pathway for the Dying Patient (LCP) despite it being recommended nationally, concludes UK research published online in the BMJ Supportive & Palliative Care journal.

Durham University researchers found that in many parts of England, staff may have limited training or support to use the care pathway, which is a model of care that enables healthcare professionals to focus on care in the last hours or days of life when a death is expected.

The pathway was jointly developed by the Marie Curie Hospice Liverpool and the Royal Liverpool University Hospitals in 2003 as a paper-based tool to help healthcare staff when caring for patients dying of cancer in hospitals, but it has been expanded to include all dying patients and has been implemented across the world in primary and secondary care settings.

It provides a framework for structuring and coordinating multidisciplinary care for the last 72 hours of life and facilitates audit by standardising the monitoring of patient needs, symptoms and care.

In the UK, the LCP is cited in National Institute of Health and Care Excellence guidance as an example of good practice and the Department of Health End of Life Care Strategy specifically encourages commissioners and providers to ensure the availability of an end-of-life care pathway in acute hospitals, citing the LCP in particular.

It has been seen by some as controversial and last year, stories in the national media described it as the “equivalent of euthanasia for the elderly” that many doctors considered worthless. These articles led to hundreds of complaints to the Press Complaints Commission.

Little is known about how much the LCP is used across the country so researchers from Durham University’s Wolfson Research Institute for Health and Wellbeing, in Stockton-on-Tees, set out to review the evidence of the eligibility, uptake and non-uptake of the LCP in various settings.

They reviewed studies published between January 1990 and July 2012 that provided information on LCP uptake and found 17 suitable papers.

Collectively, 18,052 patients were placed on the LCP, in a variety of inpatient and primary care settings, and cancer and non-cancer diagnoses.

Rachel Stocker, who led the research, found that although the LCP is widely recommended, it was only used for 47.4% of dying patients, but the studies did not make it clear what proportion of patients were eligible for the LCP.

The researchers said possible reasons for this could be a lack of knowledge, high staff turnover, and concerns about applicability, particularly for unpredictable dying trajectories.

Only one study provided complete data to assess the proportion of all dying patients eligible for the LCP.

It showed that 58% (236 patients of 407) were eligible for the LCP, of whom 81% had a cancer diagnosis.

However, of the 236 patients judged to be eligible, around a third of them (79) died without the LCP in place. They concluded: “The LCP is a well-known and well-regarded palliative care tool and this study confirms that it is used in a variety of geographical and clinical settings.

“However, this study provides evidence that around half of all dying patients were not placed on the LCP despite its availability. This raises questions about clinicians’ levels of knowledge and awareness about the LCP, and the appropriateness and applicability of this pathway.

“It is possible that clinicians are unconfident or unaware of the utility of the LCP, but equally possible that they deem the LCP to be inappropriate for patients for unknown reasons.”

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