A Grounded Theory Study Exploring Healthcare Professionals'

Experiences of Decision Making when Managing the Care of Patients

Diagnosed with End Stage Heart Failure.



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# Abstract

**Background**

End of life care has been a topic which has been debated, discussed and strategized over the last ten years as part of the government initiative to improve care for those patients with long term conditions requiring palliative and end of life care. (DH 2008, DH 2010). Studies show that despite these government and local recommendations' heart failure patients are still not being given the opportunity to access individualised end of life care and the services they require to support themselves and their families at the end of life.

**Aim**

The aim of this study was to explore the decision-making process between healthcare professionals and patients in an acute medical setting when it came to making end of life decisions.

**Method**

A constructivist grounded theory was conducted over a 12-month period in a District General Hospital in the North West of England. A purposeful sample of 15 nurses, 11 doctors and 16 patients were recruited from the acute medical setting. Data was collected using semi structured interviews and focus groups. The interviews were recorded and transcribed and data was analysed using the constant comparison and QSR NVivo.

**Findings**

Four theoretical categories emerged from the data to explain how healthcare professionals and patients negotiated the process of decision making when considering end of life care. These four categories; signposting symptoms, organising care, being informed and recognising dying were found to revolve around a core category 'vicious cycle of care' which was fast paced, turbulent and time limited. This cycle was found to disable the process of decision making between the healthcare professional and patient resulting in missed opportunity for the patient to transition to palliative care.

**Conclusion**

The emerging theory 'vicious cycle of care' offers an explanation as to why decisions were not made by healthcare professionals to transition patients with end stage heart failure to palliative care. Further work needs to be undertaken with healthcare professionals and patients to map out a 'cycle of care' which identifies key stages in the terminal stage of heart failure and correctly signposts the patient to the right healthcare care professional for intervention. Further research is required with General Practitioners to further explore the barriers to providing end of life care for heart failure patients.

# Chapter 1 Introduction

## 1.1 Research purpose and theme

The purpose of this constructivist grounded theory study was to explore the process of decision making by healthcare professionals when managing the care of patients diagnosed with end stage heart failure. It focusses on how nurses and doctors within the specialisms of medicine and cardiology make clinical decisions about end of life care and how this affects the patient's choices and quality of care. To understand fully this decision-making process it was important to also fully explore the experiences of the patient. The topic of heart failure and end of life care remains under scrutiny (NHS England 2015). The literature suggests that for heart failure patient's transition to palliative care is still not happening despite national and local policy (Cheang et al 2014, Greener et al 2014). Currently only a fraction of heart failure patients', who are high risk of mortality and morbidity, receive palliative care (Cheang et al 2014). Often patients will not have been referred to a palliative care team, had Do Not Attempt Resuscitation (DNAR) decision made within a month of death (Johnson et al 2012). It is still not clear what the most significant challenges associated with the provision of palliative care in heart failure throughout the United Kingdom are. There is a perception that palliative care services are underutilised compared with that of cancer patients (Rodriguez et al 2007, Hupcey et al 2016). This study aims to critically explore nurses and doctors' decision making with a view to better understanding why patients diagnosed with end stage heart failure are not gaining access to end of life care.

This chapter will provide the research context and background to this study introducing some of the key publications that have influenced the heart failure agenda over the last ten years. This is then followed by 'statement of the problem' which positions the research and gives a brief overview of what may be considered to be the barriers to providing end of life care. My own

personal and professional motivations will be discussed in section 1.3 and my rationale for choosing to undertake a Professional Doctorate. The research aims will be presented in section 1.4 followed by a discussion in section 1.5 on what unique contribution to knowledge this study will make to the topic of heart failure end of life care. Lastly, in section 1.6 I will provide an overview of the content of this thesis.

## 1.2 The research context

Heart failure is defined as the pathophysiological state in which an abnormality of cardiac function is responsible for the heart's inability to pump blood sufficiently to meet the body's metabolic requirements (National Institute for Cardiovascular Outcomes Research 2013). The poor function of the heart is often due to damage of the heart tissue caused by a heart attack, cardiomyopathy (deterioration of the heart muscle), valve disease and high blood pressure (National Institute for Cardiovascular Outcomes Research 2013). Before symptoms become apparent patients can present with asymptomatic structural or functional cardiac abnormalities (systolic or diastolic left ventricular (LV) dysfunction) which are precursors to heart failure. Recognition of these precursors is important because they are related to poor outcomes and starting treatment at this stage may reduce mortality in patients with asymptomatic systolic LV dysfunction (European Society of Cardiology Guidelines 2016). Identification of the underlying cause of the heart failure is crucial in determining the appropriate therapeutic interventions for example pharmacological intervention, valve replacements or repair of a valve for valvular disease (ESC 2016).

It is estimated that 800,000 people in the United Kingdom are diagnosed with heart failure and this is set to increase with an ever-increasing ageing population (British Heart Foundation Health Promotion Research Group 2012). The British Heart Foundation National Audit (2014) suggested that 1.2% of men and 0.76% of women in the United Kingdom (UK) are diagnosed

with heart failure, rising to 7.84% of men and 5.89% of women over the age of 75 years. British Heart Foundation (2014) statistics demonstrate that the prevalence of heart failure in the UK using Clinical Practice Research Datalink (CRPD) data, show that both rise steeply with age. BHF (2014) analysis shows that 0.9% of men and 0.7% of women in the UK suffer from heart failure, rising to 13.1% of men and 11.9% of women over the age over 75years (BHF 2014). Heart failure constitutes a huge burden on the National Health Service (NHS) accounting for one million in-patient days-2% of the NHS total and 13% total of all emergency admissions (National Institute for Health and Care Excellence 2010). Outcomes for this group of patients is consistently variable although data seems to suggest being managed on a cardiology ward by specialist doctors and being followed up by a Heart Failure Specialist Nurse does seem to have a positive impact on prognosis and life expectancy (Sutherland 2010). The National Institute for Cardiovascular Outcomes Research (2013) reported that 1 in 10 patients were dying in hospital and of those who survive between one quarter and one third dying within the year of their admission (NICOR 2013). There are well recognised and documented inequalities in people diagnosed with heart failure and their experience of end of life care between geographical areas and across different populations (Sutherland 2010). These inequalities in healthcare have in some cases resulted in patients with end stage heart failure and their families experiencing poor standards of care and for the patient a 'bad death'. Often this group of patients require complex medical intervention to prevent readmission into hospital but sadly the reality is that often patients with end stage heart failure will present to their local Emergency Departments or Medical Admissions Units where they are often mismanaged by medical teams who do not have the experience or skill to manage this type of patient (Sutherland 2010). Findings from a recent audit indicated that the main place of care for patients 75 years and older diagnosed with heart failure will be general medical ward followed by cardiology ward (NICOR 2013). The findings from this audit indicated that patients admitted to general medical wards appeared to be

discharged earlier with mean length of stay of 11 days compared with that of cardiology wards whose mean length of stay was 12 days. (NICOR 2013). Evidence suggests that many patients with end stage heart failure are discharged back into the community to be managed by the General Practitioner (GP) often being lost to an overburdened health care system (Care Quality Commission 2014).

Current statistics suggest (NICOR 2013, Sutherland 2010, NHS Information Centre for Health and Social Care 2009) that despite policy and guidelines (Department Health 2008, Department Health 2009, Department Health 2010) this group of patients are failing to be actively engaged in advance care planning or placed appropriately on an end of life pathway. Prognostication models (National Gold Standard Framework 2012) for heart failure do not appear to be working and this may be due to a number of factors; the unpredictable death trajectory of heart failure and the fact that the modelling has been transposed from pathways used effectively in cancer care; which may not necessarily fit heart failure. There appears to be reluctance by healthcare professionals to make a decision to place a patient with end stage heart failure onto an individualised end of life care pathway and this may be due to a number of reasons; complexity of the disease as heart failure unlike other long term conditions cannot be neatly packaged and therefore trajectory of death is often unpredictable (NHS Information Centre for Health and Social Care 2009).

A strategic plan was launched by the Department of Health (DH 2012) in an attempt to try and better support people living with long term conditions; which include heart failure, dementia, chronic obstructive airway disease (COPD) and chronic renal failure with a view to reducing the number of admissions into hospital; the overall result being a reduction in costs and an improvement in the delivery of care at the end of life. Data provided by Long Term Conditions Quality, Innovation, Productivity and Innovation (LCP QIPP) work streams suggested that patients admitted to an emergency department with heart failure typically would have more than

one long term condition and that this often was found to increase with age (DH 2012). Not surprisingly there was a significant positive relationship between proportion of the population over 65 years with heart failure and the number of admissions into hospital (DH 2012). Other factors which appear to influence emergency admissions include available appointments and opening hours at the GP practice, patients own experience of GP, social and cultural norms, economic deprivation and community support (Roland et al 2012). Evidence suggests that there may be a number of interventions which could prevent readmissions of heart failure patients and these include; education and support for self-management, rehabilitation classes, early review by a senior clinician in the emergency department and structured discharge planning (Purdy et al 2012). However, a more recent audit by The National Audit of Cardiac Rehabilitation (2015) seems to suggest that the uptake of cardiac rehabilitation for heart failure remains poor with only 3,364 out of 74,935 patients in England accessing cardiac rehabilitation services (NACR 2015).

Over the years a number of incentive schemes have attempted through financial reward to improve quality outcomes for heart failure patients. An example of this was the Quality Outcomes Framework (QOF) which was introduced in 2004 as part of the GP contract and was voluntary to all NHS Trusts. The aim of the scheme was to reward GP by awarding achievement points and payment based on disease management and patient experience. The Quality Outcome Framework data for 2007/2008 compared with other epidemiological studies (Royal College Physicians 2005) data suggested that despite these awards there were a number of patients, approx. 127,000 with heart failure, who did not appear in the QOF (2004) dataset. The result of this was that patients could not access the required diagnostics and treatment which effectively could have prolonged life and improved quality of life.

More recently incentivised schemes like Advancing Quality (AQuA) has sought to increase the treatment and management of this group of patients by detailing certain specific composite

measures which have to be achieved in order for Trusts to gain a financial award. An evaluation of the scheme demonstrated that pay for performance did have a positive impact on reducing mortality in conditions like heart failure, pneumonia and myocardial infarction (McDonald et al 2015). The reduction in mortality for these incentivised conditions was greater in the North West region that the rest of England, reducing from 21.9% to 20.1% in the North West and from 20.2% to 19.3% in the rest of England (Mc Donald et al 2015). Similarly, schemes like Commissioning for Quality and Innovation (CQUIN) were introduced for NHS Commissioners to improve quality of care for patients diagnosed with heart failure using recognised National Institute for Health and Care Excellence (NICE) standards. Evaluation of CQUIN (Sutton et al 2013) suggested that Trusts often 'played safe' and the financial gain didn't encourage healthcare professionals to stimulate innovative thinking; it could be argued that CQUIN Heart Failure has maintained the status quo for this group of patients rather than push clinical boundaries.

Similarly, other department of health initiatives like Quality, Innovation, Productivity and Prevention (QIPP) was seen as a way to improve quality by being more efficient, productive and therefore save health providers money. The belief was that care should be given closer to home, earlier intervention, standardisation of care to reduce variation, empower patients and reduce costs. Recognising that in the future there will be an increase in patients with long term conditions like heart failure the Department of Health (2012) recommended a long-term condition model based on three key principles;

1. Risk profiling using a validated risk profiling tool which will support commissioners to understand the needs of the population and manage those risks identified

2. Neighbourhood care teams- creating a functionally integrated care team at a local level made up of multi professionals to provide locally joined up and personal care

3. Self-Care Decision Making which empowers patients to maximise self-management and choice where the patient is able to decide and co-produce a plan, patients have access to information about their condition and how to manage their condition and lastly patients have access to their medical records and are active participants in all decisions ' no decision about me without me'.

Where this model of care has been applied there has been a 20% reduction in unplanned admissions to acute Trusts (DH 2012). To fully understand and appreciate how end of life care has evolved for heart failure patients it is important to gain insight into the relevant policy and guidelines. In section 1.3 I will briefly introduce some of these policies and their impact on heart failure care.

**1.3 Statement of the problem**

Despite the guidance, policy, training and financial schemes to motivate and incentivise healthcare professionals into managing end of life care for patients diagnosed with New York Heart Association stages 3 and stage 4 heart failure in their last year of life still appears to be problematic (Johnson et al 2012). Evidence suggests that very few of these patients are actively managed on an advance care plan or individualised end of life care pathway in the last year/months/days of their life (Johnson et al 2012). Certainly, the negative publicity surrounding the Liverpool Care Pathway (LCP) has not helped and has left healthcare professionals very nervous about using a pathway for fear of 'getting it wrong' and facing professional retribution and complaints from families and relatives (Department Health 2013). The point at which a healthcare professional may decide to place a patient with heart failure on an end of life pathway is often challenging due to the complexity of the disease; often the death trajectory unlike many

cancers is unpredictable and so makes the decision for healthcare professionals to place a patient on an end of life pathway more challenging. With many chronic conditions death is not an exact science and there is often no precise way of telling when someone is going to die.

Shared decision making for advanced heart failure has become both more challenging and more crucial as duration of the disease and treatment options have increased. High quality decisions are chosen from medically reasonable options and are aligned with the goals, values and preferences of an informed patient (Allen et al 2012). Health Care Professionals have a legal and ethical obligation to make sure that the patient is fully informed about their disease and can actively participate in and make decisions about their treatment and care (Long et al 2007). This involves clinicians working with patients and their families to ensure their preferences, goals and values guide informed decisions that are right for the individual patient.

Grounded in the ethical principle autonomy (Long et al 2007), judicial decisions and legislative actions have repeatedly affirmed the right of patients or their nominated advocate to choose medical treatment from reasonable medical options. To do this the patient, carers and their families need to be informed (Department of Health 2015). The informed patient is fully aware of their diagnoses and prognosis, they understand benefit and risk and so when the time comes they are able to make informed choices with their carers and families about end of life care (Beauchamp et al 2008). The dilemma is when to have the conversations about end of life care with the patient and the family. Finding time to have appropriate discussions about preferences, prognosis and medical treatment is a formidable challenge. Often what happens in reality is that these types of discussions between clinician and patient are left until a crucial time when thoughtful decision making may be impaired (Allen et al 2012).

## 1.4 Personal and professional motivations for the research

My professional involvement and interest with patients diagnosed with end stage heart failure began in 2002 when working as a senior sister in a critical care unit in the Northwest of England. Patients with acute decompensating heart failure would be admitted to the High Dependency Unit (HDU) for symptom control; often these patients would present with acute breathlessness, pulmonary oedema, cardiogenic shock, and deranged blood profiles. Immediate therapy involved relieving the patients' symptoms and reducing congestion. Once the patients' condition was normalised the patient would be discharged back to the medical wards under the care of the physician. It was during this time that I led a Trust wide initiative to redesign the hospitals observation charts and implement what was then called the Early Warning Score (Morgan et al 1997); more commonly known now as National Early Warning Score (Royal College of Physicians 2012). The NEWS is a simple scoring system which uses 6 parameters to measure physiological changes in the patient during their hospitalisation; deviation from the norm would suggest deterioration and action is taken accordingly (RCP 2012). It was during this time that I came into contact with patients diagnosed with end stage heart failure on the acute medical wards; many of these patients would trigger the NEWS and require intervention. In many cases the patient would be dying. However, uncertainty round diagnosing dying left these patients vulnerable to futile interventions (Formiga et al 2007). Often nursing colleagues would vent their frustrations at what they perceived to be a lack of support from medical colleagues when trying to initiate end of life conversations with end stage heart failure patients and their families. A brief review of the literature at the time seemed to suggest that patients were not accessing palliative care services due to poor communication between healthcare professional and patient, lack of education around end of life care and a lack of understanding around end of life care pathways (Rodriguez et al 2007). On a more personal level both my paternal and maternal grandfathers were diagnosed with heart failure. I can recall clearly how

this disease robbed them both of dignity and personhood. Both died horrible deaths in a hospital ward.

The opportunity to study a Professional Doctorate (DProf) in 2010 finally gave me the vehicle in which to explore healthcare professionals' decision making when considering end of life care for patients diagnosed with end stage heart failure. A professional doctorate is commonly defined as:

'*a programme of advanced study which, whilst satisfying the University criteria for the award of doctorate, is designed to meet specific needs of a professional group external to the University, and which develops the capability of individuals to work within a professional context'* (UKCGE,2002, p.62).

My own motivation for undertaking the D Prof was its relevance and application to practice; it provided me with the opportunity to draw on my own knowledge and expertise and it could be integrated into my every day practice. It allowed me to continue to work full-time and practice in my field of nursing which kept me professionally up to date and engaged with professional colleagues. Burgess et al (2006) argues that possessing the right research skills is essential and that knowledge alone is not sufficient to achieve a doctorate. My intention was to develop my research skills and competencies which would enable me to apply a research-based approach to all dimensions of my clinical practice. More importantly it would provide a way to produce new knowledge, to enhance and improve care for heart failure patients and add to the already existing body of knowledge in end stage heart failure and palliative care.

## 1.5 The Research Question and Aims

The aim of this study was to explore both health care professionals' and heart failure patients' experiences of the decision-making process at the end of life and the impact this may have on end of life care. A constructivist grounded theory method of enquiry was used to identify

individuals' experiences and how the decisions were made with regards to an end of life care pathway. To identify patients at the end of life the New York Heart Association functional classification was adopted (The criteria committee of the New York Heart Association 1994). A table to explain this functional classification is presented below (table 1).

Table 1: NYHA Classification System, (*Adapted from Guidelines for the diagnosis and treatment of Chronic Heart Failure: Task Force report; Eur Heart J, 2001*)

| **Class I** | No limitations on activity. No fatigue, breathlessness or palpitation on ordinary physical activity | | Annual mortality 3-5% |
|---|---|---|---|
| **Class II** | Patients are comfortable at rest but ordinary physical activity such as climbing stairs or doing housework results in symptoms | **Mild** Heart Failure | Annual mortality 10% |
| **Class III** | Patients have a marked limitation of physical activity. Although patients are comfortable at rest, less than ordinary physical activity will lead to symptoms | **Moderate** Heart Failure | Annual mortality 12-16% |
| **Class IV** | Patients have symptoms even at rest and are unable to undertake any physical activity without discomfort | **Severe** Heart Failure | Annual mortality 20-40% Worse prognosis than most cancers |

The central question for this study was guided by three research aims which are described below:

<u>Research Question</u>

How do healthcare professionals facilitate clinical decision making when considering end of life care for patients diagnosed with NYHA stage 3 and stage 4 heart failure?

**Research aims**
- To explore how health care professionals make the decision to place a patient on an individualised End of Life Care Pathway.
- To explore how decision making at end of life by healthcare professionals could affect patient's experience.
- To explore healthcare professionals' perceptions and understanding of end of life for patients diagnosed with end stage heart failure.

**1.6 Contribution to knowledge**

To date quantitative studies investigating end stage heart failure and end of life care have tended to focus on decision making in primary care around diagnosis and treatment (Horne et al 1999, Hobbs et al 2000, Selman et al 2007, Barclay et al 2011). The qualitative literature has reported issues regarding decision making in the primary care setting and barriers to communication (Song 2004, Selman et al 2007, Smith 2012, Hjelmfors et al 2014). Very few studies have explored the experiences of healthcare professionals and patients in an acute medical setting when considering how decisions may affect patients 'transitioning from acute medicine to palliative care (Greener et al 2014, Cheang et al 2016). Certainly, what is clear from the literature is end of life care planning and shared decision making in acute medical settings during the last 12 months of life is not happening in a timely manner despite government guidance (Whellan et al 2014, Sidebottom et al 2015). There is very little literature within the

specialism of acute medicine which explores the experiences of the patient. It is my intention that the findings from this study will provide a unique insight into how this decision making process occurs from a healthcare professional and patient perspective to end of life care. The findings will add significantly to the existing body of knowledge on palliative care in heart failure and will provide a 'grounded theory' for healthcare professionals in which to base local policy and guidance. My findings will provide evidence to support both local and national educational initiatives for healthcare professionals on how to identify the right time to have end of life conversations with the patient and their families. Findings from this study will provide a platform for patient user groups to begin to openly discuss what is often regarded as a sensitive topic and to begin to demystify the subject of palliation and dying.

## 1.7 Structure of the thesis

The thesis is presented over eight chapters with the first chapter detailing the purpose and theme of my study. By providing the relevant policy and guidelines I have been able to put into context the significance of undertaking this study. I have explicitly stated my own personnel and professional motivations and how these have influenced the topic of study. The aims of my research are presented along with the unique contribution this study will make to professional practice, development of policy and guidelines and the care of those patients diagnosed with end stage heart failure. The following section will outline the content of the remaining five chapters:

### 1.7.1 Chapter 2- Literature Review

In this chapter, the relevant literature is critically examined in relation to healthcare professionals' decision making and how this may affect the care of patients diagnosed with end

stage heart failure. The scoping review will present the most up to date published works and will identify a gap in the literature which my study will attempt to address.

### 1.7.2 Chapter 3-Research Design

The research design chapter will provide an opportunity to discuss and give a full account of the methodological choices made in order to meet the research aims and to answer fully the research question. I will discuss the epistemological and ontological choices made and how this has influenced this study research design.

### 1.7.3 Chapter 4- Research methodology and methods

The methods chapter begins by discussing my choice of methodology and the theoretical framework which underpins this study; symbolic interactionism. Grounded theory method is introduced and the different schools of grounded theory debated. I will argue why constructivist grounded theory (Charmaz 2016) was an appropriate method for this study. This section is concluded by considering how quality was achieved in this study and my own reflexive position as a researcher. The methods section begins by introducing the research setting and the participants'. My sampling strategy is made explicit along with recruitment and the use of semi structured interviews as a method of data collection. A detailed account is given of my data analysis and how from open coding my categories and themes emerged. Finally, this chapter concludes with a detailed account of ethical approval, informed consent and confidentiality.

### 1.7.4 Chapter 5 Data Analysis

 In this chapter the process of coding, comparing and analysing my data is discussed and how this led to the development of my theoretical category 'Navigating a vicious cycle of care'. Throughout this chapter I will give some clear examples of how this was achieved.

### 1.7.5 Chapter 6 The Findings

This chapter begins by introducing the four themes identified by applying the analytical process of constructivist grounded theory (Charmaz 2016). I use direct quotations from my participants to highlight significant concepts, categories and themes. It was important in this chapter for the participants' voices to be heard and in the right context and for it to reflect as accurately as possible their own experiences. This chapter concludes with the identification of the core category.

### 1.7.6 Chapter 7- Emerging Theory and Discussion

The discussion chapter begins by presenting my emerging ground theory followed by a synthesis of my findings in relation to the aims of this study. I will argue why these findings are significant for heart failure patients when considering quality of life, end of life conversations and decisions to transition from acute medical care to palliative care. This will be done in context of the relevant policy and guidelines presented in Chapter 1 and the literature presented in Chapter 2. New literature will be introduced into the discussion to support my theory. The limitations of my study are presented along with implications for further research and practice for both nurses and doctors' managing the care of patients diagnosed with heart failure.

### 1.7.7 Chapter 8 Conclusion Recommendations

The conclusion chapter will present a synthesis of this study bringing together the main points of my thesis and reflecting on some of the key findings. Recommendations will be made which will enhance clinical practice and inform change along with any future direction for further study.

# Chapter 2 Literature Review

## 2.1 Introduction

The purpose of this chapter is to present the extant literature with a particular focus on healthcare professionals' decision making when considering end of life care for patients diagnosed with heart failure. To assist with the understanding of this topic the literature review has been divided into four distinct parts. The first part of this chapter will provide a discussion on the place of the literature in a grounded theory study and some of the challenges faced by novice researchers. This will then be followed by a brief discussion on the use of literature in this study and how it has helped to frame my aims and research question. In part two of this chapter a definition of heart failure will be provided along with the classifications. This will then be followed by a brief overview of some of the diagnostic tests used today in healthcare. Part three will present a comprehensive search strategy which will include the review method, question and the inclusion and exclusion criteria. The evidence will then be critically appraised under specific themes identified during the process of analysis. To provide a framework in which to scope the literature the Arksey and O'Malley (2005) method will be used. This particular method is said to be useful when wanting to map out key concepts underpinning a research area particularly if the area of interest is complex or has been mapped out before (Arksey and O'Malley 2005). In part four the emerging themes from the thematic analysis will be presented; care pathways, decision making and heart failure and palliative care and heart failure, along with a critique of the literature. Finally, this chapter will conclude by summarising the gaps in the literature and where this study will make a unique contribution to the already existing body of knowledge on end of life care in patients diagnosed with NYHA stage three and stage four heart failure.

## 2.2 Part 1: The literature review in a Grounded Theory study

The tensions of undertaking a literature review when commencing a grounded theory study have been well documented and debated (Walls et al 2010, Giles et al 2013, Yarwood et al 2014). For the researcher, the timing of the literature review is often influenced by their epistemological perspective, previous experience and background in the study area (McGee et al 2007). Traditionally, quantitative studies advocate that the literature review begins prior to data collection in order to inform the research question and research methods (Onions 2006) Conversely, the inductive nature of qualitative research means engagement with the literature is often delayed until after the data is collected; an example of this being grounded theory (Richardson-Tench et al 2014). The grounded theory literature seems to suggest that there are two schools of thought when considering the timing of a literature review. The first is to delay the review until after the data is collected and categories begin to emerge (Glaser 1992). The second is to do a preliminary review of the literature with a view to undertaking a more in-depth appraisal once data analysis is complete (Strauss and Corbin 1998, Charmaz 2014). Glaser (1978) argues that the researcher should be a 'tabula rasa' (blank slate) when beginning a study. To better explain his point, he divided the literature into three categories; the first one being pure ethnographic descriptions (diaries, records, catalogues and biographies), the second one being professional and unrelated to the substantive area under research and the third professional and related to the researched area under study (Glaser 1992, p31). This dictum was based on a concern not to contaminate, be constrained by, inhibit, stifle or otherwise impede the effort of the researcher to generate categories and theoretical codes from the data (Glaser 1992). However, this is at odds with some of his writings in his book 'Theoretical Sensitivity' where he writes "It is necessary from the grounded theorist to know many theoretical codes in order to be sensitive to rendering explicitly the subtleties of the relationship in his data" (pg72). The

question remains how would the researcher know the theoretical codes if they had not been exposed to the literature.

In the Basics of Qualitative Research Strauss and Corbin (1998) acknowledge that researchers bring with them life experiences and knowledge of related literature. They stress the importance of acknowledging and using knowledge, which they term as technical and non-technical literature, to enhance theoretical sensitivity. Similarly, Charmaz (2014) agrees that it is highly unlikely that the researcher will arrive at the research project without a previous reading somehow related to and influential to the phenomena in question. In constructivist, grounded theory the voice of the researcher is positively encouraged and plays an integral part in the construction of theory. Certainly, my reading of the literature only confirmed in many cases what was already being observed in my clinical practice and potentially the gaps in knowledge.

### 2.2.1 The use of the literature in this grounded theory study

The review of the literature facilitated a familiarity with what McMenamin (2006, p134) terms the 'geography of a subject' and was central to the formulation of my research questions and more importantly helped me to focus on an area which had been overlooked. Furthermore, becoming familiar with the technical and non-technical literature provided an opportunity to review current themes, policy and guidance which had to date provided guidance for healthcare professionals' decision making when considering the care of patients diagnosed with end stage heart failure. It is important to mention here that the process of reviewing literature was on a continuum; the literature was reviewed at the beginning of my study, during data analysis as concepts and themes emerged and towards the end when my core category began to emerge. If an interesting concept or theme emerged following an interview this would be followed up by reading a paper, a book or visiting a website. This dipping in and out of the literature for me was an essential part of the constructivist grounded theory process and often helped in making

sense of my discoveries. For example, dipping in and out would involve identifying key themes from a transcript and then actively searching in the literature for information to try and make sense or understand what this theme meant to my participants and their lived experience. The dipping in and out of the literature helped to put the pieces of the jigsaw together and enlighten my understanding rather than influence my interpretation of the data. In terms of engaging with existing theoretical concepts my undertaking of postgraduate studies had already exposed me to some of the well-known theories like: The Cognitive Continuum (Hamm 1988), Information Processing theory (Carnevali et al 1984) and Intuitive-Humanist theory (Benner 1984). However, in keeping with the grounded theory ethos I decided to put these theories to one side and allow my theory to emerge from the data during the process of analysis and constant comparison. This approach to extant theories is what Henwood and Pidgeon (2006, p350) refer to as 'theoretical agnosticism' rather than theoretical ignorance when considering the use of literature in the early stages of a grounded theory study.

A preliminary literature review was undertaken at the beginning of my study in order to satisfy the requirements of the University Ethics Committee and the National Research Ethics Committee (NREC). This initial review of the literature was crucial in identifying and framing the problem sufficiently, identifying gaps and providing a justification as to why this study was required. To gain a greater understanding of the complexities of heart failure and to provide some background to this study part two of this chapter will provide a brief overview of the pathophysiology of heart failure and some of the key definitions.

**2.3 Part 2: Key definitions and classifications of heart failure.**

**2.3.1 Definition of Heart Failure**

The European Society of Cardiology (ESC 2016) define heart failure "as a clinical syndrome characterised by typical symptoms of breathlessness, ankle swelling and fatigue, that maybe

accompanied by signs of elevated jugular venous pressure, pulmonary crackles and peripheral oedema" (Ponikowski et al, p2136). There are multiple aetiologies which can lead to the diagnosis of heart failure and these include ischaemic heart disease, hypertension and diabetes. According to Lloyd-Jones et al (2002) three quarters of all heart failure patients will have pre-existing hypertension which doubles the risk of developing heart failure in comparison to normotensive patients. Less common causes of heart failure and in decreasing order of prevalence are cardiomyopathies, infection (viral myocarditis), toxins (cytotoxic drugs, alcohol), valvular disease and arrhythmias (Kemp et al 2012). The signs and symptoms of heart failure are often the result of the clinical sequelae of inadequate cardiac output and lack of venous return. Cardiac output can be defined as the volume of blood ejected by each ventricle per minute (Vaswani et al 2016). It is not uncommon for patients to complain of fatigue and in most cases this is due to the failing heart not being able to meet the bodies metabolic demand. Other common symptoms include breathlessness caused by increased pressure in the pulmonary capillary bed due to ineffective flow from the left ventricle (Johnson et al 2012).

## 2.3.2 Types of Heart Failure

The terminology used to describe heart failure is based on measurement of the left ventricle ejection fraction and falls into three main categories (LVEF). The first category is patients with a normal left ventricle ejection fraction (LVEF). This is usually referred to as heart failure with preserved ejection fraction (HFpEF) and is in the range of ≥50%. The second category refers to those patients who have a reduced left ventricular ejection fraction (HFrEF) and typically is in the range ≤40%. The third category is fairly new and has been introduced by the European Society of Cardiology (2016) guidelines in recognition that there are some patients who sit in what they term as a 'grey area' (Ponikowski et al 2016). These patients are referred to as having a mid-range ejection fraction (HFmrEF) and present with ejection fractions typically between 40-49%. It is thought that identifying this third group will stimulate further research into the

underlying characteristics, pathophysiology and treatment of this group of patients. Patients diagnosed with HFmrEf demonstrate similar characteristics to those patients diagnosed with HFpEF.  However, some clinicians would argue that attention to this third classification is of no real benefit as current research into HFpEF has yet to demonstrate any real benefits in terms of survival (Delepaul et al 2017)

### 2.3.3 Classification

Heart failure is commonly classified using the New York Heart Association (NYHA) functional classification. This uses a four-stage approach to assessing a patients' tolerance to physical exercise (The criteria committee of the New York Heart Association 1994). Patients classified as NYHA stage 1 heart failure have cardiac disease with limitations or symptoms with ordinary activity. Those patients with NYHA stage 2 have a slight limitation on physical activity, they are comfortable at rest but ordinary activity can result in fatigue, palpitations, dyspnoea or angina. In NYHA stage3 patients have little tolerance for ordinary exercise becoming breathless when undertaking less than ordinary exercise. The final stage, NYHA stage 4, patients are unable to carry out any physical activity without discomfort (The criteria committee of the New York Heart Association 1994). It is recognised that the NYHA functional classification used in isolation to measure symptoms of heart failure is unreliable in identifying LV dysfunction (Raphael et al 2007).  The NYHA as a diagnostic tool has been criticised for being too subjective and relying extensively on the observer's interpretation and recording of the patient's functional capacity (Hunt et al 2009).

In response to the evolution and progression of the disease the American College of Cardiology (ACC) and the American Heart Association (AHA) put together a new classification based on four stages (Hunt et al 2009). This classification of heart failure unlike the NYHA functional classification provides an objective assessment as well as recognising the structural changes to

the heart. Patients in stage A are at high risk of developing heart failure with no structural disorder of the heart. Those patients classified as stage B will have structural disorder of the heart with no symptoms. Stage C patients will have past or current symptoms of heart failure associated with structural heart disease. Lastly, stage D patients will be end stage who require specialised interventions which may include transplantation, ventricular assist devices (LVAD)[1] or palliative care. The ACC/AHA recognised that the staging of heart failure (like the staging of cancers) would establish risk factors and structural prerequisites which in turn would provide a new dimension to treating heart failure. Identifying these early signs of left ventricular dysfunction was felt to be crucial in providing early therapeutic intervention and so reducing significantly mortality and morbidity (Hunt et al 2001).

### 2.3.4 Diagnosing Heart Failure

The diagnosis of heart failure if done early on in the disease trajectory can significantly improve the patient's quality of life (McMurray et al 2012). However, diagnosing heart failure very much depends on the patient recognising the symptoms and the healthcare professional being able to diagnose the heart failure. In many cases patients present to their GP with non-specific symptoms which can be difficult to diagnose and can be attributed to other diseases like chronic lung disease (Kelder et al 2011). Symptoms which may be considered more specific like orthopnoea and paroxysmal nocturnal dyspnoea are less common especially in patients with milder symptoms (McMurray et al 2012). More specific symptoms like elevated jugular venous pressure or apical impulse for those doctors whom maybe less experienced can be difficult to diagnose. For the patient and their families, the failure to diagnose can lead to delays in treatment, delays in correct referral pathways and multiple visits to the GP (Rutten et al 2002).

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[1] A ventricular assist device (VAD) — also known as a mechanical circulatory support device — is an implantable mechanical pump that helps pump blood from the lower chambers of the heart (left or right ventricles) to the rest the body. A VAD is used in people who have weakened hearts or heart failure (Vaswani et al 2016)

The European Society of Cardiology recommend where heart failure is suspected to undertake in the first instance an electrocardiogram (ECG) and an echocardiogram (McMurray et al 2012). The echocardiogram in particular can give more structural information about the heart along with, chamber volumes and valve function (Borlaug et al 2011). These initial tests can dictate the types of treatment that the patient would receive like beta blockers, ACE inhibitor drugs for systolic dysfunction or cardiac surgery for aortic stenosis. Other diagnostic tests may include measuring the blood natriuretic peptide (a group of hormones which are raised when the heart is diseased) chest x-ray, and routine laboratory tests. Cardiac magnetic resonance (CMR) is considered to be the 'gold standard 'in diagnostic tests and is said to provide accuracy and reproducibility of volume, mass and wall motion (Kramer 2015). The limitations of this test include availability, cost and inability to image with certain metallic implants like implantable cardioverter defibrillator (ICD[2]) and cardiac resynchronization therapy (CRT) [3] (Kramer 2015).

In summary, key definitions and classification of heart failure has been presented in order to provide an understanding of this complex syndrome. The following section (part 3) will begin by presenting my search strategy followed by the literature review question, inclusion and exclusion criteria. The Arksey and O'Malley's (2005) scoping framework will be presented in order to demonstrate how themes were identified; these will then be critically discussed.

## 2.4 Part 3: A Comprehensive Scoping of the Literature

The methodology for this scoping review was based as previously stated on the framework outlined by Arksey and O'Malley (2005). The review included the following five stages; 1)

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[2] Implantable cardiac defibrillators is a battery-powered device placed under the skin that will monitor the patient's heart rate. Thin wires connect the ICD to the heart. If an abnormal heart rhythm is detected the device will deliver an electric shock to restore a normal heartbeat. (Vaswani et al 2016).

[3] Cardiac resynchronisation therapy is used in defects such as bundle branch blocks which can cause poor contractility of the ventricles. A lead is placed on the epicardial surface of the left ventricle, usually through the coronary sinus and two other leads are placed in the RA and RV. Both ventricles are simultaneously activated with an electrical impulse to allow synchronous contraction which improves ventricular contraction (Vaswani et al 2016).

identifying the review question 2) identifying relevant studies 3) study selection 4) charting the data and 5) collating, summarising and reporting the results and 6) an optional consultation exercise. For the purposes of this study stage 6 was not considered relevant and therefore was not included. This method of reviewing the literature was considered appropriate because of its fit with the aims and objectives of this study. Like qualitative research the process of scoping is an iterative process and so requires a certain amount of reflexivity and engagement with the literature at key stages of the research process. The method of scoping enabled a comprehensive searching of a wide source of evidence, important when considering the depth and breadth of this topic, which could then be systematically reviewed.

### 2.4.1 Review Questions

To begin the process of scoping a broad review question was written in order to facilitate a comprehensive review of the literature. Arksey and O'Malley (2005) suggest having a broad review question helps to enable in depth and broad results rather than a "highly focussed review question" (p8) which may limit the search to specific designs. It is recommended with any scoping review that the purpose, concept and context of the review is made clear in order to position the review when searching for evidence (The Joanna Briggs Institute 2015). In this study, the concept was defined as decision making, the target population is healthcare professionals and patients and the context was considered to be end of life care and heart failure. This review was guided by the following question:

*'What is known from the existing literature about healthcare professional's decision making when considering end of life care for patients diagnosed with NYHA stage 3 and stage 4 heart failure?'*

### 2.4.3 Search Strategy

A comprehensive search of healthcare literature was undertaken in two distinct phases. Firstly, a preliminary review was undertaken between October 2012 to April 2013. The purpose to identify gaps in the literature, familiarise myself with extant literature, identify research aims and objectives and provide a robust proposal for the University Ethics committee and NREC. The second phase of the search commenced in April 2015 to April 2017 when it was evident that no new themes were emerging from my data and theoretical categories had been saturated. The databases used to search the literature included MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL) PsycINFO, Cochrane Database of Systematic Reviews, EThOS (Electronic Theses Online System), British Nursing Index (BNI), Scopus and Web of Science. The grey literature was sourced and this included conference papers, media (newspapers, radio, television), government websites, Google, Google Scholar and a website called Care search (care search.com). The scoping process included hand searching textbooks and journals and then following leads from reference lists. The search was carried out using free text terms, synonyms and Boolean operators to enable as full a search of the literature as possible. To assist with the large volumes of literature the software package 'End Note' version five programme for windows was used. Written records were also kept of my searches with dates and times of searches and papers yielded. Email notifications were set for the duration of this study to alert me to any up-to-date literature. The key terms and alternative terms and synonyms used to search the literature are presented in the following table:

Table 2: Key terms and synonyms used to search the literature

| Key Terms | Alternative terms or synonyms |
|---|---|
| Heart Failure | Heart Failure, congestive heart failure, decompensated heart failure, heart failure reduced ejection fraction, heart failure preserved ejection fraction |
| End of Life | Dying, end of life, palliative, hospices, terminal care, palliative care |
| Healthcare Professional | Healthcare Professional, doctor, nurse, multi-disciplinary team, allied health professional |
| Adult Patient | Adult Patient, patient, male patient, female patient, elderly patient, medical patient |
| Decision making | Decision making, shared decision making, judgement, professional autonomy |
| Acute Care | Medical Ward, emergency care, emergency ward, medical admissions, care of the elderly ward, geriatric ward, |

## 2.4.4 Search Results

The initial scoping of the literature after using the key search term identified n= 4,451 bibliographic citations. These papers were then screened further for suitability by applying the inclusion and exclusion criteria. Once the downloading procedure of citations was completed any duplicates found in EndNote were deleted. Additional records were included; these were 20 books, 6 newspaper articles and 20 government guidelines and reports. Of the papers assessed for eligibility n=219 the full text articles included for review were n=59 (see appendix 10)

Figure 1  Flow chart demonstrating the search process and the search results. Adapted from Prefered Reporting items for Systematic Reviews and Meta Analyses, PRISMA Flowchart (Moher, Liberate, Tetzlaff, Altman 2009)
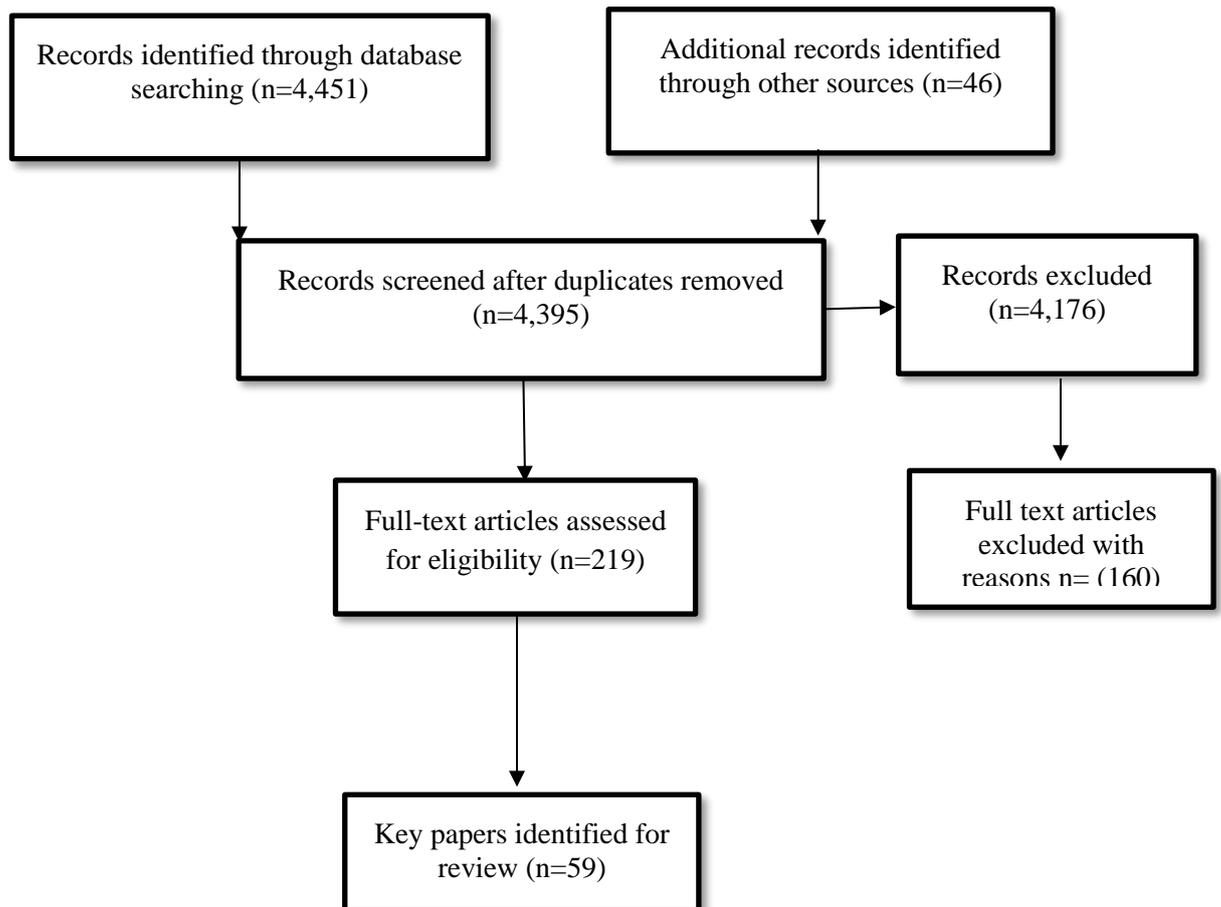
**2.4.5 Charting the Data**

The process of charting the data involved what Arksey and O'Malley call "sifting and sorting" (p15) of key papers to identify common themes. This involved reviewing each individual paper and writing a narrative which included jotting down some of the emergent issues raised by the participants in the studies. To capture these themes a thematic framework was developed in order to visualise some of the core themes or concepts. During this phase, it was important to keep going back to the original review question and my inclusion criteria to make sure of its fit with my study. In the following section, part 4 of this review, each of the themes will be now be introduced and the literature critiqued.

**2.4.2 Study identification and selection**

A two-stage screening process was used to assess the relevance of studies which met my study inclusion criteria. For the first level of screening only the title and abstract of citations was reviewed to avoid wasting time on those studies which did not fully meet the inclusion criteria. A screening tool was developed (see appendix 11) which enabled scrutiny of each study. All abstract and citations which were deemed relevant after the title and abstract screening was complete were then acquired for the full text article. The following inclusion and exclusion criteria were developed in order to facilitate this screening process:

Eligibility Criteria

- Studies that explored healthcare professionals' decision making when managing the care of adult patients diagnosed with NYHA stage 3 and stage 4 heart failure

- Studies which explored end of life care and palliation in patients diagnosed with NYHA stage 3 and stage 4 heart failure

- Studies which addressed the relationships between the patient and healthcare professional when considering end of life decision making

- Studies which explored healthcare professionals and patients' experiences in an acute medical setting

- Studies undertaken between the years 1997 and 2017

Studies which did not meet the eligibility criteria included

- Studies not written in the English Language

- Studies which do not relate directly to the subject of heart failure, end of life or palliative care

- Studies which may involve children or young adults up to and including 18 years of age.

- Studies which explore healthcare professionals and patients' experiences of decision making in a coronary care unit.

- Studies which explore healthcare professionals' decision making when considering end of life care for patients with device therapies like LVAD or ICD

## 2.5 Part 4 The Emerging Themes: A Critique of the Literature

Following the process of scoping the literature and undertaking a thematic analysis, four very distinct themes emerged to explain the experiences of healthcare professionals when making end of life decisions with patients diagnosed with end stage heart failure. These themes were as follows:

- Care Pathways

- Decision Making and Heart Failure

- Palliative Care and Heart Failure

In the following section these three themes will now be explored in a little more detail and the underpinning literature presented.

## 2.5.1 Care Pathways

A care pathway can be defined as a "complex intervention for the mutual decision making and organisation of predictable care for a well-defined group of patients during a well-defined period" (Vanhaecht et al 2007, p154). Care pathways form all or part of the patients' medical record of care and facilitate the evaluation of outcomes for continuous quality improvement purposes (Jenkins and Jones 2007, Kwan and Sandercock 2004, Timmins 2009). Care pathways were first introduced to healthcare in the United states in the 1980's to provide healthcare professionals with a means to monitor clinical standards (Duffy et al 2011). The adoption of care pathways in the United Kingdom in the 1990's came about following the need to provide evidence base practice for stroke care (Kwan and Sandercock 2009). The term integrated refers to a combined pathway of care and a multidisciplinary documentation recording system (Timmins 2005, Jenkins and Jones 2007). The care pathway is based on expert opinion, guidelines, protocols and evidence based practice, research and development (Timmins 2009, Vanhaecht 2011). The aim of the pathway is to improve multidisciplinary communication by providing a 'tick box' to indicate if a particular intervention has been delivered; deviation from the variance has to be recorded on the pathway. The pathway was seen by many healthcare professionals as being revolutionary as it allowed a degree of freedom in being able to make autonomous clinical decisions (Griffiths 2007). However, some would argue that the prescriptive and often 'recipe following format' of the care pathway did not allow nurses to use their own clinical judgement or make informed clinical decisions (Duffy et al 2011, Currie and Harvey 2000, Atwal and Caldwell 2002). Interestingly, a systematic review by Kwan and Sandercock (2009) failed to draw any conclusions in relation to the economic benefits of care pathways over standardised care. Conversely, Croucher (2005) found that there was a wide variability in the quality of integrated care pathways being developed in the United Kingdom and that the quality varied across many health organisations.

**2.5.2 The Liverpool Care Pathway**

This variation in providing quality care to the dying and their families in acute care hospitals was recognised by Mills et al (1994), Rodgers et al (2000) and Middlewood et al (2001) as being sub-optimal and as a consequence prompted the development of the 'Liverpool Care Pathway' (LCP). In the United Kingdom (UK) the hospice model of care had long been considered the gold standard in providing support to the dying patient and their families (Ellershaw et al 1997, Ellershaw and Ward 2003, Ellershaw and Wilkinson 2011). Based on a service improvement methodology, a project was established between the Royal Liverpool University Hospital NHS Trust and the Marie Curie Hospice Liverpool to develop an integrated care pathway (LCP) based on the hospice setting which could be transferred to the acute care setting (Ellershaw et al 1997). The aim of the pathway was to provide holistic care which would focus on the physical, psychological, religious, spiritual and social aspects of care. (Ellershaw 2007). There were a number of different versions of the LCP; the last version, version 12, launched on the 8th December 2009 focussed on decision making and supporting clinicians to decide if the patient should be commenced on the LCP and new prompts to support decisions on hydration and nutrition (Edmonds et al 2009).

In 2000 a National Cancer Plan was published by the government as part of its modernisation agenda to improve care of the dying. The following year the LCP was recognised as good practice by the NHS Beacon Programme launched to identify services making a significant different to the modernisation agenda (NHS Beacon Programme 2001). This was then followed by the launch of the NHS End of Life Care Programme to support the implementation of best practice in end of life care; the LCP was seen as an example of how best this could be achieved (DH, 2003). In addition, to the LCP two other tools were recommended by the NHS End of Life Care Programme and these were the Gold Standards Framework (GSF,2012) and the Preferred Priorities for Care (DH, 2008). The three tools were quickly adopted by the 28 Strategic Health

Authorities across England to manage care of the dying in each local setting. By 2011 the LCP had received endorsements in a number of policy documents and guidance and these included the National Institute for Clinical Excellence and General Medical Council (NICE 2004, GMC 2010).

The abundance of evidence in favour of the LCP would suggest its impact was positive on improving care and support for the dying patients and their families (Ellershaw et al 2001, Ellershaw and Murphy 2005, Jack et al 2003, Jack et al 2004, Gambles et al 2006, Verbeek et al 2006, Verbeek et al 2008, Ellershaw et al 2008). However, a key criticism from academics of the LCP was it lacked any underpinning 'gold standard' evidence in the form of Randomised Control Trials (Chan and Webster 2010, Chan and Webster 2013, Chan, Webster and Bowers 2016). This concern was openly raised in a publication in the journal of Age and Ageing by a hospice doctor Sanjay Shah (2005) who was concerned that data reported had been too descriptive. The response by the LCP team to this comment at the time was that the pathway "has the potential to impact on the culture of the delivery of care to dying patients in a way that a relatively small team of palliative care professionals could not do" (Gambles et al 2005, p198). During this time a number of non-randomised studies were published from the Netherlands which reported that the LCP had made a positive impact on the delivery of care to the dying patient both in nursing homes and tertiary hospitals (Veerbeek et al 2006, Veerbeek et al 2008, Veerbeek et al 2008, Heide et al 2010). The findings from these studies seem to suggest that the LCP had improved care of the dying by reducing the amount of medication given, reducing bereavement levels in relatives and improving symptom burden ( Veerbeek et al 2006, Veerbeek et al 2008, Veerbeek et al 2008, Heide et al 2010).

In response to the criticisms surrounding the LCP Chan and Webster (2010) undertook a systematic review of all randomised control trials (RCT), quasi-randomised and high quality before and after studies. The aim was to assess the effects of end of life care pathways compared

with usual care (no pathway) across all healthcare settings. The review identified 920 potentially relevant titles but none of the studies met the inclusion or exclusion criteria. The review concluded that there was insufficient evidence to make any recommendations regarding the use of end of life care pathways. A second systematic review was undertaken in 2013 (Chan and Webster 2103) using the same inclusion and exclusion criteria. The aims were similar to the previous review but there was more focus on the symptom severity and quality of life of the dying. The updated search found 2042 potentially relevant titles. The authors (Chan and Webster 2013) found no studies fitting their inclusion criteria and concluded that without high quality evidence (RCT) decision making using end of life pathways, the commonest one being the LCP, should be avoided. More recently an update of a Cochrane review (Chan and Webster 2013) was undertaken to investigate if end of life care pathways like the LCP were effective. Like the previous reviews the aim was to search scientific databases for clinical trials with a particular focus on the effect of the end of life care pathway on patients, carers and their families compared with a control group that received usual care (Chan, Webster, Bowers 2016). On this occasion, a total of 3028 articles were screened and only 1024 were assessed after duplicates were removed. Only one cluster RCT (Constantini et al 2014) met the review inclusion criteria (Chan, Webster and Bowers 2016). The authors concluded that there was limited evidence of the effectiveness of end of life care pathways and therefore were not able to demonstrate important benefits for the patients, families and carers.

### 2.5.3 The withdrawal of the LCP

The concerns around the LCP were first raised publicly in the United Kingdom in an article published in the Daily Telegraph (Devlin 2009) following receipt of a letter from Professor Peter Millard Emeritus Professor of Geriatrics, and Dr Peter Hargreaves Consultant in Palliative Medicine who claimed that some patients were wrongly commenced on the LCP and that for many patients this may have prematurely hastened their deaths. The media furore surrounding

the pathway and the harrowing stories shared by families led to an independent inquiry. The inquiry was conducted by an eminent panel made up of clinicians, experts and lay people led by Baroness Julia Neuberger (Neuberger et al 2013). The panel considered a range of evidence which included written submissions from the public and healthcare professionals, testimonials from professional bodies and other organisations. To inform the panel a rapid review of published research on end of life care pathways was commissioned by the National End of Life Programme. This was led by academics from the Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care (Parry et al 2013). The evidence on integrated pathways was gathered from four systematic reviews; this included more than thirty publications mainly sourced predominantly in the United Kingdom the rest from the Netherlands, United States, Australia, Ireland and China. Qualitative studies were excluded. The key messages concurred with Chan and Webster (2013) that there was no strong evidence on potential benefits, adverse effects or risks for managing the dying phase in end of life care (Parry et al 2013). The authors found that end of life care pathways may improve symptom management, improve communication and improve families' experiences but further robust studies were required to provide strong evidence (Parry et al 2013).

The culmination of findings from the inquiry and recommendations were finally published in a document called 'More Care Less Pathway- A Review of the Liverpool Care Pathway' (Neuberger et al 2013). The inquiry found there was a lack of candour amongst some clinical staff, a lack of compassion, poor leadership and poor communication. Surprisingly, the inquiry found an unwillingness amongst some healthcare professionals to engage in the process of decision making or even to discuss death with either the patient or their families. It is important to acknowledge that the inquiry did report some pockets of good practice. These included areas where there was high quality training and where there was evidence of senior clinicians taking the lead in the decision making (Neuberger et al 2013). There were forty-four recommendations

made by the inquiry made under 25 themes. These included addressing deficiencies in documentation, prognostication, diagnosis of dying, communication, clinical decision-making consent, cardio-pulmonary resuscitation and care planning. The panel concluded that the LCP should be phased out by 2014 and be replaced by an 'individualised end of life care plan'.

In response to the Neuberger inquiry (Neuberger et al 2013), the Leadership Alliance for the Care of Dying People, a coalition of 21 organisations, published a document 'One Chance to Get It Right' (Leadership Alliance for the Care of Dying People 2014). The document outlined five priorities of care which aimed to put the patient at the centre of care, these included; communicating clearly, communicating sensitively, shared decision making, meeting the needs of families and individualised care. This was promptly followed by the National Palliative and End of Life Care Partnership (2015) 'Ambitions for Palliative and End of Life Care' a framework detailing six ambitions for the delivery of excellent care to the dying and their families. The main thrust of this document was that each person should be seen as an individual and have access to fair care which is co-ordinated and reviewed regularly by staff whom are competent. (National Palliative and End of Life Care Partnership 2015). For those patients diagnosed with a non-malignant illness this was a major step forward in recognising the need for equal access to palliation. The need for inclusivity meant that the ambitions to reform end of life care were not disease specific and so failed to acknowledge the complexity of decision making for healthcare professionals in non-malignant diseases, for example heart failure. Interestingly, a more recent critical analysis of the LCP found that the pathway was used far beyond its original remit and as a result became the focus of what was both good and bad in palliative care (Seymour and Clark 2018). In the next section end of life care planning and heart failure will be explored and the challenges of prognostication.

## 2.5.4 End of Life Care and Heart Failure

The disease trajectory for heart failure unlike many cancers is not linear and therefore it makes it very difficult to prognosticate and plan end of life care. Heat Failure often follows an unpredictable course with periods of stability interrupted by exacerbations which may lead to instability and ultimately death (McIlvennan et al 2016). To assist in prognostication there has been a plethora of diagnostic tests developed all aimed at providing the clinician with data to predict disease trajectory. These include clinical indicators like the New York Heart Association (NYHA) classification, exercise tolerance tests, electrocardiography to measure ejection fractions, and simple biochemical markers in particular B-type natriuretic peptide (BNP) and N-terminal pro-BNP. As no single parameter is a perfect predictor other scoring system have been developed which include the Heart Failure Survival Score (HFSS) employed in the selection of cardiac transplantation and the Seattle Heart Failure Score (SHFS). Whilst it is recognised that prognostication in heart failure is difficult there are recognisable signs that the patient requires palliation and these include; recurrent episodes of decompensation within six months, intractable NYHA IV, signs of cardiac cachexia and poor quality of life (Jaarsma et al 2009). These clinical markers should prompt the healthcare professional to engage with the patient and their families in end of life discussions.

In contrast, the patient once diagnosed with heart failure often overestimates their own survival making it difficult to engage in conversations about end of life care planning. In a study comparing patient predicted life expectancy and model predicted life expectancy, patients overestimated their life expectancy by 40% (Allen et al 2008). This can make it difficult for healthcare professionals in identifying the optimal time to engage in end of life conversations with the patient. Other strategies have been used to identify when a patient may be in the last 12 months of life. The Gold Standards Framework Proactive Identification Guidance (2016) surprise question 'Would you be surprised if the patient were to die in the next year, months,

weeks, days'? aims to support both community and hospital staff in identifying those patients who may be at the final stage of life. The 6th edition incorporates three main trajectories of illness including rapid predictable decline (cancer), erratic decline (heart failure) and organ failure (GSF, PIG, 2016). Evidence suggests that using the surprise question can optimise quality of life for patients and their families by providing timely opportunities to discuss end of life care (Murray et al 2002. Small et al 2010, Murray and Boyd 2011).

In a quantitative study, Barnes et al (2008) used validated questionnaires to survey 542 patients diagnosed with heart failure across sixteen GP surgeries in four diverse locations in the United Kingdom. The aim of this study was to identify factors available to GP'S that were predictive of mortality in patients diagnosed with heart failure and to report specify and sensitivity of prognostic information. All patients met the eligibility criteria if they were over the age of 60, symptomatic heart failure NYHA II-IV, could speak English and had no significant cognitive impairment. The patients were asked to complete at three monthly and twelve-monthly intervals; a service use questionnaire (adapted from Skilbeck et al 2002), Kansas City Cardiomyopathy Questionnaire, SF-36, Geriatric Depression Scale (five item) and NYHA classification. The researchers reported that women had a 58% lower risk of death compared to men (HR 0.42, 95% Confidence Interval (CI) 0.25-0.72). Those patients who self-reported NYHA III -IV had an 81% higher risk of death than those with a NYHA I or II (HR 1.83, 95% CI, 1.09-3.08) (Barnes et al 2008). The prognostic question 'Would I be surprised if this patient were to die in the next 12 months? found GP's accurately predicting death in 11 of the 14 patients that died (sensitivity 79%) and correctly identified 133 of the 217 who did not die (specificity 61%). The findings are maybe not that remarkable when considering other simple clinical markers could have been available to the GP to assist in predicting deterioration like blood profiles or lack of response to treatment. These are not mentioned here in this study. There were very few NHYA IV recruited to this study which may explain the overall low mortality figures.

We are told there is a lack of diagnostic accuracy which is surprising considering progression to an echocardiogram would have provided more robust data on the classification of heart failure.

Similar findings were reported by Johnson et al (2012) when prospectively collecting data from patients (n=126) known to heart failures nurses working in two integrated cardiology palliative care teams. The aim was to prospectively assess the care received by patients with advanced heart failure using the following criteria: evidence of recognition of advanced heart failure in people who died within 12 months of referral or re-referral, evidence of planning end of life care and evidence of access to palliative care services. The data collection sheet included information like dates referred to the heart failure nurse, the surprise question, referral to palliative care, DNAR-CPR and preferred place of care. The researchers found that the surprise question was agreed in 88/126 (70%) of patients and 78 of these patients (89%) died within 12 months. Planning of end of life care was evident in 64% and half the patients were referred onto palliative care mostly initiated by the heart failure nurses (Johnson et al 2012).

A limitation of Johnson et al (2012) audit was it lacked the rigor of a well-designed research study limiting the generalisability of the findings to other clinical settings. Furthermore, the number of data sets collected was reduced significantly due to the availability of heart failure nurses across both clinics. However, the findings from both studies (Barnes et al 2008, Johnson et al 2012) seem to suggest that if the surprise question is applied correctly it could assist GP's in identifying those heart failure patients who maybe in the final stages of life. In contrast, Small et al (2010) caution against the use of the surprise question as a standalone prognostic tool stating "its use will inhibit the initiation of a palliative care approach with these patients". (p 740). These sentiments are echoed by Haga et al (2012) who after comparing the Seattle Heart Failure Score with the Gold Standard Framework Prognostic Indicator Guide found that both indicators had poor prognostic accuracy when applied to NYHA III-IV heart failure and as a

consequence were considered to be a barrier to palliative care. Along with the surprise question other initiatives were introduced to try and improve the planning of end of life care. In the next section, advance care planning will now be discussed within the context of end of life care planning and heart failure.

**2.5.5 Advance Care Planning and Heart Failure**

Advance Care Planning (ACP) is a "voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline" (NHS End of Life Care Programme 2008, p5). The aim of the ACP discussion is to document accurately individual's concerns, record care planning goals and document preferences and wishes towards the end of life. Under the terms of the [4]Mental Capacity Act (2005) formalised outcomes of the advance care planning might include:

  i.   Advance statements to inform subsequent best interest decisions

 ii.   Advance decisions to refuse treatment which are legally binding if valid and applicable to the circumstances at hand

iii.   Appointment of Lasting Powers of Attorney appointed by an individual should they lose capacity

More recently, ACP has been seen as an ongoing process which includes discussions about goals of care, resuscitation, palliative care, surrogate decision making and advance directives (Patel et al 2012, Costello 2017, Maciver et al 2018). Current guidelines suggest that all patient with a chronic life limiting illness should be offered ACP before time critical situations occur (Royal College of Physicians 2009, DH 2015, European Society of Cardiology 2016). However,

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[4] People who lack capacity- a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain (Mental Capacity Act 2005)

despite these recommendations the evidence suggests that only a small proportion of patients and their families will have the opportunity to share preferences of care with a clinician (Seal 2007, Denniss et al 2017).

Studies undertaken in both primary and secondary care suggest that there are a number of barriers to initiating ACP which may be precluding patients and families from having these important conversations. Vleminck et al (2014) qualitative study involved five focus group interviews of GP's (n=36) with the aim of understanding barriers to initiating the ACP. Findings from this study suggest that barriers occurred more frequently with heart failure patient's due to a lack of familiarity by the GP with the terminal phase of the illness. The surprising lack of patient awareness about their diagnosis and prognosis was cited by the GP's as a further barrier to initiating ACP conversations (Vleminck et al 2014). Similar findings were reported by Ahluwalia et al (2013) who in a prospective observational study set out to evaluate the extent to which physicians working in a busy out-patient department engaged in advance care planning with heart failure patients. Data was prospectively analysed this included 71 audio tapes of patients aged 65 years and older (n=52) and their physicians (n=44). The findings concurred with Vleminck et al (2014) that physicians were reluctant to engage with ACP because of lack of time, not knowing what aspects of ACP to discuss and a lack of skill and confidence in having end of life discussions (Ahluwalia et al 2013). Limitations of Ahluwalia et al (2013) study was the sample was limited to patients 65 years and older and therefore the findings could not be generalised to other populations. Similarly, Vleminck et al (2014) recruitment of GP's was predominantly male with very few female GP's participating in the focus groups. Both studies failed to seek perspectives from other individuals like the patient's families, nurses and other specialists who could have provided additional insights into the issues surrounding ACP.

In contrast, a systematic review and meta-analysis undertaken in the Netherlands by Houben et al (2014) demonstrated that when the ACP is implemented correctly it can have significant

benefits for the patient and their families; these include improved decision making between the patient and healthcare professionals on preferences of care. These findings are supported by Weathers et al (2016) who after undertaking a systematic review of randomised control trials found that advance care planning not only improved decision making in older patients at the end of life but decreased the number of acute hospitalisations. Both Houben et al (2014) and Weathers et al (2016) concluded that more experimental designs need to be undertaken in various different healthcare settings including the community.

### 2.5.6 Summary

In summary, engagement by healthcare professionals in end of life care planning for patients diagnosed with heart failure remains poor despite the changes made to government policy and guidelines. The complexities of the disease coupled with the difficulties to prognosticate have made identifying the terminal phase for healthcare professionals challenging. For the patient and their families this has meant lost opportunities to make shared decisions. It is clear that changes made following the Neuberger inquiry have failed to make a significant impact in end of life care for heart failure despite the introduction of communication and educational programmes for healthcare professionals. This study seeks to explore why despite government guidance there is still a gap in decision making when considering end of life care planning with heart failure patients. In the next section, the theme 'medicalisation of dying' will be discussed and the impact this may have on patients, carers and families when considering end of life care and decision making.

### 2.6 Decision Making and Heart Failure

End of life decision making in acute care is complex involving difficult decisions which can often be emotionally demanding for both the healthcare professional, the patient and their families (Barclay et al 2011). The prognostic uncertainty of heart failure makes it extremely

difficult for physicians to know when is the best time to involve the patient in the decision-making process. Equally, the patient diagnosed with heart failure can be faced with a number of challenges which may include decisions about medication, treatment plans, transplantation, devices and end of life care. In the face of uncertainty patients do not always make logical decisions which can be further exacerbated by a lack of information and the overuse of medical jargon. (Goodlin et al 2008). Studies have demonstrated that patients often make decisions in the context of substantial symptom burden, depression, and coexistent cognitive impairment (Benkelman et al 2007, Rutledge et al 2006, Dickson et al 2007). This reduced cognitive impairment can lead to a lack of decision making capacity which often puts the family member in the role of surrogate decision maker (Lang et al 2004, Delgado et al 2009)

The SUPPORT study (Connors et al 1995), a pioneering investigation into end of life decision making practices reported substantial shortcomings in the provision of care for acutely unwell patients. Phase 1 of the study a multi-site investigation into the delivery end of life care concluded that poor communication resulted in many patients receiving unnecessary interventions that they did not want and experiencing moderate to severe pain at the end of life. Phase 11 of the SUPPORT study involved nurses who had been given specific training to facilitate communication on end of life care with the patient and their families, in addition physicians were provided with prognostic models to assist in estimating likelihood of death. The study found that the intervention made no significant difference in decreasing the time to decide to obtain a DNAR. However, the narrative data from the study demonstrated that the nurses played a significant role in providing the patient and families with emotional support and providing guidance in end of life decision making.

Nurses are recognised in having particular insight into patient's wishes as they spend most of their time with the patient and the families and as a consequence develop a trusting relationship (Puntillo et al 2006). The unique relationship between the nurse, patient and their families

allows information to be shared and can broker the gap between the patient's lack of understanding and the doctor's over medicalisation of the dying process (Costello 2001, Hockley et al 2005). Furthermore, the therapeutic proximity and the close relationship with the patient can assist in signalling to the nurse the patient's readiness to discuss end of life issues.

**2.6.1 Shared Decision Making**

In response to the absence of medical guidance on 'shared decision making 'in end of life care the GMC published a document entitled 'Treatment and Care towards the End of Life' (2010). The guidance states that any patient with capacity should in collaboration with their doctor make informed decisions about their end of life care. The mantra was repeated in the governments publication 'No decision about me, without me (NHS 2012) clearly setting out an agenda to put the patient at the centre of the decision-making process. Such definitions have been echoed by the American Heart Association (Allen et al 2012) who argue that every patient should be informed of their diagnosis, prognosis, risks and benefits of any interventions. According to Xu et al (2016) in the last decade the decision-making model in medicine has moved from one of hierarchical and patient centred to a shared model.

However, there is some evidence that suggests that not all patients prefer an active role in the decision-making process, and preferences may vary depending on the context and severity of illness. In a quantitative study Burton et al (2010) recruited 85 consecutive patients (n=85) (52 men median age 65.5 years, 33 women, median age 64 years) attending for elective diagnostic coronary angiography to assess if shared decision making occurred between the patient and cardiologist. Before the procedure patients were presented with five cards in random order to and asked to choose the card which best represented their preference. Patients electing card A-B were designated 'active decision makers', patients choosing card C were designated 'shared decision makers' and cards D and E were designated passive decision makers. Post procedure

two senior medical students were instructed to observe the interaction between the cardiologist and the patient and complete the OPTION Score. The OPTION Score consists of twelve items that focus on methods employed by the doctor to include his or her patient in the decision-making process. Prior to leaving the clinic the patients were asked to complete two questionnaires; The Perceived Involvement in Care Scale (PICS) and The Comrade Satisfaction Scale. Findings from this study suggest that patients irrespective of preferences were more confident in decisions when they perceived more involvement or when the consultations were longer (p=0.001, coefficient =0.276). Only 7% of the patients said they wanted to make the decision about their treatment themselves. The majority of patients 60% said they preferred not to make decisions themselves and 34% wanted the doctor to make the decision. Patients were found to be generally confident in the choice of treatment (COMRADE Scale). The involvement in the decision making seemed to be higher in those patients diagnosed with extensive coronary artery disease. Whilst these results highlight the complexity of doctor-patient communication the findings only relate to one specific diagnostic test; coronary arteriography and therefore could not be generalised to other medical settings or populations.   Additionally, the patients were all of a similar age (over 60 years) and their preference was for passive decision making which one could argue in a more heterogenous sample may have yielded very different results. Finally, the perceptions of the cardiologist were not included which may have given a more comprehensive understanding of the phenomena under investigation.

In an American study, Lown et al (2009) undertook a qualitative study to explore how patients and physicians describe attitudes and behaviours that facilitate shared decision making. Two physicians and two educators were tasked with facilitating four three-hour focus groups. The participants recruited were primary care physicians (female n=20, male n=21) and patients (female n=29, male n=15) with chronic long-term conditions which included heart failure, diabetes, hypertension, rheumatoid arthritis, chronic leukaemia and liver transplant. The

patients were already known to their respective physician and were chosen because they had multiple health interactions and expressed an interest in doctor-patient communication.

Data was analysed thematically and revealed six theoretical categories of paired physician and patient themes which included; act in a relational way; explore/express patient's feelings and preferences; discuss information and options; seek information, support and advice; share control and negotiate a decision; patients act on their own behalf; physicians act on behalf of the patient. Lown et al (2009) reported that the study emphasised the dynamic process of shared decision making and provided an insight in to the influences and behaviours of both the patient and the physicians. Lown et al (2009) acknowledges that conversations may have been inhibited by having both the patient and the physician in the same room. Furthermore, the sample recruited was restricted to primary care physicians and patients diagnosed with chronic health conditions limiting the transferability of the findings to other populations and settings.

### 2.6.2 Patients' and Families' Experiences of Decision Making

Evidence suggests patients may prefer to play a passive role in the decision-making process particularly towards the end of life. Rodriguez et al (2008) conducted a telephone survey of 90 adults diagnosed with heart failure. The patients preferred role in treatment decisions was assessed using the 'Control Preferences Scale' (CPS). Patients were asked about their involvement in decision making during their most recent clinic visit. The responses were measured using a subscale of the Perceived Involvement in Care Scale (PICS). Data was analysed using descriptive statistics. Of the 90 patients recruited the majority were elderly (mean age 70.1 years; range 42-88years), male (94.4%), white (85.6%), married (56.7%), and retired (67.7%). Most patients had a NYHA class 11 score (55.6%) characterised by a slight or mild limitation to activity. The results from the CPS regarding role preferences in decision making showed that 43 patients (47.8%) preferred a passive role. Only 19 patients (21.1%)

preferred an active role, and 28 patients (31.1%) preferred a collaborative role. The results from the PICS decision making subscale showed that, in regard to perceived involvement in decision making 41 patients (45.6%) reported that they expressed some opinion, either agreement or disagreement about the types of interventions suggested, 18 patients (20.0%) said they suggested a certain type of care, 9 patients (10.0%) said they insisted on a particular kind of care and 18 patients (20.0%) expressed doubt about their physician's recommendations.

Similar findings were reported by Matlock et al (2010) who interviewed 22 patients with symptomatic heart failure using semi-structured interviews. Questions posited were" Can you tell me a time about any important or difficult decisions you have had to make about your heart condition"? Two distinct styles emerged: active decision maker (55%) who was able to consider treatment options and consider impact on quality life and passive (45%) decision maker who did not identify difficult decisions and was happy to trust in the physician to make treatment choices. Both Rodriquez et al (2008) and Matlock et al (2010) studies are limited in that both studies used relatively small sample sizes. In both studies, the patients recruited were predominantly male, white with a mean age of 65 years and therefore would argue the findings would not be transferable or generalisable to other populations or settings.

The family experience of decision making according to the literature depends on the honesty of the physician and how much information is given. In a prospective mixed methods cohort study Apatira et al (2008) explored surrogate decision makers attitudes towards balancing hope and telling the truth. One hundred and seventy-nine participants were interviewed in four intensive care units. Overall 93% (166/179) of the surrogates believed that avoiding discussions about prognosis was not acceptable way to maintain the families hope. A total of 48% 87/179 believed being given the right information prepared them emotionally for death and 13% (23/179) surrogates felt having a clear understanding of the prognosis would allow better support of the patient and the families. Interestingly, 13% (23/179) of the surrogates were strongly against

disclosure on the grounds that it would lead to 'false hope'. For some 3% (6/179) the discussion by the physician about prognostic information should be withheld for fear of the emotional damage it could cause both to the patient and their families. The strength of this study is it large sample size and ethnically diverse sample, However, the families were interviewed during the first week of the patient's admission to ICU and perceptions about prognostic information could have changed during the patient's ICU stay.

### 2.6.3 Healthcare Professionals' experiences of Decision Making

End of life decision making can be a challenge for nurses working in medical acute care wards. According to the nurses the reasons for this are lack of end of life education, poor communication with medical colleagues and a lack of consensus and understanding amongst healthcare professionals about end of life care planning (Clarke and Ross 2006, Thacker 2008, Rice et al 2008). Surprisingly, very little has been written in the literature exploring acute care nurses' experiences in end of life decision making. In a literature review Wilson and Kirshbaum (2011) found that the majority of literature exploring nurses' perceptions of end of life was undertaken in critical care units, oncology and palliative care. In a more recent study Gagnon and Duggleby (2014) reviewed 16 papers to explore nurses' perceptions of end of life care in acute medical and surgical wards. The search was undertaken using three data bases; CINAHL, PsyInfo and MEDLINE. The findings suggested that nurses found it difficult to deliver end of life care and make decisions when challenged by the biomedical model of care. Nurses reported poor communication and collaboration with medical colleagues which often led to the provision of futile care. A study by Thompson et al (2005) reported similar findings and found that nurses were trying to deliver good end of life care but were being 'pulled in different directions'. In a grounded theory study Thompson et al (2005) interviewed 10 nurses to explore nurses' perceptions of end of life care working in an acute care setting. Data was analysed using the constant comparative method. The core category 'creating a haven for safe passage' described

the basic social process nurses were experiencing when delivering end of life care. The four sub themes; facilitating and maintaining a lane change, getting what's needed, being there and manipulating the care environment recognised the nurses and physician's awareness that death was approaching for the patient and that there need to be a move from curative to palliative care. The sub theme 'facilitating and maintaining a lane change became increasingly important to nurses when wanting to facilitate a care plan and make decisions about end of life care. Nurses acknowledged that changing lanes was easier to achieve when there was compelling evidence that the patient was in the terminal phase of their illness. The strengths of this study were in its trustworthiness and attention to providing transparency of the coding process. The emerging codes were checked by other members of the research team and the findings were member checked with clinical colleges. The grounded theory was presented to clinical colleagues working in palliative care and acute medicine who acknowledged the 'fit and grab' of the theory. A limitation of this study was the participants recruited were all female nurses. Future studies would need to consider recruiting male nurses in order to understand from their perspectives end of life care. Furthermore, the sampling was limited to two medical units where the nurses had not been exposed to palliative care interventions. This may have introduced prejudice to the results as the overall perception of the nurse towards palliative care may have been negative.

In contrast, Hauptman et al (2008) conducted a survey of internists, GP's, physicians, geriatricians and cardiologists selected randomly from the American Medical Association Master file of physicians. A total of 1,450 physicians (cardiology n=600, internal medicine n=300, GP n=300, and geriatrics n=250) were surveyed with the aim of investigating physician's beliefs about advanced heart failure management. Of the 1,450 surveys only 59.6% (n=734) responded (cardiologists 51.4 %, geriatricians 64.8%, GP's 57.7% and interns 57.7%. The report found that when considering management decisions cardiologist were more likely to

consider ICD deactivation in terminal heart failure (cardiologists 87%, geriatricians 78%, interns and GP's 70%). However, discussion with patients and families about potential device deactivation was very uncommon across all physician specialities. More surprising was the general physician's belief that they should be the initiators of end of life discussions rather than the nurse or pastoral staff. Furthermore, cardiologists believed they should initiate these discussions (73%) whereas the interns, GP'S (78%) and geriatricians believed that they were best placed to have these discussions. Hauptman et al (2006) acknowledged that the degree to which the self-reports accurately reflect practice is questionable. Future studies may benefit from qualitative data like observing the physicians in practice or undertaking interviews to explore fully physicians' attitudes and behaviours towards end of life care.

## 2.6.4 Summary

In summary, evidence seems to suggest that patients do prefer the shared model of decision making but this seems to change to a more passive role as the heart disease progresses and the patient becomes more terminal. Nurses involvement in this decision-making process seems to vary depending on the level of expertise, relationship with the medical teams and colleagues understanding of end of life care planning. It is clear from the literature that the biomedical model of care still exists and that this model has had an impact on the involvement of both the nurse, patient and their families in the decision-making process. Literature reviewed so far has identified a gap in understanding healthcare professionals' experiences of end of life care in the acute medical care setting. My thesis aims to bridge this gap by exploring healthcare professionals' and patient's experiences when managing advanced heart failure across the specialism of acute medicine.

**2.7 Palliative Care and Heart Failure**

**2.7.1 Provision of palliative care**

The integration of palliative care into heart failure services still remains inadequate despite evidence suggesting the benefits of referral to both the patient and their families. A survey of lead palliative care consultants (n=233) in England reported 197 (85%) services accepted heart failure patients whilst 26 (11%) of the services did not. The most common reason for not accepting heart failure patients was lack of resources and beds, implications for staff training and organisational decision. Fifteen services (6%) had specific referral criteria for heart failure patients which included without symptomatic improvement, recurrent hospital; admissions and severity of heart failure. Only twelve services (5%) had developed treatment guidelines (Gibbs et al 2006). A more recent survey undertaken in the UK by Cheang et al (2014) with 499 respondents (42% palliative care providers) reported that 47% of palliative care providers received less than 10 referrals and only 3% received more than 50 referrals of patients with heart failure annually (Cheang et al 2014). According to Selman et al (2007) the lack of palliative care models for heart failure in primary and acute care may explain why service provision remains woefully inadequate.

**2.7.2 Doctors' perceptions of palliative care for heart failure**

In the UK, Hanratty et al (2002) conducted an exploratory study to identify doctors' perceptions of the need for palliative care for patients diagnosed with heart failure and the possible barriers. The sample included seven speciality groups of doctors; 2 GP'S, 2 Cardiologists, 1 Care of Elderly Consultant, 1 General Medicine Consultant and 1 Palliative Care Medicine Consultant. The participants were interviewed in focus groups which were taped and lasted approximately 80 minutes. The study reported that there were three main barriers to developing a palliative care/heart failure service; the organisation of healthcare, the unpredictable course of heart

failure and the doctors understanding of roles. The doctors believed that the health system worked against providing holistic care and that this was further exacerbated by professional rivalry and control. In a similar study, Brännström et al (2010) undertook a qualitative study to explore physician's experiences of palliative care when managing the care of patients with advanced heart failure. A consecutive sample of 3 cardiologists and 12 internists were recruited and interviewed in a care of the elderly outpatient clinic. Open ended questions were used like "Please tell me your experience of palliative care for heart failure patients"? to encourage narration. Data was thematically analysed. Three main themes emerged from the coding: facing patients with an unpredictable disease trajectory, facing difficult situations regarding the withdrawal of treatment and acknowledging the necessity for better structured follow ups. The physicians agreed that the referral to palliative care meant withdrawal of treatment and this often meant taking away the patients hope. Like Hanratty et al (2002) study the physicians believed the process of referral to palliative care would be less problematic if there was clarity on who was principally responsible for the patients' medical care. In both Hanratty et al (2002) and Brännström et al (2006) studies the samples were relatively small and only reflected the opinions of one professional group. Hence generalisability would be limited. Furthermore, Brännström et al (2006) study did not report how the data once coded was member checked or verified questioning the trustworthiness of the findings.

### 2.7.3 Medicalisation of Dying

The term 'medicalisation' has been associated with "the sense of a profession reaching to far: into the body, the mind and even the soul itself" (Clark 2002, 905). In many cases 'medicalisation' has been blamed for the lack of referral from the cardiologist to the palliative care teams (Taylor et al 2017). The literature on the medicalisation of dying seems to suggest that death is no longer 'natural' but something orchestrated by doctors in the acute care hospital setting (Seymour 1999, Clarke, 2002, Gellie, 2015). The premise that death should happen

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'naturally' in the privacy of one's home in the bosom of the family has been replaced by a medical-technological model of care which is seen by many healthcare professionals as the gold standard of palliative care (Seymour, 1999). One of the most influential philosophers on this topic of death and dying, Ariès Philippe in his book 'The Hour of Our Death' describes death as moving from the simple familiarity of the 'tame death' to the 'dirty' and 'wild' event of the medicalised death. Here death and dying is redefined as a technical problem to be managed and treated by doctors rather than excepted as a natural process of living. According to Philippe (1981) "the doctor cannot eliminate death, but he can control its duration, from the few hours it once was, to several days, weeks, months or even years" (Philippe, 1981, p585). In his seminal text 'Medical Nemesis' Ivan Illich draws similar conclusions to the medicalisation of dying in which he argues that modern medicine "has brought the epoch of natural death to an end (Illich 1976, p207). In Western Societies, where death has become medicalised and where curative procedures are prioritised ahead of palliation (Economist Intelligent Unit 2010), many physicians are reporting patient death as a failure rather than the inevitable outcome of a disease (General Medical Council 2010).

For heart failure patients this medicalised model of care has created a barrier to the process of shared decision making between the patient and healthcare professional when considering end of life care (Bloomer et al 2011). Nordgren et al (2004) in a qualitative study interviewed 2 physicians and 5 registered nurses to explore perceptions of palliative care in a coronary care unit (CCU). The study identified a number of obstacles to providing good palliative care and a dignified death for patients. These include problems with the environment, lack of clear guidance, insufficient knowledge, and unnecessary suffering. Nogdren et al (2004) reported that physicians would often prescribe futile treatments or investigations because of personal fears associated with death. The nurses in this study believed that the physicians' decisions were based on a biomedical model of care which did not consider the patients suffering. More

recently, Ziehm et al (2016) in a cross-sectional survey of healthcare professionals (physicians n=95, GP n=46, resident cardiologist n=13, hospital cardiologist n=18, other n=18, nurse n=71, nurse in hospital n=50, community nurse n=19) found that 49.1% of the participants preferred to continue active treatment rather than refer to palliative care seeing the change of therapy as a defeat. Interestingly, the majority of participants in this study still believed that death was a taboo subject within society and that patients did not accept that life is limited because they had received a diagnosis of heart failure. Both Nogdren et al (2004) and Ziehm et al (2016) studies had relatively small sample sizes and their studies were located in only one hospital so it would be difficult to generalise their findings. However, what these studies illustrate is the continuation of the medicalisation of the dying process despite the advancements in palliative care.

### 2.7.3 Transitioning to Palliative Care

According to Gott et al (2011) transition is defined as "a change of focus in the goals of a patients care from 'active treatment' where the focus is on cure or management of chronic disease, to a 'palliative care 'approach where the focus is maximising quality of life" (p1). The transition model historically has been applied to cancer care and more latterly transposed onto heart failure. However, there is limited evidence to support the use of this model in heart failure and its impact on the transition process (O'Leary et al 2009). In a qualitative study, Gott et al (2011) interviewed 58 healthcare professionals involved in the provision of palliative care in both primary and secondary care. A total of four focus groups were held in GP practices, two focus groups and four interviews in two acute trusts and two focus groups in a hospice. To maximise the sociodemographic diversity of the patient populations the interviews were held across two different city locations. The interviews were tape recorded and analysed using NUD*IST. Findings from this study reported that prognosis was not routinely discussed with hospital in-patients, representing a key barrier to transitioning to palliative care. The use of the surprise question as advocated in policy guidance (DH 2008) was acknowledged by

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participants'. However, participants' working in secondary care acknowledged that it was difficult conveying the prognosis to patients and their families. Primary care professionals confirmed that patients were often discharged home with 'false hope' of a cure because this information had not been conveyed. Key barriers identified to a smooth transition to palliative care included 'standing back' in an acute hospital situation, the presence of professional hierarchies which prevented junior doctors and nurses being able to input into clinical decisions and poor communication.

A more recent study by Wong et al (2016) investigated the effects of home based transitional palliative care for patients with end stage heart failure. The participants all met the study inclusion criteria and had been discharged from hospital with end stage heart failure and referred for palliative care. There were 84 participants (n=84) who met the inclusion; 43 participants' (n=43) were allocated to the intervention and 41 participants (n=41) to the control. The intervention consisted of weekly follow-ups and telephone calls in the first 4 weeks and then monthly follow up thereafter by the multi-disciplinary team. The primary outcomes were the number of readmissions and count of readmissions within the first 4 weeks and 12 weeks. Secondary outcome measures included changes in symptom control between the intervention and control group. The results of the study demonstrated a significantly lower readmission rate in the intervention group than the control group at 12 weeks (intervention 33.6% vs control 61.0%). The mean number of readmissions for the intervention and control groups respectively, 0.42 (0.10) and 1.10 (0.16) and the difference was significant (p=0.001). When compared with the control group the intervention group experienced significantly higher clinical improvement in depression (45.9%v16.1%, p<0.05) and dyspnoea (62.2%v 29.0%), p<0.05). The study findings suggest that when patients do transition successfully into palliative care readmission rates into hospital are significantly reduced and symptom burden is improved. The strength of this study is in its design and the reliability of its findings, However, Wong et al (2106)

acknowledges that the healthcare system in Hong Kong may differ from those in other countries. Therefore, studies would need to be undertaken in other countries with larger samples to confirm internal and external validity of the findings.

**2.7.4 Summary**

In summary, palliative care is a precursor to enhancing quality of life for patients who are in the terminal phase of heart failure. However, there are a number of barriers which seem to preclude patients from making this transition. Firstly, the model of transition, historically used in cancer care, does not appear to work for heart failure patients resulting in patients 'being stuck' in a vicious cycle of care. Secondly, the unpredictability of heart failure and the uncertain disease trajectory makes prognostication difficult and results in physicians avoiding referral to the palliative care team. Thirdly, the presence of professional hierarchies in secondary care seem to prevent the more junior doctors and nurses from engaging in the decision-making process. Lastly, the medicalised model of care still appears to exist within the domain of medicine and as a consequence patient with long term conditions, like heart failure, fail to transition to palliative care services.

**2.8 Scoping Review Findings**

The aim of this scoping review was to identify the extent and range of literature on the topic end of life, decision making and heart failure and as a consequence identify gaps in the existing literature. The scoping exercise enabled the mapping of existing literature and the opportunity to identify some of the recurrent themes. The themes identified following this review were put under three main categories; care planning, decision making and heart failure, palliative care and heart failure. Of course, these themes are not exhaustive but for the purposes of giving an overview were felt to represent the main concerns of patients, families and healthcare professionals. The findings from this review suggest that the topic of end of life decision making

in heart failure is both complex and multifaceted. There is an uncertainty and unpredictability in the disease trajectory of heart failure which makes end of life decision making for both healthcare professionals and the patient challenging. It is clear that government policy and guidance has not provided a model of care to facilitate and support this decision-making process. In fact, there seems to have been little progress made in heart failure since the Neuberger Report recommendations (Neuberger et al 2013) in facilitating the transitioning of heart failure patients to palliative care. The continued existence of 'professional dominance' in medicine has disenfranchised ward nurses from end of life decision making. According to Freidson (1970) 'professional dominance' exists where one profession has influence over another profession; this hierarchy leads to subordination and a decrease in the participation of decision making. As a consequence, end of life decisions are made to late in the disease trajectory resulting in the patient and their families experiencing poor quality care.

The majority of studies were found to explore end of life and decision making in clinical areas like oncology, critical care and palliative care. There seems to be a dominance of qualitative studies in heart failure but these tended to focus primarily in the out-patient setting. Very few studies have explored the healthcare professionals and patient's experiences in making end of life decisions in acute medical care. Gaps exist in understanding the barriers to decision making and the impact it has on end of life and the transition to palliative services. For many patients with heart failure their experiences of quality care will be influenced by healthcare professional's decision making in acute medical wards. It therefore seems timely and important to explore this phenomena in this clinical environment.

**2.9 Conclusion**

This chapter has presented the rationale, design and findings of a scoping review to explore healthcare professionals' decision making when managing end of life care for patients

diagnosed with end stage heart failure. The chapter began by providing a definition of heart failure and its aetiology in order to provide some context and meaning of this terminal condition. An overview of how the scoping exercise was undertaken was given with a clear illustration of my search strategy. This was then followed by introducing the themes which emerged from the scoping exercise. In chapter three the design which underpins this study will be critically discussed and why the grounded theory method was considered the most appropriate method to guide my research aims and answer my research question' *How do healthcare professionals facilitate clinical decision making when considering end of life care for patients diagnosed with NYHA stage 3 and stage 4 heart failure?*

# Chapter 3 Research Design

## 3.1 Introduction

The aim of this chapter is to give a full account of the methodological choices made in order to meet the research aims and to answer fully the research question. I am fully aware of the debates surrounding qualitative and quantitative research. However, it is important to lay bare the rationale about the epistemological and ontological choices made and how this has influenced this study research design.

This chapter begins with an explanation of the research focus and the questions which have framed this study. A brief overview will be given of the constructivist paradigm used in the conduct of this study. Symbolic Interactionism as the theoretical perspective will be discussed and its integral links with the grounded theory method. A discussion of the various grounded theory schools will be discussed with a rationale given to the choice of grounded theory method for this study. To undertake this study I had to address the challenges of undertaking a grounded theory and how theory is constructed. Lastly the process of rigor will be discussed its relevance to this study and how it was achieved.

## 3.2 Research Focus

The aim of this study was to explore both health care professionals' and heart failure patients' experiences of the decision-making process at the end of life and the impact this may have on the patient having a good death. A constructivist grounded theory method of enquiry was used to identify individuals' experiences and how the decisions were made with regards to an end of life care pathway. The study and the data gathering process were initially guided by the following aims:

1)      To explore how health care professionals make the decision to place a patient on an End of Life Care Pathway.

2)      To explore how decision making at end of life by healthcare professionals could affect patient's experience.

3)      To explore healthcare professionals' perceptions and understanding of end of life for patients diagnosed with end stage heart failure.

The methodological choices and research design for this study were influenced by the research question. To explore this phenomenon, it was important for me to be able to engage fully with the participants and to understand from their perspective what is was like to make decisions about end of life care. The choice of paradigm was therefore crucial in providing me with the right tools, framework and structure to meet the study aims. A paradigm can be defined as a worldview or a set of propositions that explains how the world is perceived and a paradigm of inquiry informs a researcher as to what is important, what is legitimate, what is reasonable, concerning systematic inquiry (Sarantakos, 1993).

Paradigms in healthcare are often split into two distinct epistemologies that of interpretivist/constructivist and positivist/post-positivist. The interpretivist/constructivist paradigm emerged from the Chicago School in the 1920's and 1930's and was made famous in the 1960's by authors like Glaser and Strauss (1967), Herbert Blumer (1969), Berger and Luckman (1967) and Rubin and Rubin (2005). During this time there was a move from the positivist and deterministic approaches used by classical social scientists and a refocus on the way social science began to construct meanings, negotiate and manage individual groups within various social and historical contexts. Before this movement the methods of research were largely quantitative and firmly based on the positivist paradigm (Saks and Allsop 2007). The

interpretive paradigm precipitated the development of the tools we now know as qualitative methods. These included methods like grounded theory, phenomenology, symbolic interactionism and more recently poststructuralism and postmodernism. The qualitative methods sought to understand from the participant's perspective their own experience rather than seek to measure and categorise behaviours and attitudes. The interpretivist researcher focuses on the understanding of research respondents, pursuing the analysis based on the constructivist ontological position that individuals negotiate meaning (Crotty 2011). According to Guba and Lincoln (1994) constructivism adopts relativist ontology (relativism) a transactional epistemology and a hermeneutic dialectical methodology. Crotty (2011) believes constructionism is 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. Quite simply the constructivist view is that the world is not discovered but constructed.

Critics of the interpretivist or constructivist paradigm regularly imply that approaches to human inquiry are rife with threats to validity and that they are of no scientific value (Peck et al 1999). Validity in quantitative approaches relies on rigorous adherence to methodological rules and standards. When these same rules are applied to qualitative research it does not work and that is because interpretive research is often seen as to subjective and lacking in rigor (Mishler 1990, Angen 2000). In an attempt to rectify this position qualitative researchers have either adopted quantitative criteria or disregarded validity as an issue in qualitative research (Silverman 1993). Smith (1984) suggests that it is time we "dispense with the traditional ideas of objectivity and truth and realize that we are beyond method" (pg. 390). Methodological criteria no matter how rigorously applied to qualitative research will not produce the objectivity desired by positivist researchers (Sandelowski 1993). To explore the human experience requires a more fluid,

contextual and relational understanding and therefore requires an interpretative approach which seeks to understand human thought, speech and action; clearly adopting reductive positivist approaches in this study would not have yielded the type of information or level of understanding required to explore health care professionals decision making when managing the care of patients diagnosed with end stage heart failure.

In comparison the positivist paradigm maintains that reality is fixed and that objective knowledge can be produced through rigorous methodology (Clark 1998). Positivism focusses on establishing scientific facts though the use of scientific method and quantification (Saks and Allsopp 2007). Whilst constructivists may ascribe subjective meaning to objects in their world positivists subscribe no meaning at all instead meaning is discovered through scientific measures and objectivity (Crotty 2011). The historical evolution and nature of positivism was first conceived by French philosopher in the 18th and 19th century Auguste Comte. Comte saw sociology as the very culmination of positivism: a science of man (sic) that would complete the historical evolution of the hierarchy of the scientific disciplines (Giddens 1987). Positivism was cemented in sociology through Comte's idea of transforming society on the basis of science. Herbert Spencer's organic theory of society began to build on the work of Comte and there was a move towards a more evolutionary model which saw society viewed as having the same evolutionary principles in its development as biological organisms. The dominance of positivism peaked in the United States with the structural functionalist work of Talcott Parsons and Robert Merton only then to decline in the 20th century with the emergence of poststructuralist and postmodernist paradigms.

Post positivism provided a vehicle for those scientists who did not necessarily agree to the positivist's way of thinking (Clark 1997). The main influences in promoting post-positivist philosophy were the works of Karl Popper (Popper1959), Jacob Bronowski (Brownowski 1950, 1956), Thomas Kuhn (Kuhn 1970) and Charles Hanson (Hanson 1958). Fundamentally, a

different conceptualisation of truth was proposed by the post-positivists. Like positivism, metaphysical considerations were still deemed to be an important part of the sphere of science (Bronowski 1956). However, in contrast, a realist perspective of science was advocated with unobservables deemed to have existence and the capability of explaining the functioning of observable phenomena (Schumacher and Gortner 1992). Theoretical explanations therefore had greater predictive value. Like the positivists, science was still deemed to require precision, logical reasoning and attention to evidence but was not confined to that which could be directly perceived. Evidence could be drawn from empirical methods like interviews, self-reports, questionnaires (Bronowski 1956).

Acknowledgement of post positivism has formed the rationale of a number of papers (Clark 1998, Poole and Jones 1996, Schumacher and Gortner 1992) which articulate the need to retain and value all methods and warn against dismissing the empirical approach based solely on the weaknesses of positivism philosophy. Despite the openness of post-positivism to other means of inquiry it can be argued that it still has some of the fundamental weaknesses of positivism and may be inappropriate for some types of nursing enquiry (Angen 2000). The methods used when adopting a post positivism paradigm will still require the researcher to seek causation, predict and explain which is why it often doesn't lend itself to investigating complex human experience (Guba 1990). Further criticism of positivism is its inability to give insufficient detail to a persons lived experience (Rubin and Rubin 2005; Bryman 2001). However, what is agreed upon by a number of authors (Bowling 2002, Saks et al 2007, Crotty 2011) is that the research method needs to be able to answer the research question. The aim of this study was to explore both healthcare professionals and heart failure patient's experiences of end of life decision making. To do this I needed to inhabit and be a part of the culture of healthcare professionals managing the care of 'heart failure' patients. I needed to be able to interpret how the culture was

constructed and how behaviours and experiences affected the decision-making process both for the healthcare professional and the patient. The paradigm therefore most suited to this type of inquiry would be interpretivist /constructionist.

### 3.3 Symbolic Interactionism – A Theoretical Perspective

Symbolic Interactionism is a theoretical perspective that explains human life and human experience (Blumer 1969, Denzin 2004). The beginnings of symbolic interactionism can be attributed to pragmatist philosopher and social psychologist George Herbert Mead when as a faculty member at University of Chicago he formed a core group of faculty called 'the Chicago school of Pragmatism' (Baldwin 1986, pg. 10). Mead provided the foundations for Symbolic Interactionism. His teaching spanned a period of 40 years principally at the University of Chicago during the early twentieth century; the writings of Mead were famously summarised in his book Mind, Self and Society (Mead 1934). Meads work was heavily influenced by Charles Darwin and Mead like Darwin believed that our development was part of an evolutionary process. Meads work focussed on behaviour reflecting the pragmatist's view of John Dewey and William James that knowledge is created through action and interaction of self-reflecting beings (Corbin and Strauss 1998). Consequently, behaviour starts with a reflection on a problem and options to deal with it are tested. The consequences of these actions direct future interactions. Beneficial behaviour is repeated while behaviour that does not achieve the required result is modified. This idea echoes Darwin's theory of evolution in which traits that benefits individuals are naturally selected and repeated while those that are not useful become less common over time. Meads theory of the development of self has taken a central place in sociological social psychology and encompasses innovative theories of action and temporality which Anselm Strauss (1987) Corbin and Strauss, (1998) and Glaser and Strauss, (1968) helped to preserve.

Herbert Blumer, one of Meads students, continued the work of Mead at University of Chicago integrating much of Meads work with others whose ideas were foundational in symbolic interactionism like John Dewey, William James, Charles Horton Cooley and Charles S Pierce. The development of the two schools resulted in two varieties of symbolic interactionism, the Chicago School and the Iowa School, both remaining in the pragmatist tradition but each with a different philosophy of science. There is a third approach within symbolic interactionism called the dramaturgical approach made famous by Erving Goffman. Goffman viewed life as a staged drama where interaction was something like a religious ceremony filled with ritual observances. Goffman like many of the symbolic interactionists gave 'self' a prominent place in his writings (Charon 2010). Goffman's focus was not on the self-concept carried by an actor from situation to situation but the socially situated self-developed in and governing specific interactions. According to Goffman (1959) the self is something of collaborative manufacture that must be produced anew on each and every occasion of social interaction.

Symbolic Interactionism assumes that language and symbols play a crucial role in forming and sharing our meanings and actions (Blumer 1969). Symbolic Interactionism views interpretation and action as reciprocal processes each affecting the other. This perspective recognises that we act in response to how we view our situations. In turn our actions and those of other people affect these situations and subsequently we may alter our interpretations of what is, was or will be happening (Blumer 1969). Blumer (1969) believes that Symbolic Interactionism allows the researcher to confront an empirical  world that is available for observation and analysis; to raise abstract problems with regards to that worked; to gather data through careful and disciplined examination of that world; to unearth relationships between categories of such data; to formulate propositions with regards to such relations; to weave such propositions into a theoretical scheme; and to test the problem, the data, the relations, the propositions, and the theory by renewed examination of the empirical world. Charmaz (2014) believes that Symbolic

Interactionism inspires theoretically driven research and leads to fresh theoretical implications. Grounded Theory methods offer the analytical tools and can provide the methodological momentum for realizing the potential of symbolic interactionism in empirical enquiry.

Whilst Blumer's (1969) symbolic interactionism has acted as the lens or the theoretical perspective underpinning Grounded Theory, there have been critics of Blumer (1969) who believe that the theory only deals with the micro- sociological and not the larger questions which may concern the shape of society, individual's perceptions, and society as a whole (Lewis 1992, Anells 1996). Criticism has been directed at symbolic interactionism for ignoring influences like class struggle, and moral structures therefore producing a distorted view of social phenomena (Abercrombie, Hill, Turner 1986). More recently Glaser (2005) has refuted the necessity for using symbolic interactionism or any other theoretical framework claiming that a person's behaviour and concerns should be allowed to emerge without the constraints of a theory. Glaser (2005) believes a solution to this dilemma is to use one of his theoretical coding families provided in his text *'Theoretical Sensitivity'* (Glaser 1978) which according to Glaser (2005) is compatible with the Glaserian Grounded Theory method. Chamaz (2014) argues that symbolic interactionism can offer grounded theorists an open ended theoretical perspective that can inform grounded theory studies. The researcher is able to draw on symbolic interactionism's major strength of combining theory and method into a coherent unified whole without forcing the data. Charmaz (2014) considers symbolic interactionism and grounded theory methods to fit and complement each and advance one another with the aim of constructing theory. Evidence suggests that symbolic interactionism has been applied successfully to a wide range of issues in healthcare such as classification systems, clinical trials, exploring social worlds and studying the work setting (Clarke et al 2003). Within nursing recent applications of symbolic interactionism have focussed on a wide range of topics including personal identities in organ

transplantation (Edgar 2009), and interaction and relationships between nurses/patients and families (Lowenberg 2003).

This study's aims were to understand the interaction and relationships between the patient, nurse and doctor when it comes to decisions making and end of life care. Using a symbolic interactionist approach I sought to understand from the patient's perspective what was it like to be diagnosed and live with NYHA stage 3 and NYHA stage 4 heart failure; how did the disease define the patient and how did this affect how they interacted with healthcare professionals with regards to decision making and end of life care. Blumer (1969) believes that human beings interpret or define each other's actions instead of simply reacting to each other's actions. Consequently human interaction is mediated by the use of symbols, by interpretation or by ascertaining the meaning of one another's actions (Blumer 1969). After the action is completed the effects of this action are interpreted or given meaning and then alter the persons perspective and definition of the situation. This changed perspective and definition of the situation can then influence future actions of the individual (Charon 2010). An example of this process can be witnessed on a hospital ward where a patient is admitted for treatment for their heart failure. A nurse will focus on determining the patient's definition of the situation; conduct an assessment to define the situation for her or himself, as well as ascertaining the physician's definition of the situation. Health behaviours might be changed through interaction with other healthcare professionals. The person's self-image (definition of self) might be improved through positive interaction with others. Where interaction and communication may fail is where you have a power struggle in a relationship between the healthcare professional and the patient. Studies undertaken have demonstrated the importance of sharing power in order to allow shared decisions to be made when considering end of life care (Norton et al 2000). The imbalance of power can often result in the patient losing their autonomy to make a decision which may later affect the course of treatment and ultimately end of life care (Martin 1998, Clover et al 2004).

The theoretical perspectives of symbolic interactionism provided the foundation for this study which was to explore healthcare professional's decision making when managing the care of those patients diagnosed with end stage heart failure. Symbolic Interactionism therefore provided an important theoretical underpinning to the grounded theory approach used in this research. Like Charmaz (2014) I concur that we are part of the world we study and the data we collect.

## 3.4 Grounded Theory- The Method

The Grounded Theory Method was originally developed by two sociologists, Barney Glaser and Anselm Strauss (Glaser and Strauss 1967). Both came from very different philosophical backgrounds. Glaser graduated from the Colombia University where his thinking about research was heavily influenced by Paul Lazarsfeld, a well-known innovator of quantitative methods. Strauss graduated from the University of Chicago where there was a long and strong tradition in qualitative research. Strauss during his studies was influenced by pragmatists like Mead (1934), Dewey (1922), Hughes (1971) and Blumer (1969). Grounded Theory emerged as a result of Glaser and Strauss's sociological research program on dying in hospitals (Charmaz 2000, Strauss and Corbin1990, 1998, 2008). The findings from this study resulted in a book titled 'The Awareness of Dying' (Glaser and Strauss 1965). This was followed by the publication of 'The Discovery of Grounded Theory: Strategies for Qualitative Research (Glaser and Strauss 1967) which provided systematic strategies for qualitative research practice. Glaser and Strauss's aims were to move qualitative inquiry beyond descriptive studies into the realm of theoretical frameworks, thereby providing abstract, conceptual understandings of the phenomena being studied (Charmaz 2014).

Although grounded theory was originally described by Glaser and Strauss in the mid 1960's the literature reviewed seems to suggest that there was a difference of opinion in the original authors

views since the original publication of the book 'The Discovery of Grounded Theory: Strategies for Qualitative Research (Glaser and Strauss 1967, Glaser 1978). Strauss (1987) began to link grounded theory with the idea of verification of theory moving away from Glaser's concepts and emphasis on the analysis of social processes. This change in thinking resulted in Strauss publishing a book titled 'Qualitative Analysis for Social Scientists' (Strauss 1987). Following the publication of this book and in collaboration with Juliet M Corbin (Corbin and Strauss 1990,1998,2008) a book titled 'Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory was published which moved grounded theory further away from the emphasis on emergent theoretical categories and more towards the idea of verification (McCann and Clark 2003). Glaser (1992) argued that Strauss and Corbin (1990, 1998, 2008) procedures forced data and analysis into preconceived categories, ignored emergence which resulted in full conceptual description not grounded theory.

### 3.4.1 Schools of Grounded Theory

The divergence away from the original classic Grounded Theory (Glaser and Strauss 1967, Glaser 1978) has led to three very distinct schools of Grounded Theory; Classic Grounded Theory (Glaser 1978), Straussian Grounded Theory (Strauss and Corbin 1990, 1998,2008), Constructivist Grounded Theory (Charmaz 2000). Whilst each of these schools of grounded theory may have different standpoints and slightly different conceptual frameworks all begin with inductive logic and subject data to constant comparison with the aim of producing a grounded theory (Charmaz 2014). All variants of grounded theory offer ways of collecting, managing and analysing qualitative data with the aim of constructing or developing theory. Choosing the right variant of grounded theory for this particular study involved exploring the grounded theory literature.

### 3.4.2 Classic Grounded Theory

The classic version of grounded theory, founded by Glaser and Strauss (1965, 1967), has its ontological roots in critical realism. Critical realism assumes that an objective world exists independently of our knowledge and belief and as such the researcher is considered to be independent of the research (Anells 1996). Glaser's (1992) emphasis on emergence reflects the belief that the relationship between the researcher and the focus of the study should remain objective. Delaying the literature review is one such strategy employed to prevent the researcher becoming contaminated with preconceived ideas (Glaser 1992). Central to the classic grounded theory method and what makes it unique from other qualitative methods is the data analysis process. The process begins with a basic description and moves to conceptual ordering and then onto theorizing (Patton 2002). Data analysis is accomplished through an elaborate set of coding processes. Coding is not simply part of the data analysis it is the fundamental analytical process used by the researcher (Corbin and Straus1990, 1998 2008). The coding is what transports the data from transcript into theory. Glaser's (1992) version of grounded theory assumes categories emerge from the data and a tentative theory is discovered.

### 3.4.3   Straussian Grounded Theory

Strauss's background as a pragmatist and symbolic interactionist shaped the evolution of his approach to grounded (Charmaz 2014). This can be seen in his collaboration with Juliet Corbin where they shifted to a more relativist approach with constructivists leanings and asserted that 'multiple meanings' must be sought during the research inquiry (Strauss and Corbin 1990, 1998, 2008). Both Strauss and Corbin (1990, 1998, 2008) rejected the positivist view that theory is 'out there' waiting to be discovered and instead assumed that reality is a product of interpretation and construction by the enquirer. The epistemological stance is non-dualist and

subjective; the researcher is part of the research and formulates the theory along with the focus of the research. Unlike Glaser's (1992) classic approach the researcher is actively involved not separate from the method and is encouraged to acknowledge his or her experiences (Strauss and Corbin 1990, 1994, 1998, 2008). The lack of generalisability and reproducibility is not seen as a flaw because of the relativist view that reality is constructed rather than found (Strauss and Corbin1990, 1998, 2008).

Critics of this method state that they have over complicated grounded theory by making it overly structured (Glaser 1992, Kendall 1999). Kendall (1999) believes the use of coding paradigm, matrices and axial coding is inconsistent with the purpose of grounded theory and that the Straussian method allows escape for those who are struggling with the idea of conceptualisation. Further criticism has been levelled at the idea of verification and that Strauss and Corbin (1990) somehow subscribe to it being an integral part of the process. On further reading it is clear that for Strauss and Corbin (1990) verification is not one of finding proof but rather a seeking of support for statements of relationships between concepts (Strauss and Corbin 1990, p109).

### 3.4.4 Constructivist Grounded Theory

Charmaz (2014) chose the term constructivist grounded theory to describe a method which acknowledges subjectivity and the researcher's involvement in the construction and interpretation of data. Constructivism is a research paradigm that denies the existence of an objective reality, "asserting instead that realities are social constructions of the mind, and that there exist as many constructions as there are individuals" (Guba and Lincoln 1989 pg. 43). Within the constructivist framework the objectivity talk of scientists becomes just part of the discourse of science through which a particular version, vision of human life is constructed (Burr 2003). Similar to Straussian grounded theory, constructivist begin with a review of the literature to determine what has been done in their field of interest. A constructivist may begin

with a set of questions and aims which is in contrast to classic Grounded Theory who advocate having no preconceived ideas before entering the research setting (Andrews and Hernandez 2012). This difference in the timing of the literature review and the subtle differences in coding is what make the Straussian and Constructive method differ from Classic Grounded Theory. Epistemologically constructivism emphasises the subjective interrelationship between the researcher and the participant and the co construction of meaning (Hayes and Oppenheim 1997, Pidgeon and Henwood 1997). Researchers in their "humanness" are part of the research endeavour rather than objective observers, and their values must be acknowledged by themselves and by their readers as an inevitable part of the outcome (Appleton1997, deLaine 1997, Guba and Lincoln 1989, Stratton 1997).

What is common between all three schools is that they begin with induction which is viewed as the key process and end with deduction. Glaser (1992) criticises what he believes to be the over emphasis on deduction believing that in a grounded theory study it is what exists in the data rather than what might be. However, commonalities between three schools can be seen in the methods where the researcher is required to code, memo, constantly compare data, theoretically sample and use theoretical sensitivity. Charmaz (2014), Strauss and Corbin (1998) would argue that there is a third process and that is abduction and that it is abduction which potentially assists the researcher to construct theory. I will now discuss this in a little more detail.

### 3.5 Constructing Theory

Theory in qualitative research is sometimes seen as an organised coherent and systematic arrangement of concepts to define and explain some phenomenon or part of reality (Silverman 2005). A theory can also be described as consisting…." plausible relationships produced among concepts and sets of concepts" (Strauss and Corbin, 1994 p.278). Birks and Mills (2013) define theory as an explanatory scheme compromising of a set of concepts related to each other through

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logical patterns of connectivity. According to a positivist view of science the credibility of a theory depends on its ability to explain the evidence obtained by our senses. Criticism of positivist empiricism points out that there is no clear borderline between the evidence of our senses and theory (Popper 1959). Qualitative researchers seem to understand theory in a similar way to logical positivists, namely, as a set of statements that depend on empirical content for their validity (Bendassolli 2013). What is clear is that to generate theory the researcher needs to address the distinction between inductive and deductive enquiry within grounded theory. In the literature induction is loosely defined as going from particular or singular statements to universal general ones (Bergdahl et al 2015). Bulmer (1979) views induction as the key process with the researcher moving from the data to empirical generalisation and on to theory (Bulmer 1979). Deduction is defined as moving from the general or theory to the particular (Bergdahl et al 2015). A study is called deductive if the research question is based on, or deduced from a theory (Thorne 2000, Patton 2002, Yin 2003, Elo and Kyngas 2008). Charmaz (2014) believes what distinguishes grounded theory from other qualitative methods is theoretical sampling which requires a particular form of reasoning and abduction. Abduction (or retroduction) introduced by the American philosopher C.S Pierce refers to the process of studying facts and devising a theory to explain them (Cunningham 1998: pg. 833). Abduction begins with the researcher examining inductive data and observing a surprising or puzzling finding that cannot be explained with conventional theoretical accounts. After scrutinizing the data, the researcher entertains all possible theoretical explanations for the observed data, and then forms hypotheses and tests them to confirm or disconfirm each explanation until he or she arrives at the most theoretical explanations for the observed data. Hence, abduction begins but does not end with induction. Rather the search for a theoretical explanation involves an imaginative leap to achieve a plausible theoretical explanation. Abduction brings creativity into inquiry and takes the iterative process out of grounded theory into theory construction (Charmaz 2014). Within

the grounded theory approach the importance of abduction has been recognised by Coffey and Atkinson (1996, pg. 155) stating that 'abductive reasoning lies at the heart of grounded theorizing, furthermore they claim that:

"*Our important ideas are not in the data and how ever hard we work, we will not find those ideas by simply scrutinizing our data ever more obsessively. We need to work at analysis and theorizing and we need to do the intellectual imaginative work of ideas in parallel to the other tasks of data management".*

What appears to be important here is that abduction is used creatively and used as a bottom up approach to generate a theory; so facts, observations and data are collected and connected together in order that hypotheses can be made. Charmaz (2014) believes that abduction provides an important path for interacting with data and emerging analysis during the grounded theory journey. In fact using abduction helps to re-examine data and provide explanatory theory to your surprising findings. Grounded theory can be thought of an abductive method because it involves reasoning about experience for making theoretical conjectures, inferences and then checking them through further experience- empirical data (Deeley 1990, Charmaz 2014, Peirce 1958). Critics of abduction see it as limiting creativity because it is tied with previous knowledge (Kelle 2014). However, Charmaz (2014) argues that when researcher brings to their studies their own strands of knowledge to theorize puzzling findings then imaginative theory can grow.

The aim of this study was to inductively produce a substantive theory generated from the data which would explain the decision making process between healthcare professionals and patients diagnosed with heart failure when it came to end of life decision making. The substantive theory would explain the phenomena but also be relevant to the contextual boundaries of my research questions. How this was achieved will be discussed in detail in my Findings Chapter.

## 3.6 Choice of Grounded Theory

The aim of this study was to go beyond the lived experience and to understand what influenced the decision-making process for both healthcare professionals and the patients diagnosed with end stage heart failure. The choice of method was therefore important to allow the participants to have a voice and tell their stories. Acknowledging and making sense of my own professional and personal experiences became significant when choosing a grounded theory method. Charmaz (2014) believes that researchers cannot separate themselves from their experiences or be objective about their data. Instead she argues that researchers make consistent and subjective interpretations of the data grounded in their perspectives, privileges positions, interactions and geographical locations (Charmaz 2009). Consideration was given to my own ontological and epistemological positioning. Evans (2013) emphasises the importance for all novice researchers to understand the different philosophical assumptions that underpin each of the grounded theory methods and to take into consideration one's own philosophical beliefs in order to choose the right method. With my already established knowledge in nursing and having a family member diagnosed with heart failure it would have been difficult to be completely objective. Epistemologically constructivists believe that it is impossible to separate the inquirer from the inquired. It is the interaction between the two that creates the data that will emerge from the inquiry (Guba and Lincoln 1989). The sensitive and complex nature of the topic under exploration required me to build relationships with participants and encourage reciprocity in order for participant's to give an honest account of their experiences. The constructivist grounded theory method allowed a more equal position of power within the relationship and encouraged me to adopt a more reflexive stance. This reciprocal relationship is what I believed would yield rich and meaningful data and result in a constructed grounded theory which could be applied to practice.

The classic grounded method was considered but as previously mentioned it was felt that it was to objectivist and scientific. The flexibility of this method was appealing but Glaser (1978) insists that the researcher must remain objective. To really understand the phenomena and to fully understand the participant's views I felt that this approach could potentially lead to a lack of engagement with participants and consequently result in data being too superficial and as a consequence lack in richness and depth. By having a more reciprocal and open partnership with participants it was hoped that this would result in a more honest and engaging dialogue.

Arguably, the Strauss and Corbin (1990,1998, 2008) grounded theory method with its ontological and epistemological likeness to constructivist grounded theory could have been adopted for this study. The detailed guidance produced by Strauss and Corbin (1998) does make this method attractive to a novice researcher. However, for the purpose of this study the method was considered to be to structured and formalised and was considered to lack a degree of reflexivity and flexibility that is attributed to constructionist grounded theory. Critics of this method believe it is too rigid and prescriptive particularly the process of data analysis which some have argued does not allow categories to emerge but forces the data (Glaser 1992), Keddy et al 1996, Charmaz 2009, Birks and Mills 2013). I was keen not to force the data but to allow the concepts and themes to emerge. Charmaz's (2014) method of data collection is fluid and cyclical and requires the researcher to interact with the data by initially coding, focused coding, theoretical sampling, theory development and theoretical memoing in order to produce categories and a formal theory which has fit and grab. For the researcher this meant constantly asking questions of the data and reliving and re envisioning interactions with participants on the acute medical wards. This constant comparing and going back and revisiting the participant's was an important part of the research process in understanding the process of decision making and how this may have impacted on patients and their families. It also directed the questions and the direction of the study.

Using grounded theory for the novice researcher can be challenging due to the plethora of conflicting opinions and unresolved issues regarding the nature and process of grounded theory. Cutcliffe (2000) advises novice researchers to explore these areas of conflict and have awareness before embarking on a grounded theory study. With this in mind I will discuss briefly some of the challenges I had to consider before embarking on my study.

## 3.7 Challenges of Grounded Theory

### 3.7.1 Methodological Slurring

According to Glaser et al (2004) researchers using grounded theory feel the need to extol its virtues, argue its position regarding other methods and re-write its methodology. What has added fuel to this debate is students of both Glaser and Strauss whom have subsequently gone onto develop their own versions of grounded theory thus exacerbating the divide and contributing to what Stern (1994) refers to the erosion of grounded theory. This confusion has led to some studies being labelled grounded theory when in fact there is no evidence of theoretical coding (Strauss and Corbin 1994). Baker et al (1992) adds to the debate by arguing that failure to explicate qualitative methodologies is resulting in a body of nursing knowledge that is mislabelled. Morse (1991) warns that unexamined mixing of methods can lead to a "sloppy mishmash". Baker, et al (1992) contended that method slurring can contribute to a lack of rigor. Despite these cautions many believe it is possible to develop standards of validity in grounded theory which may cross perspectives or mix methods (Taylor 1993). Johnson et al (2001) suggest that there are no 'pure' qualitative methods. However, if rigor is applied and attention is paid to data collection, data analysis and theorizing from the data it is possible to combine methods with relative success (Johnson et al 2001). Interestingly, Charmaz (2014) does not appear to be drawn into the debate about 'method slurring' and maybe this is because constructivist grounded theory in her words is a 'constellation of methods' evolved from Glaser

and Strauss (1967) and Strauss and Corbin (1998) grounded theory methods. Charmaz (2014) accepts that grounded theory per se has evolved and continues to evolve from the original or classic method of Glaser and Strauss (1967) and that the mixing of these methods has provided researchers with a contemporary method (constructivist grounded theory) to construct theory with fit and grab.

### 3.7.2 Methodological Rigor

Methodological rigor in qualitative research continues to create debate and controversy particularly as to 'what is rigor' and how this applies to social scientists. According to Emden and Sandelowski (1998) the notion of validity in qualitative research has been "championed, translated, exiled, redeemed and surpassed" (Emden and Sandelowski 1998), p.207). Aroni et al (1999) believes methodological rigor is the means by which we demonstrate integrity and competence a way of demonstrating the legitimacy of the research process. Without rigor there is a danger that the research may become fictional journalism worthless as contributing to knowledge (Morse et al 2002). Some would argue that we have taken the meaning of rigor to the extreme resulting in a lack of creativity versatility artfulness and sensitivity (Sandelowski 1993). Janesick (1994) defined the term 'methodolating' as a "slavish attachment and devotion to method" (p.215) that has resulted in an over emphasis on methods to the exclusion of creativity. However, it is accepted that there has to be some sort of methodological or technical procedures to guard against the investigators conjuring up concepts and theories that do not authentically represent the phenomenon of concern (Hammersley 1992). If care is not taken pseudoscience can potentially replace science (Johnson 1999).

Historically initial conceptualisations of validity were taken from the experimental/quantitative ideals of reliability and validity research based on the positivist philosophy (Le Compte and Goetz 1984). Traditional definitions were felt to add quality and provide a good benchmark by

which the quality of all research could be judged (Popay et al 1998). Reliability referred to the stability of findings whereas validity represented truthfulness of findings (Altheide and Johnson 1994). The incompatibility of these terms with their underlying scientific assumptions and beliefs did not fit the interpretivist view of social scientists. Lincoln and Guba (1989) pioneered the way with criteria of rigor which could be applied to naturalistic enquiry and provide a way of understanding the differences and similarities between qualitative and quantitative research. These criteria translated internal validity to credibility, external validity to transferability, reliability to dependability and objectivity to confirmability.

Credibility addresses the issue with 'fit' between respondents' views and the researcher's representation of them (Schwandt 2001). It poses the questions of whether the explanation fits the description (Janesick 2000) and whether the description is credible. Credibility is demonstrated through a number of strategies: member checks, peer debriefing, prolonged engagement, persistent observation and audit trails (Lincoln 1995).

Transferability refers to the generalizability of inquiry. How can the study findings can be applied to other situations. Often the samples used in qualitative studies are small and so it is difficult to generalize findings to larger populations and situations. Lincoln and Guba ( 1994) suggest that the researcher provides sufficient contextual information about the fieldwork but also sufficient thick description of the phenomenon to provide the reader with a understanding of the phenomena so it can be compared with other relevant studies.

Dependability is achieved through a process of auditing. Researchers are responsible for ensuring that the process of research is logical, traceable and clearly documented (Schwandt 2001). Dependability can then be demonstrated through an audit trial where others can examine the researcher's documentation, methods of data collection, decisions made and end product (Tobin et al 2004). Reflexivity is central to this audit trial and so it is important for researchers

to keep a record of the research process, internal and external dialogue. Auditing can also be used to authenticate confirmability.

Confirmability is concerned with establishing that data and interpretations of the findings are not a figment of the researcher's imagination but are clearly defined from the data. Here steps are taken to ensure that as far as possible the study findings represent the voice and experience of the participants and not the characteristics and preferences of the researcher. Shenton (2004) suggests that the use of triangulation is perfect for reducing the effect of researcher bias. Triangulation can be described as a method of verification where different methods can be used to gain a greater insight into phenomena from a number of perspectives (Saks and Allsop 2007). The process of confirmability in a mixed methods study (establishing truth) can become confusing when seeking verification because of the combining of ontologies and epistemologies of both qualitative and quantitative science. Whilst the challenges for researchers is to demonstrate thoroughness in their work, blindly incorporating mixed methods may lead to vague impressions rather than increasing robustness and rigor of the study. Oburst (1993) argues that many who triangulate fail to make explicit how validation was achieved.

Charmaz (2014, pg. 337) proposes four criteria by which to evaluate credibility and rigor in a constructivist grounded theory study: Credibility, Originality, Resonance and Usefulness. Credibility requires that the researcher acquires a depth of understanding of the research context through the consistent use of constructivist grounded theory techniques. This is demonstrated by the depth of observation, constant comparison of data, the testing of emerging categories and findings which are grounded in data. One question Charmaz (2104) asks the researcher "*Has your research provided enough evidence for your claims to allow the reader to form an independent assessment-and agree with your claims?*" (pg 337). The criteria of originality specifically focus on coding, concepts and theoretical framework. Charmaz (2014) asks "*How does the grounded theory challenge, extend or refine current ideas, concepts and practices?*

*"*(pg. 337). Resonance is concerned with the extent to which the researcher has uncovered and depicts the full nature of the experience. It offers the opportunity to check with participants if the data is meaningful and if the analysis provides greater insight into their world and lived experience. The final criterion usefulness is about how useful your findings will be to those who participated and do they provoke further research in your area of interest.

There are secondary criteria which can provide additional benchmarks of validity which may not be relevant to every study but provide flexibility and application (Whittemore et al 2001). These include explicitness, vividness, creativity, thoroughness, and congruence. Explicitness is similar to auditability and refers to the maintenance of explicit records and decisions made by the researcher in the process of undertaking a study. Vividness encompasses the presentation of rich data, thick descriptions that are vivid and artful. Creativity challenges traditional ways of thinking and demonstrates novel methodologies and ways of thinking whilst still remaining grounded in scientific rigor. Thoroughness refers to adequate sampling and data saturation that result in full exploration of the phenomena. Lastly congruence refers to the connectedness between the research question and the method, between the data collection and analysis, between current study and previous literature and between the findings and implications for the study. For this study it was important to demonstrate that rigor had been applied in order to enhance the trustworthiness and truthfulness of the study findings. Sandelowski (1993) argues that issues of validity in qualitative studies should not be linked to 'truth' or 'value' as they are for positivists but to 'trustworthiness' which becomes a matter of persuasion whereby the researcher is viewed as having made those practices visible and therefore auditable. Clearly this shift in thinking moves away from the researcher being the judge of quality to the consumer being the overall evaluator of a study. According to Rolfe (2006) a study is trustworthy if and only if the reader of the research report judges it to be so.

### 3.7.3 Demonstrating quality in this study

To ensure dependable and authentic findings I will make clear in my methods chapter the process of recruitment, sampling, data collection and data analysis using a constructivist grounded theory method. This information should permit others to see how my findings followed from recruitment of participants to analysis of the data. I have made clear the requirements which are needed for constant comparison and theoretical saturation in my findings chapter to ensure the reader of sufficient and rigorous iteration between data collection and data analysis so to avoid superficial inductive conclusions. I have clarified and recorded the detailed objectives of the research study (not just the aim) and how theoretical concepts were achieved and how these concepts emerged from the data. I explain in my findings chapter the process of theoretical saturation and discuss in detail how this affected data collection and data analysis.

Research journals provided an auditable trial along with observation notes and demographic data pertaining to participants recruited to this study. Writing a journal provided an excellent means in which to reflect on the research process, raise self-awareness and guard against my own implicit influences, biases and prejudices. To minimize these bias I have made explicit my assumptions and frameworks throughout this study. The writing of theoretical memo's provided a rationale and a platform to understand the developing constructs, ideas about codes and their relationships and developing theory. Having access to regular supervision gave an opportunity to discuss my emerging findings and to receive critical feedback. Regularly justifying emerging conclusions to colleagues, friends and experts in the specialism of cardiology provided a way of 'member checking' and to re-examine critically emerging themes. Lincoln and Guba (1985) consider member checks to be the most single most important provision that can bolster studies credibility. In the case of this study informants were offered a copy of their transcript to read

and verify. Further member checking included presenting findings and themes back to the cardiology business group, doctors, nurses and patient user groups.

To achieve auditability and dependability I define the procedures that were employed to collect data and to analyse the data in my methods chapter. The detailed analysis found in my findings chapter will provide evidence of how I arrived at my conclusions. To improve the internal consistency (internal validity) interview data from each participant was constantly compared for theoretical constructs which in turn informed the interview questions. Records of how these interview questions developed (see appendix 8) were kept along with the interview transcripts. Claims for generalisability and fit depend on identifying similarities of differences in the context in which the theory was applied (Rolfe 2006). This involved employing the constant comparison method to determine whether a substantive theory fits new data. The issue of transferability (external validity) is concerned with the extent to which the findings of one study can be applied to other situations (Merriam 2009). Within the positivist paradigm the concern often lies in demonstrating that the findings can be applied to a wider population. Since the findings of my study are specific to a particular population and environment (patients diagnosed with end stage heart failure) it would be difficult to generalise my findings to other situations and contexts. Stake (1998) argues that although each study may be unique it is also an example of a study within a broader group and as a result the prospect of transferability should not be dismissed. I concur with Stake (1998) that whilst my study is specific to a group of heart failure patients in a district general hospital in the north of England the findings which when compared to other similar studies could be transferable to a larger population. My intention is to provide sufficient contextual data about the fieldwork plus thick description of the phenomena under investigation to allow readers to have a good understanding of the study and to be able to confidently compare and critique my findings.

**3.7.4 Reflexive position and application to this study**

The term reflexivity is associated with qualitative research, the domain of which is the in depth exploration of research topics in terms of concepts, beliefs and motivations (Parahoo 2014). Charmaz (2014) describes reflexivity as being how the researcher's interests, positions, assumptions influenced his or her inquiry. A reflexive stance informs us how the researcher conducts his or her research, relates to the research participant's and represents them in the written reports. Neill (2006) put forward the argument that reflexivity/reflection is an important part of the data analysis in a grounded theory study as long as it does not become a distraction from the data. Reflection can be an important part of the comparative process.

The concept of reflexivity is widely discussed in the literature revealing a complexity of definitions over which there is little consensus. Often in the literature the words reflexive and reflection are used interchangeably without making clear the application and not attempting to discriminate between the two terms. Finlay (2002) recognises this lack of clarity and attempts to resolve it by placing the two concepts at opposites end of a continuum with reflection at one end concerned with 'thinking about' and reflexivity at the other end concerned with as she puts it 'more immediate' continuing dynamic and subjective self-awareness'. Boud (1985) defines reflection in the context of learning as: a generic term of those intellectual and affective activities in which individuals engage to explore experiences in order to lead new understandings and appreciations. Lincoln and Guba (2005) describe reflexivity as a process of recognising constructs that implicitly and explicitly influence the research process. Finlay and Gough (2003) identify five variants of reflexivity: introspection, intersubjective reflection, mutual collaboration, social critique and discursive deconstruction. Introspection is the process of formulating the research question and it is where the researcher begins to use their own reflecting, intuiting and experiences to engage with the topic and research question.

Intersubjective reflection requires the researcher to begin to explore the mutual meanings emerging within the research relationship. Mutual collaboration seeks ways in which to co-opt participants as co-researchers and vice versa. Social critique offers the opportunity for the researcher to reflect on power imbalances or social tensions between the researcher and the participant. Lastly, discursive deconstruction is about the meaning of language and how it's used and how this impacts on modes of presentations. Finlay (2002) believes these five variants of reflexivity can help the researcher navigate their way through the swamp of reflexivity and credibility depending on the researcher's aims and objectives.

Being reflexive in the research process is therefore to acknowledge that 'we are always on the corner somewhere' (Richardson 1992, p.104). The process of reflexivity identifies and acknowledges the limitations of research. McDermott and Varenne (2010) believe that reflexivity makes us question assumptions inherent in the research process research topic, concepts and theories which may be constructed through power and privilege. Questioning these assumptions has made it necessary to question my own philosophy, traditions and beliefs and how I position myself within this study.  This involved questioning preconceived categorization of what is being researched, those being researched and how the research was being done. My background as a critical care nurse was considered and how my knowledge experiences and professionalism may in some way shape or distort my interactions with the healthcare professionals and patients in this study. These concerns and preconceptions were managed by keeping a research journal and having extensive and open dialogue with supervisors, friend's colleagues and peers. Engward et al (2015) believes that these are important considerations in all qualitative research including grounded theory as it makes the researcher question how knowledge and understandings are situated within epistemological frameworks. When considering grounded theory studies theoretical sensitivity can emphasise the reflexive use of self particularly in the process of developing research question and doing analysis (Callery and

Hall 2001). Reflexivity which is directed at the interview and participant observation process can supplement theoretical sensitivity because assumptions which may be taken for granted by the researcher and the participants can influence data collection. Silverman (1998) suggests the detailed audio tapes of interviews provide a method for demonstrating reliability in qualitative research.  In this study all participants' interviews were recorded and transcribed verbatim for detailed description and accuracy.  This enabled the checking of the written transcript alongside the audio recordings to enhance the auditability of the analysis and provide a way for me to check and re check the dialogues in the context of each interview.

To enhance dependability (reflexivity) and keeping with the paradigm of this study and the philosophical premise in which it was undertaken I have written this study in the first person. To write in an objectivist stance or 'third person' would seem awkward. Sandelowski (1986) believes that the typical language of a quantitative report is the neutral passive voice which is intended to convey distance between the researcher and the participant. Clearly this style of writing would be inappropriate for a constructivist grounded theory study where the relationship and partnership with participants is both equal and reciprocal. Webb (1992, p 750) iterates these sentiments by stating that;

*"it is not only acceptable but indeed for writing about qualitative research to use an active first person form or language. To do is inconsistent with the epistemology of the approach and constitutes some form of mystification in which the social elements of the research encounter are hidden from scrutiny, preventing readers from evaluating the adequacy of the research"*.

With this in mind I will continue to write in the first person in order to make clear my role and/ or position in this study and the role of the participants. What is important to me is that the voice of the participants is heard and is not overshadowed by my views and opinions; clearly the data collected should be a true and accurate reflection of their experiences.

**3.8 Conclusion**

The writing of this chapter has given me an opportunity to explicitly state my research focus and questions and my rationale for choosing grounded theory method. I argue why it is an appropriate method when exploring decision making by healthcare professionals managing the care of heart failure patient's at the end of life. This chapter began with a comprehensive discussion on symbolic interactionism (the theoretical framework underpinning this study) and its importance in framing my study. I clearly outline the different schools of grounded theory and give a rationale as to why constructivist paradigm was the most appropriate to address my research questions. In the following chapter, a full description of the research methods will be given beginning with an overview of the setting, demographics of the participants, how participants were recruited, the sampling process, data collection and data analysis.

# Chapter 4 The Research Method

## 4.1 Introduction

Using a grounded theory method is appropriate when little is known about the area of study, the generation of theory with explanatory power is an outcome and there is an inherent process imbedded in the research situation that is likely to be explicated by grounded theory methods (Birks and Mills 2003, Charmaz 2014). The aim of this study was to explore the decision making process that healthcare professionals use when making decisions about end of life care for patients diagnosed with end stage heart failure. There is very little empirical evidence to support how decisions are made particularly during the transition from acute medical care into palliative care (Gott et al 2011, Allen et al 2012). Evidence suggests that poor decision making can result in the patient experiencing a 'bad death' (Watts 2012). Using constructivist grounded theory, I wanted to explore this phenomenon in more depth and construct a theory which would have meaning and relevance to my participants. Grounded theory as a specific methodology guides the researcher in moving from systematically collecting data to producing a conceptual theory (Charmaz 2014).

The purpose of this chapter is to provide a detailed account of how this constructivist grounded theory study proceeded and the methods employed. To set the scene I begin with a brief overview of the research setting and participant demographics. A detailed account of how participants were recruited and the process of sampling will be discussed. The process of data collection will be discussed. A full account of how university and National Research Ethic Service North West (NRESNW) are given along with the process of informed consent.

## 4.2 Research setting

This study was undertaken in a District General Hospital in the North West of England. The hospital has 524 beds and provides general surgical, general medical, paediatric, maternity

and outpatient services. The hospital currently serves a population of 250,000 of which 91.4% born in England, 0.9% Pakistan, 0.9% Bangladesh, 0.7% India, 0.9% Scotland, 0.6% Ireland, 0.4% Wales, 0.3%Northern Ireland, 0.2% Kenya, 0.2% China (Census 2011). Top occupations of residents range from skilled labour, administrative work and leisure work. The socio-economic factors are generally poor and the area is regarded in top 10% national deprived area's in the country. Circulatory diseases including heat disease are the most common cause of early death and rates are 55% higher than the national average. Indicators of morbidity and deprivation are reflected in the high attendance to the Emergency Department.

**4.3 Gaining Access**

Mander (1992) and Cormack (1980) highlighted the importance of identifying local managers or gatekeepers who have the experience and expertise to both recognise a research proposal value and suggest the appropriate route by which to seek access to participants. The Trust Director of Nursing gave permission to access the site and provided initial clinical contacts. Hoyland et al (2015) recommends developing partnerships ideally with those who share an interest in your study and understand its value. Initial contact was made with the Trust Heart Failure Nurse. His expertise, knowledge and insider status within the organisation proved invaluable and was pivotal in assisting gaining access to my participants. The Head of Nursing and the Clinical Director were powerful allies and had significant influence over their respective professional groups. This helped in influencing both the doctors and nurses and gave me the opportunity to attend clinical meetings, ward meetings and ward rounds. Casell (1988) acknowledges the difficulties in gaining access and labels these physical access and social access. The physical access to the Trust had already been granted by National Research Ethics Service North West (NRESNW), Trust Director of Nursing and Research and Development Manager (R&D). The social access required seeking out those healthcare professionals who

would champion my study and assist in gaining access to participants. The Trust at the time was in Care Quality Commission (CQC) 'special measures' and so outsiders like me were viewed initially with suspicion. Overcoming these challenges required adopting a number of different strategies which included; being visible around the wards, spending time working shifts alongside the nurses and offering to facilitate any teaching sessions on the wards. This Corra and Willer (2002) refer to as paying back some sort of fee to the participants. By adopting these strategies, it helped to break down barriers, develop trusting relationships and be seen one of the team.

## 4.4 Recruitment of Participants

A total of 47 participants (n=47) were recruited to this study over a one-year period commencing in January 2014. Recruitment adhered to the original research proposal which was approved by the university and National Research Ethics Service North West (NRESNW) (appendix 5 and 6). A grounded theory study in the beginning does not require a limit on the number of participants to recruit. Data is collected until it is saying nothing more about the concepts being explored (Cutcliffe 2000). However, to fulfil the requirements of the ethics committees an arbitrary number of 60 (n=60) participants was given. Initially recruitment of patients began on the cardiology ward but it was clear after undertaking four interviews with healthcare professionals that patients were admitted to any ward across the directorate of acute medicine. Often beds were allocated on a daily basis by the bed manager and ward location depended on bed availability on that day. Hence, to recruit patients it was decided that regular checks would need to be made daily of the Electronic Medical Records System (EMR) along with twice weekly reviews of the Echocardiograms. The recruitment of registered nurses (n=16) included a number of various grades; staff nurse (n=5), ward manager (n=2), ward sister (n=1), specialist nurse (n=5) and trainee advance practitioner (n=3). Similarly, the doctors (n=15) recruited held different grades and had expertise across different medical specialisations; FY1 (Foundation

year 1) (n=1), FY2 (senior house officer, year 2) (n=2), specialist registrar (years 1-6) (n=7) and

consultant (generally qualified over 9 years) (n=5). A total of 16 patients were recruited to this

study (n=16); there were 12 males (n=12) with a mean age of 71 years and 4 females (n=4) with

a mean average age of 73 years. There was one palliative care consultant recruited to this study

who was based in the local hospice and who provided two sessions per week for the Trust.  It is

important to mention here, that at the time of this study the Trust did not have a Transform Team

to deliver the strategic vision recommended in NHS England 'Transforming end of life care in

acute hospitals; The route to success how to guide' (NHS England 2015).  A structure of the

palliative care team is presented below in figure 2.

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                        ┌─────────────────────────────┐
                        │  Palliative Care Consultant  │
                        │  2 Sessions per week=8 hrs per│
                        │            week              │
                        │    Based in Local Hospice    │
                        └─────────────────────────────┘
```

| Specialist Palliative Care Nurse | Specialist Palliative Care Nurse | Specialist Palliative Care Nurse | End of Life Co-ordinator |
|---|---|---|---|
| 37.5 hrs per week | 37.5 hrs per week | 37.5 hrs per week | 37.5 hrs per week |
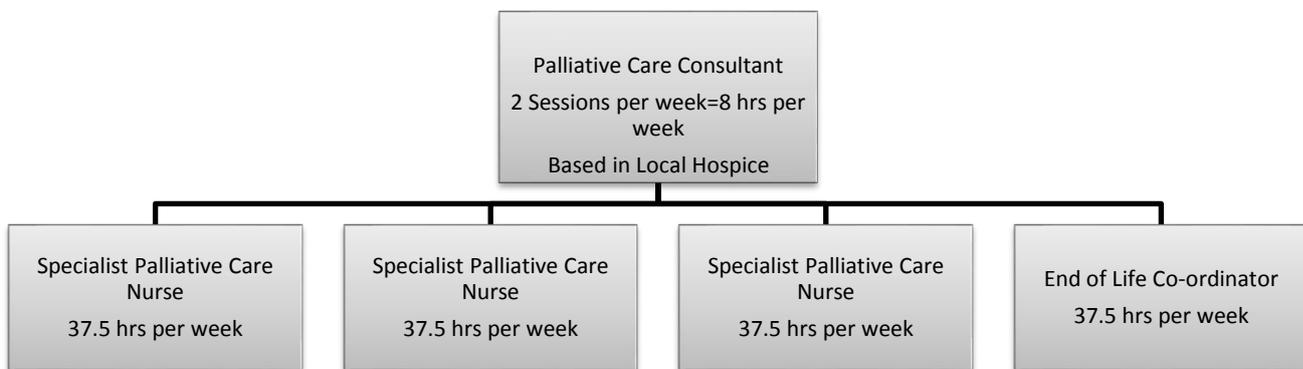
Figure 2 Palliative Care Team Structure

The tables below give information on the profiles of the participants recruited to this study; names of the participants are pseudonyms to protect their identity.

Table 3 Profile of the Nurses

| No's | Name | Grade of Nurse | Gender | Clinical Area |
|------|------|----------------|--------|---------------|
| 1 | Ella | Staff Nurse | Female | Care of Elderly |
| 2 | Joanne | Staff Nurse | Female | Acute Medicine |
| 3 | Danielle | Staff Nurse | Female | Acute Medicine (Respiratory Ward) |
| 4 | Bob | Staff Nurse | Male | Acute Medicine (Respiratory Ward) |
| 5 | Jade | Staff Nurse | Female | Acute Medicine |
| 6 | Liz | Ward Sister | Female | Cardiology Ward |
| 7 | Debbie | Ward Manager | Female | Acute Medicine |
| 8 | Anne | Ward Manager | Female | Medical Assessment Unit |
| 9 | Pauline | End of Life Co-ordinator | Female | Corporate Nursing |
| 10 | Sarah | End of Life Specialist Nurse | Female | Medicine Business Group |
| 11 | Jane | Cardiology Specialist Nurse | Female | Cardiology |
| 12 | Steve | Heart Failure Specialist Nurse | Male | Cardiology |
| 13 | Rebecca | Palliative Care Nurse | Female | Medicine Business Group |
| 14 | Jenny | Trainee Advance Practitioner | Female | Medicine Business Group |
| 15 | Kelly | Trainee Advance Practitioner | Female | Medicine Business Group |
| 16 | Mary | Trainee Advance Practitioner | Female | Medicine Business Group |

Table 4 Profile of the Doctors

| No's | Names | Grade of Doctor | Gender | Clinical Specialism |
|------|-------|-----------------|--------|---------------------|
| 1 | Shabib | FY1 (Foundation Year 1) | Male | Medicine (Cardiology) |
| 2 | Fiona | ST2 (Speciality Trainee) | Female | Medicine (Care of Elderly) |
| 3 | Tim | ST2 (Speciality Trainee) | Male | Medicine (Care of Elderly) |
| 4 | Liam | stR 1 (Specialist Registrar year 1) | Male | Medicine (Cardiology) |
| 5 | Andrew | stR 1 (Specialist Registrar year 1) | Male | Medicine (Cardiology) |
| 6 | Steve | stR1 (Specialist Registrar year 1) | Male | Medicine (Care of Elderly) |
| 7 | John | stR2 (Specialist Registrar year 2) | Male | Medicine (Care of Elderly) |
| 8 | Paul | stR2 (Specialist Registrar year 2) | Male | Medicine (Care of Elderly) |
| 9 | David | stR2 (Specialist Registrar year 2) | Male | Medicine (Care of Elderly) |
| 10 | Amina | stR2 (Specialist Registrar year 2) | Female | Medicine (Cardiology) |
| 11 | Ahmed | Consultant | Male | Medicine (Cardiology) |
| 12 | Geoff | Consultant | Male | Emergency Medicine |
| 13 | Simon | Consultant | Male | Palliative Care |
| 14 | Siddiqui | Consultant | Male | Medicine (Care of Elderly) |
| 15 | Patel | Consultant | Male | Medicine (Care of Elderly) |

Table 5 Profile of Heart Failure Patients

| Name | Gender | Age | Ethnicity | Diagnosis | Ejection Fraction | NYHA | Diabetic | Co-Morbidity |
|------|--------|-----|-----------|-----------|-------------------|------|----------|--------------|
| Barry | Male | 63 | White | LVF | <20% | | NIDDM | |
| Graham | Male | 71 | White | NSTEMI LVF | <35% | | | Pulmonary Oedema |
| Maggie | Female | 92 | White | AF | <35% | | | |
| Fred | Male | 84 | White | MI | <35% | | NIDDM | |
| Patrick | Male | 70 | White | LVSD | <35% | | NIDDM | |
| Eric | Male | 70 | White | NSTEMI | | | NIDDM | |
| Paul | Male | 64 | White | NSTEMI | <30% | | IDDM | COPD |
| Frank | Male | 75 | White | LVSD | <30% | | IDDM | CCF |
| Pauline | Female | 68 | White | CCF/HF | <35% | | | |
| Heather | Female | 50 | White | CABG | <35% | NYHA 3 | | Pericardial effusion post-surgery |
| Allan | Male | 74 | White | CCF/HF | <20% | NYHA 4 | | DNAR CCF |
| Peter | Male | 78 | White | CCF | <27% | | IDDM | Aortic Valve replacement |
| Brian | Male | 63 | White | HF/AF | <20% | | NIDDM | COPD |
| Flo | Female | 85 | White | HF/AF NSTEMI | 35-40% | | | IHD |
| Jo | Male | 78 | White | HF/Atrial Flutter | <14% | NYHA 4 | | IHD, COPD Liver Disease Anaemia |
| Tony | Male | 65 | White | NSTEMI/ LVSD | <18% | NYHA 3 | | COPD |
| | **Abreviations**<br>1 NIDDM -Non-Insulin Dépendent Diabètes Mellites<br>2 IDDM –Insulin Dépendent Diabètes Mellites<br>3 LVF-Left Ventricular Failure<br>4 MI-Myocardial Infarction<br>5 NSTEMI – non ST Elevation Myocardial Infarction<br>6 LVSD –Left Ventricular Systolic Dysfunction<br>7 CABG- Coronary Artery Bypass Graft<br>8 AF-Atrial Fibrillation<br>9 NYHA-New York Heart Association functional class<br>10 CCF-Congestive Cardiac Failure<br>11 IHD –Ischaemic Heart Disease<br>12 COPD-Chronic Obstructive Pulmonary Disease<br>13 TB-Tuberculosis<br>14 LVD-Left Ventricular Dysfunction<br>15 DNAR- Do Not Attempt Resuscitation order | | | | | | | |

**4.5 Sampling Strategy**

Grounded theory uses non-probability sampling where the sample numbers and data sources are unknown at the commencement of a study (Glaser and Strauss 1967, Strauss and Corbin 2008). In order for concepts and categories to emerge during the data analysis, the need for sampling of specific data sources continues, the sampling moves from purposeful to theoretical sampling as categories begin to emerge. (Cutcliffe 2000). Glaser (1978) acknowledges that in the initial stages of a study, researchers will go to groups which they will believe will maximise the possibilities of obtaining data and leads for more data on their question. They will also begin by talking to the most knowledgeable people in order to source and track down more data (Glaser 1978). In this study purposeful sampling began initially on the cardiology ward. It was important to gather rich textual narratives which would illuminate the experiences of the participants and would provide initial codes to inform data gathering. The following sections will describe my sampling strategy.

**4.5.1 Inclusion criteria**

The inclusion criteria into the study were as follows:

- Patients diagnosed with heart failure with New York Heart Association Functional (NYHA) Classification Grade 3 or 4

- Ejection Fraction $\leq 35$

- Male and female patients over the age of 21 years

- Registered General Nurses working in acute medical wards

- Consultant Physicians and Consultant Physicians with sub-speciality in heart failure

**4.5.2 The exclusion criteria:**

The exclusion for this study was as follows:

- No patients who are awaiting heart transplantation or on a transplant list

To identify if a patient met the inclusion criteria the medical notes were checked for the NYHA functionality score and ejection fraction. The NYHA score was not always recorded in the medical notes; healthcare professionals were found to not always be familiar with the score. A more reliable way of checking was to review the patient's echocardiogram results. The echocardiogram provided reliable clinical information, like the patients ejection fraction, which would indicate if the patient was a stage 3 or stage 4 heart failure.[5] The ejection fraction (EF) is considered an important measurement in determining how well your heart is pumping out blood, in diagnosing heart failure and monitoring deterioration (Sutherland 2010). A significant proportion of patients with heart failure can have a normal ventricular ejection fraction at echocardiography. Previously called diastolic heart failure, it is now referred to as heart failure with normal ejection fraction (HFNEF) or HF with preserved ejection fraction.

**Preserved ejection fraction (HFpEF)** – also referred to as diastolic heart failure. The heart muscle contracts normally but the ventricles do not relax as they should during ventricular filling (or when the ventricles relax).

**Reduced ejection fraction (HFrEF)** – also referred to as systolic heart failure. The heart muscle does not contract effectively and less oxygen-rich blood is pumped out to the body

**Mid-Range Ejection Fraction (HFmrEF)-**also referred to as diastolic heart failure. A new category to include patients whose left ventricular ejection fraction is in the range 40-49%.

The patients who were identified as meeting the inclusion criteria were given an information sheet by the heart failure nurse or the ward manager. This met with the ethics committee request of having a clearly identified 'gatekeeper' who would make the initial contact with the patient.

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[5] Echocardiogram is a non-invasive technique in which ultrasound beam is transmitted via a transducer placed on the chest wall. It allows real time images of the heart and provides immediate diagnostic information about cardiac structure and function (Hinds and Watson 2008).

Because of the sensitive nature of the discussion the ethics committee had requested words like 'end of life' or 'end of life care' be removed from the information sheet. This was done to avoid causing unnecessary anxiety or distress to the patient. The nursing staff would inform me if the patients were happy to participate in the study. In total three patients refused to participate in the study; there were no reasons given.

To engage the healthcare professionals posters were initially distributed across all acute medical wards and clinical departments. The posters included information about the study and had both mine and my supervisors contact details should anyone have any questions. A few ward managers and consultant colleagues were difficult to contact so information was emailed to them by request. The hospital at the time had undergone some major restructure of nurse leadership following a poor Care Quality Commission report (CQC). This intense scrutiny by the CQC had led to some healthcare professionals initially being suspicious of outsiders and as a consequence reluctant to engage with the study. To try and break down these barriers and reduce anxieties I decided to undertake a number of clinical shifts on the cardiology ward. This provided an opportunity to get to know the team and to familiarise myself with the daily routine of the ward. A period of one month was spent working alongside nursing colleagues, mainly during the weekends, where I would assist in delivering basic nursing duties. This method of engagement was eventually extended to all wards and included providing some teaching sessions for the nurses. It was during this time an invite was extended by Dr Ahmed one of the consultant cardiologists to join his ward rounds. The rounds happened three times a week and allowed me time to get to know the medical teams and conversely for them to begin to trust me. This initial investment of my time was crucial in breaking down barriers, getting people on side with my research and developing trusting relationships with the healthcare professionals. Charmaz (2014) considers these types of reciprocities to be important if wanting to establish

ongoing relationships; to ignore such reciprocities weakens the chance of obtaining telling data and can potentially dehumanise the research participant.

## 4.6 Theoretical sampling

Theoretical sampling is the process of data collection directed by evolving theory rather than by predetermined population dimensions (Strauss, 1987). This method of sampling enables the researcher to seek people, events and information to illuminate and define the properties, boundaries and relevance of a category or set of categories. To begin purposeful sampling was used to gather data from the participants; initially on the cardiology ward. The interview questions were open ended to allow participants to define their own experiences of end stage heart failure. So for example the healthcare professionals questions would be "*Can you tell me what you consider the challenges to be managing the care of patients with end stage heart failure*? For the patients a similar open ended question would be used like" *Can you tell me about your heart failure condition?*" Using these types of open ended questions would relax the participants and encourage them to talk about was important or central to their experiences. Once the interviews progressed questions like "*What may prevent you having end of life discussions with the patient*"? Or for the patient "*What do you understand about the term heart failure*?" was added. In most cases asking open ended questions yielded very rich textual data which was initially coded line by line. After transcribing four interviews themes began to emerge from my data which were to further direct my questioning and sampling. For example themes like '*giving information', seeking information', 'confident knower 'and 'giving hope'* emerged early on when initially coding participants' transcripts. The healthcare professionals found '*giving information'* to patients about end of life care challenging because they did not want the patient to '*give up hope'*. The patient on the other hand would try and '*seek information'* in order to make an informed decisions about their end of life care. To explore these themes questions were added; for the health care professionals the question would include

*"How would you approach end of life conversations with the patient and what dictates the information given?* And for the patient *"Do you feel you have had sufficient information to make an informed decision about your heart failure care"*? The writing of memos and constantly comparing data identified gaps and this further directed my questions and sampling.

As the research progressed and the theory developed interview questions became more focussed, building on the analysis of previous interviews. The sampling moved from purposive to theoretical once focussed coding of the transcripts was complete and categories began to emerge from the data. Glaser and Strauss (1967) were clear that selecting additional groups to develop theory is based on theoretical relevance in the development of emerging categories. For example, after ten interviews it became clear that end of life decision making was influenced by the healthcare professionals ability in *'giving information'.* In subsequent interviews and to explore this focussed code theoretical sampling was undertaken with healthcare professionals working across care of elderly wards, medical assessment unit and palliative care. What became clear was the issue of working outside your 'professional comfort zone' and how this impacted on *'giving information'.* The following table will give you some indication of how these questions evolved from ongoing data analysis and how this led to the theoretical category *'Being informed'.*

| Example | Commentary |
|---|---|
| *Interviewer: Do you find patients ask you for information or do you think that the doctor or nurses readily make available information about the end stage of heart failure?* <br><br> *Cardiology Ward* <br> *Ward Sister: I think it is divided with the younger ones sometimes with the internet they tend to believe what they read on the internet. They* <u>*come to us like mini doctors*</u> *and they will tell you what is wrong with them and what tablets they should be on because that's* <u>*what google tells them. They should be on so*</u> | *Interview 9* <br><br> *This ward sister talks about her interaction with the patient and how the 'internet' has provided a way of providing information about heart failure. There is a feeling of antagonism here "they come to us like mini doctors". The interviewer wanted to explore what information was given to the patient and if there were any barriers. There is an indication that giving information to patients who are 'ignorant' of their condition is easier than those who have searched the* |

| | |
|---|---|
| *I find them more difficult than those patients who are ignorant about the condition or don't want to...yes I know it heart failure and all they say is "it's going to kill me" and they don't want to know. <u>I find the ones that internet search are the most difficult ones.</u> The ones who don't want to know but once you have sort of brought that out it is <u>something that you can control</u>. It is something we can manage they are actually interested to listen to what you have to say. It's a mixed divide really*<br><br>*Interviewer: That's interesting. I was talking to one patient the other day and picking up on the issue of fear of dying she said "I didn't want to say anything or ask the question am I going to die".*<br>*Do you think patients hold back?*<br><br>*Ward Sister Yes i think it is a fear because they don't understand it properly. There is part of them that doesn't want to understand it because <u>the minute they start to understand it almost becomes real.</u> Their future is all planned and that's going to happen it is the fear because you know "oh heart attack it kills you". If I have a heart condition it's going to kill me. So I suppose it like people with cancer <u>some people don't want to know because if they don't know it's not happening....it's the ostrich affect putting your head in the sand.</u>* | *information on 'google' There is recognition that giving information may cause anxiety and fear for the patient. '<u>Controlling information</u> seems to be an important factor in how much and what information is given to the patient.* |
| *Interviewer: How much information do you think patients want to be given about their heart failure condition?*<br><br>*Medical Ward-Respiratory*<br><br>*Ward Manager: I think a lot of patients want to know about their condition. I think a lot of it is lack of communication. I know as a senior nurse… and again it can be <u>language barrier</u> between the nurse and the patient as we are multicultural and some of the nurses don't understand.    So    I    think    lack    of* | *Interview 11*<br><br>*To obtain comparative data the interviewer explored with a ward manager her experiences 'giving information'. In terms if interview 9 this interview was about understanding the idea of controlling information. From this interview it was clear that patients wanted information but there were barriers like language, finding the right time'. Information was given in a way that was often difficult for patients to understand or wasn't explained fully.* |

| | |
|---|---|
| *communication…..because I have been on a ward where I have had relatives and patients or they tend to do it when you are doing your medicines. I know this is a time when we should not be disturbed…. But this is when they are <u>coming forward</u> and they are saying nurse can you tell me what's actually happening….They don't know because no one has told them… the doctors have spoken at the end of the bed <u>they have not explained to the patient. I think we should be explaining a lot more</u> to the patients than what we are doing.* | |
| *Interviewer: Do you think patients are better informed?*<br><br>*Cardiology Doctor: I think the younger generation they usually ask questions and they <u>go to google to look up the condition</u>. The older generation have the old mentality…. They <u>believe that the doctors know best and are in the doctor's hands</u>….. And again it is difficult because you <u>don't want to upset the patient</u> that much…maybe I am too emotional…*<br>*But usually when I tell the patient about the results I tell them step by step and then I <u>tell them what they need for that moment</u> and leave it for the next time….really it's a problem to be honest <u>we should tell them everything at that time but we just don't want to upset them</u> all in one go and then go you're going to die…….* | *Interview 15*<br><br>*In this interview the doctor discussed the challenges of 'giving information' and why often information is withheld to avoid the patient becoming upset. There was an overall realisation that being honest and telling was the right thing to do. Again comparative data was collected to explore 'being honest' 'avoiding upset' and how this may affect the relationship between the nurse, doctor and patient over time.* |

Figure 3 Examples of evolving interview questions relating to the theoretical category 'Being Informed'.

The following section presents how ethical approval was sought and how participants were informed and consented for this study.

## 4.7 Ethical Considerations

Conceptually, the ethical considerations of both quantitative and qualitative research are the same; safety and protection of human rights. There are three main ethical principles which have to be adhered to these include; the right to fair treatment, the right to protection from discomfort

and harm and the right to autonomy and confidentiality (Burns et al 2001). The Research Governance Framework for Health and Social Care (D.o.H 2005) requires that all research involving human subjects, patient data, National Health Service (NHS) staff or facilities adheres to explicit set of principles and guidelines. The framework requires that projects not only meet with ethical approval, but that studies demonstrate rigor, in terms of their appropriateness; choice of methodology and the capacity and skills of the researcher. The proposal for this constructivist grounded theory study was submitted to the University Research, Innovation and Academic Engagement Approval panel along with National Research Ethics Service North West. This study was given NRESNW approval on 16[th] August 2013 and University approval on 28th October 2013. Access was granted to the NHS Trust by Trust Research and Development (R&D) Director from 30th November 2013 to 30[th] November 2014. The study began in January 2014. Conditions to this approval included removing the word 'end of life' from the patient documentation to avoid distress to patients; it was agreed the first approach to the patient would be a ward nurse. The issue of death, dying and terminal illness is a sensitive topic and therefore the committee requested that measures were put in place to verify the patient's awareness of their terminal condition. To fulfil this request medical note were checked and the doctors consulted on the level of patient awareness before interviewing the patient. To manage any distress appropriately the nurses and palliative care team agreed to provide counselling for the patient if they became distressed during or after the interview. A written progress report was submitted to NRESNW 3[rd] August 2015.

### 4.7.1 Informed consent

An information letter was given to each participant (appendix 1 and 2) prior to consent giving a brief introduction to the study and details of what participating would involve. Each participant was told that an interview would last approximately 45 minutes and that the interview would be recorded. The participants were informed that the interview data would be coded to protect

anonymity and confidentiality. Assurance was given that taking part in the study was voluntary and that they could withdraw at any time without having to give a reason. It is important in any research study that the participants are able to give voluntary consent; this means without coercion (D.o.H 2005). Participants need to be given time to discuss the research with family and friends, read through the information and be able to clarify any questions with the researcher before consenting to take part in the study (Booth 2002). In this study the heart failure nurse and ward manager were the identified 'gatekeepers' and it was agreed they would make the first initial contact with the patient. The information sheet would be given to the patient during clinical review or daily care and would be left for the patient to read and discuss with their families. This process worked well allowing the patient to make a voluntary decision. On the day of the interview a check phone call was made to the ward in case the patient had changed their mind. The complex disease trajectory often meant patients were not well on the day of the interview; symptoms could rapidly change depending on changes to medications. These interviews were postponed and alternative dates if appropriate would be given by the ward manager or heart failure nurse.

Consent for this study was not sought from participants until 24 hours had elapsed. Permission was gained from the ward manager to approach the patient for consent. The consent form came in two parts (appendix 3 and 4). The first part gave details of the participant's name, date of birth and hospital number. The second part of the form required the participant to read and sign to indicate that they understood the purpose of the research and that they were fully informed. These forms were then collected by the researcher and stored in a locked box in a filing cabinet. The participants were informed that if they wish to have a summary of the interview this would be made available on completion of the study. Only two participants requested copies of their

transcripts; one doctor and one nurse. As previously mentioned 3 patients refused to participate in this study.

**4.7.2 Confidentiality**

The Data Protection Act 2018 applies in Scotland, England, Wales and Northern Ireland. It regulates the processing of information relating to individuals, including the obtaining, holding, use or disclosure of such information. The Act gives individuals rights of access in relation to personal data which is about them – which means that participants' can ask for copies of personal data collected by a researcher. It requires that anyone who processes personal data must comply with eight principles, which make sure that personal data are: fairly and lawfully processed, processed for limited purposes, adequate and relevant, accurate and up to date, not kept for longer than is necessary, processed in line with individual rights, kept secure and not transferred to other countries without adequate protection.

Johnson and Long (2007) suggest that details about participants should be anonymised at the first opportunity. Each participant recruited to this study was allocated their own unique identification number which was only known to me. All typed transcripts were saved in word on my computer which was password protected. I was privy to 'insider information' which gave a good insight into the culture and politics of the organisation. However, this information was recorded as field notes and was not used as data due to the sensitive nature of its content. During the course of this study it was necessary to have access to patient identifiable data for example medical notes, ward handover sheets and nursing care plans. Access to these documents was kept to a minimum and only availed when required for the purpose of my research. Professionally, being a registered general nurse I am bound by a professional code of conduct; Nursing and Midwifery Council Code of Conduct (NMC 2015). The code is very clear about respecting individuals privacy and confidentiality; clause 5 of the code states;

5 Respect people's right to privacy;

"*As a nurse or midwife, you owe a duty of confidentiality to all those who are receiving care. This includes making sure that they are informed about their care and that information about them is shared appropriately*"

I have a responsibility and a duty of care to report any aspects of patient care which may be perceived to be harmful or neglectful. The NMC code states (NMC 2015)

16.1 "*raise and if necessary escalate any concerns you may have about patient or public safety, or the level of care people are receiving in your workplace or any other healthcare setting and use the channels available to you in line with our guidance and your local working practices*".

Johnson and Long (2007) concur that if researchers do become aware of information or if peoples safety or vulnerability is in question then you as a researcher have a duty to report the matter to a senior colleague. I was fully aware that should I have had concerns then professionally I was obliged to report these concerns to senior nurses, managers and my supervisors.

## 4.8 Data Collection Methods

All is data according to Glaser (Glaser 2002). However, data can vary in quality, relevance for emerging interests and usefulness for interpretation (Charmaz 2014). Prior to collecting my data thought was given to the types of methods at my disposal and what method would yield the information required to answer my research questions. Charmaz (2014) believes mechanistic application of methods can yield mundane data which may only result in producing routine reports. Therefore, choice of method, its practicality and application were important to achieving this study aims and objectives.

### 4.8.1 Semi structured Interviews

The decision to use semi structured interviews in this study was based on the need to explore and understand from the participant perspective the phenomena under investigation. The 'semi structured interview' has been long used as a data gathering tool in qualitative research (Wimpenny et al 2000). With semi structured interviewing the researcher gives the interview its initial direction but then the semi-structural emergent nature of the interview can shift control to the participant (Corbin and Morse 2003). Charmaz (2014) likens semi-structured interviewing to 'intensive interviewing' in constructivist grounded theory where a gently guided one-sided conversation takes place that explores a person's substantial experience with the research topic. Charmaz (2014) believes that intensive interviews open up interactional space in which the participant can relate his or her experience. The key characteristics of intensive interviewing are as follows:

1.  Selection of participants who have first-hand knowledge that fits the research topic

2.  In-depth exploration of participants experiences and situations

3.  Reliance on open ended questions

4.  Objective of obtaining detailed responses

5.  Emphasis on understanding the participants perspective, meaning and experience

6.  Practice on following up hunches, hints, implicit views and actions

Undertaking the semi-structured interviews involved, on a weekly basis, organising and negotiating an interview schedule with healthcare professionals across eight acute medical wards. Telephone calls were made at the beginning of each week to the wards where the patient had been identified by the heart failure nurse. This was an important step in the process of organising the interview as the unpredictable nature of heart failure meant that patients health

status could change rapidly over a 24-hour period. To schedule interviews with the healthcare professional required a little more planning due to the business and unpredictable nature of acute medicine. Often an interview was planned only to be cancelled on the day due to demands of a busy clinic or ward. To capture the detail of what was spoken by the participants it was decided to record each interview. This involved using my i-Phone which was discreet enough not to cause participants concern and the quality of the recording good enough to capture what was said above the ward noise. Consent was sought prior to commencing the interview from the participants to use my i-phone; there were no objections raised.

The interviews involved face to face conversation with the participants, were exploratory in nature and were guided by open-ended questions about different aspects of decision making. A total of 16 nurses (n=16), 15 doctors (n=11) and 16 patients (n=16) were interviewed over a 12-month period from January 2014 to December 2014. To facilitate the patient interview a quiet room was made available by the ward manager which provided privacy and space to discuss without interruptions their experiences. On occasion interviews had to take place at the bedside and this was dependent on the patient's condition on that day. The nurses were interviewed in a ward office so they were at hand if required to go back on duty. Arrangements were made to interview the specialist nurses in their respective offices. The doctors were interviewed either in their offices, on the ward or in the post graduate centre. A short introduction prior to the interview was used to explain the research goals, to answer questions and make participant's feel at ease. Before interviewing Charmaz (2014) encourages the researcher (particularly the novice researcher) to develop a script to avoid the awkward, poorly timed and intrusive questions. My script began with a few open-ended questions and as concepts emerged I would develop my questioning further sometimes departing from the script to probe and pursue interesting ideas (appendix 8). Often the script would grow as more questions were included and I became more analytical about the data. Charmaz (2014) advices to ask 'softer questions'

first to foster relationships with participants so for patients I would begin by asking '*Would you like to tell me a about your heart condition? Can you tell me what brought you into hospital?* These questions were particularly helpful in gauging the participant's understanding of their heart failure condition. The questions got the participant to talk and open up about their own individual story. Once the talking began I could then focus on questions that were more relevant to the study. A similar strategy was adopted for the healthcare professionals where I would begin the interview by asking '*Can you tell me what you perceive to be the challenges looking after patients with heart failure?* or *What is your understanding of end of life care?* Participants were given time and space to give account of their own personnel experience. The interviews varied in length from 20 minutes to 60 minutes (average time was 25 minutes).

I was aware that interviewing patients on a topic which could be described as 'sensitive' could illicit some powerful responses such as anger, sadness, remorse, fear and anxiety. With this in mind and in discussion with the ward managers it was decided that if a patient became distressed then the interview would stop and support sought from the nursing team. Dickson-Swift (et al 2007) believes one of the most important elements when undertaking in depth interviewing on a sensitive topic is to build a rapport with participants. In my study the process of building rapport started with recruitment. On some occasions a number of emails or conversations would be had with the healthcare professionals before an interview. I worked a number of shifts on the cardiology ward so healthcare professionals got to know and trust me. Often the patient was on the ward for a number of days prior to the interview which provided an opportunity to build a rapport and answer any questions before the interview. A concern of mine was to limit the power imbalance which can occur between the researcher and the participant. I wanted to generate meaningful data so it was important to develop a trusting relationship with participants based on the idea of shared mutuality and reciprocity. To navigate this problem the interview schedule was flexible to allow participants to choose a time and a location which suited them. The

interview script had open ended questions which allowed participants to assume that they had a degree of power over the direction of the interview. The use of 'small talk' about the weather, families, work, holidays and type of day created a more mutual and easy conversation. Using self-disclosure was a way to build relationships with participant's a sort of 'getting to know you' which did help to normalise the interview. Participants would ask questions like W*hat made you choose this topic to research?* Or *Why are you interested in heart failure*? Being honest and answering these questions helped to break down barriers, create a safe environment to talk and enhance the reciprocal nature of the interview.

### 4.8.2 Focus Groups

Kitzinger (1994) defines the focus group approach as 'group discussions organised to explore a specific set of issues'. According to McDaniel and Bach (1996) such discussion takes place in a social setting, moderated by a group leader, so as to generate descriptive or explanatory information. This explicit use of group interaction differentiates focus groups from other types of data generation interview (Vaughn et al 1996). Indeed, there is a belief amongst some that interaction between participants in a focus group may reveal information that would be difficult to obtain in an individual interview (Kingry 1990, Stewart 1990). Kitzinger (1996) suggests that a focus group can be used to examine what people think, how they think, why they think in a specific way and their understanding and priorities. This is consistent with fundamental qualitative research assumptions that advocate the insider's standpoint. The focus group can provide validation or refute emerging findings and so can lead to different patterns and specific themes. A focus group can be used when access to certain groups or populations is problematic (Lane et al 2001). In this study arranging individual interviews for some doctors was difficult due to time constraints and clinical commitments. Arranging a focus group provided a more flexible approach to accessing doctors and capturing meaningful data. Two focus group interviews were arranged. Purposive sampling was used to access a population of care of elderly

doctors and cardiologists across the specialism of medicine. A total of 12 doctors and 3 trainee advance practice nurses were recruited to two focus groups. Each group varied in size; focus group 1 (n=7), acute medicine, had 2 ST2 Specialist Trainee, 2 consultant physicians (care of elderly) and 3 specialist registrars. Focus group 2, cardiology included (n=8) 1 consultant, 2 stR year one registrars, 2 stR year two registrar and 3 trainee advance practitioners. According to Krueger and Casey (2014) groups comprising of six to eight members allow the researcher to engage in in depth enquiry regarding specific behaviours and perceptions. The setting for focus group 1 was the stroke unit teaching room. The setting for focus group 2 was the post graduate teaching centre. Roberts (1997) believes the success of a focus group is all in the planning. In this study I liaised with the post graduate secretary so dates could be planned and put into the respective diaries. I provided the healthcare professional information sheet along with a brief outline about the focus group and what it would involve. I had already at this point interviewed a number of nurses and doctors and so themes and categories had emerged which I wanted to probe. With this in mind I added questions to the interview script which reflected these emerging themes. Examples of these included: *Could you describe what you think a palliative care pathway would look like for heart failure patients? What would you consider to be the clinical indicators that would prompt you to place a patient on an end of life care pathway*?

Lane et al (2001) considers the moderator the person who sets the mood of the group by creating a non-threatening, warm, accepting, enthusiastic and objective environment which encourages all group members to share their views. In this study the focus groups were held over a lunchtime period and medical representative's kindly provided lunch. This created a welcoming environment and generated a more relaxed atmosphere. Facilitating both groups required good communication skills. There was one senior doctor in the cardiology group who proved to be quite domineering and insisted on monopolising the group time and questions. This gave little opportunity for more junior group members to share their experiences. Managing this member

of the group was difficult but careful re directing of questions allowed others to participate and share experiences of decision making. During the focus groups I tried to encourage debate, explore inconsistencies and clarify group responses. Throughout the duration of the meeting I took my own notes of my informal observations. I was aware that current monitoring of clinical standards by CQC may inhibit participants from sharing with me deep seated feelings and issues. I assured participants that what they discussed would be in confidence and that I would appreciate their honest response to my questions. All participants were told that the interview would be audiotaped. No one in the group objected. Participants were told that the findings would be reported back to Trust Board, clinical meetings, and ward meetings with a view to improving patient care. Each focus group lasted between 40 -60 minutes.

### 4.8.3 Field Notes

My field notes were written in a diary and were my own personnel informal observations, reflections, conversations, interactions, frustrations, challenges and successes. The field notes written on my informal observations were supplementary data and became helpful in understanding the experience of decision making from the participants perspective. Often notes would be written out of sight of participants to avoid disruption. I found writing immediately helped to capture ideas and events and this was usually done in a quite space away from the wards or in the comfort of my home. Occasionally I would use an audio tape but found this was not always as affective as writing down my thoughts on paper. I found that the writing of field notes complimented my interviews and gave some context and depth to the phenomena being explored. The field notes were helpful in capturing my immediate responses, the environment and participants' non-verbal behaviours. The writing of memos provided a way of advancing the analysis of the data and providing a platform to conceptualise. I will discuss memos in more detail and provide examples of how this was achieved in the following chapter, data analysis – practical application.

**4.9 Conclusion**

This chapter has provided an in-depth discussion on the research methods used in this study to address the research aims to construct a grounded theory. The research setting and demographic was provided to give background and relevance to the phenomena being explored. The process of ethics and informed consent were deliberated with relevance to the sensitive nature of the topic and how this was managed within the context of this study. The methods of recruitment, sampling and data collection have been discussed and some of the challenges. The following chapter will now describe in detail the process of data analysis and its practical application to this study.

# Chapter 5 Data Analysis

## 5.1 Introduction

Grounded theory is primarily a method of analysis which calls for each phase of inquiry to raise the analytic level of the data analysis (Bryant and Charmaz 2012, Urquart, 2013, Charmaz 2014). Developing theoretical categories is a central part of this analytic process. The process of coding, comparing, and saturating theoretical categories with data leads to an emerging theory (Bryant and Charmaz 2012, Charmaz 2014). During the process of analysing my data I was guided by Charmaz (2014) constructivist framework; initial coding, focused coding, axial coding and theoretical coding. Using this framework allowed me to move from initial coding of my transcripts to a more in depth conceptual analysis of my data. With a grounded theory study the researcher needs to immerse themselves in the data in a way that embeds the narrative of the participants in the final research outcome (Charmaz 2014). It was therefore important to stay close to my data throughout the process of my analysis to get a real sense of my participants' views and experiences. The following chapter aims to give a detailed account of my analytical process the challenges along the way and give some clear examples of how this was achieved.

## 5.2 Field Notes

Field notes if well written can show the actions, processes and events that constitute what is happening in the setting (Charmaz 2014). Field notes can also provide a rich source of data which can complement interview data and provide a unique insight into the world of the participant (Charmaz 2014). Capturing the non-verbal communication was an important part of my analysis along with what was said during the interviews. It was often the day to day interactions on the wards between the healthcare professionals and patient that would inform an emerging category or raise a question. The field notes provided a way of probing beneath the surface and digging into the scene. The field notes once written were coded and then the data

used to compare with my interview transcripts. This provided a way to verify participants' narratives with my own informal observations and to compare emerging themes. Below is an example of one of my field notes.

| Example of field notes | | Open Coding of field notes |
|---|---|---|
| Thursday May 1st 2014 My reflections | 'Recruited three more nurses today. Two of the nurses were newly qualified and one had been qualified 30years. Interesting mix of views and opinions. All discussed the importance of <u>honesty and information</u> giving to the patients. However all believed that it was a <u>Doctors role</u> to talk with the patient about End of Life Care. I was surprised about the clear <u>demarcation between the nurse and doctor role</u> when discussing or giving bad news. The opinion was that the nurses were there to <u>'mop up'</u> after the doctor had spoken to the patient. There was a reluctance to acknowledge the importance of advance directive although all three did not appear to have a clear understanding of what this meant. No one seemed to understand or have read any Department of Health guidance on heart failure. One nurse told me she chose the heart failure link nurse role because it was <u>one of the roles given on a list you could choose from</u>....... Nurses appear to be <u>disempowered</u> and as a consequence do now wish to enter into end of life conversations. <u>Seeking approval</u> from the doctor appears to be | Being open<br><br>Hierarchy of information giving<br><br>Defining roles<br><br>'Mopping up'<br><br>Lacking engagement<br><br>Seeking approval<br><br>Levels of information giving |

| | important and is something I need to pursue. There also appears to be <u>levels of information giving.</u> This is something that I have not come across before and needs further probing. | |

Figure 4 Example of one of my field notes

## 5.3 Transcriptions

The most commonly mentioned rationale for working with transcriptions is that it gives a more accurate representation of 'what happened' (Hammersley 2010). Transcriptions can provide a highly detailed and accessible representation of the phenomena or social interaction in focus (Peräkylä1997). In this study the process of transcribing began as soon as was practical following the interview. It was important to capture as accurately as possible what participants had said during their interviews. This meant transcribing the digital files verbatim. Hammersley (2010) highlights the importance of making decisions early on in the transcribing process on how to represent the recorded talk. This may include capturing the sounds participants make, whether the participant laughs, cries, capturing the speed at which a participant talks and the intonation (Hammersley 2010). I decided that it would not be necessary to include what Hammersley (2010) calls 'back-channel noises' or 'non-word elements' for example coughs, umm and ahh. However, it was important to capture what Goffman (1959) refers to as information 'given off' or non-communication like long pauses, silences or where participants expressed emotion.

To facilitate the process of transcribing a digital media software package Inq Scribe was downloaded onto my home computer. The software was straightforward to use with on line tutorials provided for new users. On average an interview would last 40 minutes which would take 5 -6 hours to transcribe; a total of approximately 180 hours for 30 interviews. The process

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of navigating around each interview was made easier by using 'time codes'. This gave the option of revisiting interesting topics or sections of a conversation with ease. Once the interviews were transcribed the transcript was exported into a word document where it was stored in an electronic folder and was password protected.

Regularly engaging with my data meant frequently listening to some distressing and often personal narratives about living with end stage heart failure. This cumulative effect of listening to personal narratives and closeness to my participants occasionally left me feeling sad. My professional training and work as an intensive care sister helped to ground me and gave me coping strategies to manage what was at times a rollercoaster of emotions. Kiyimba et al (2015) believe this emotional impact can often be overlooked or go un-recognised by inexperienced researchers. Taking sensible action to minimise this distress involved having debriefing sessions with my supervisors, my peers and talking with my clinical colleagues.

### 5.3.1 Managing the data

Glaser (1998) famously states in his book '*Doing Grounded Theory: Issues and Discussions'* "all is data" (p.8). The use of multiple data sources in this study was consistent with the principles of grounded theory (Charmaz 2006). The data sources included interviews, field notes, notes on informal observations, reflective diary, memos and diagrams. The nature of qualitative interviewing often meant that engaging with participants was either a famine or a feast. There were weeks where there may be one or two interviews and then months where interviewing happened on a weekly basis. These peaks and troughs did come as a surprise but allowed me the time to organise a large amount of data. From the beginning each interview/transcript was given a unique identity code. Once the transcripts were coded they were stored electronically as word documents on my computer which was password protected. To protect participants identity and to maintain confidentiality each participant was given a pseudonym.    Paper copies of the interviews used for initial coding were stored alphabetically

in an A4 folder and locked in an office cupboard. Initially keeping track of my memos was slightly more problematic. The random nature of memo writing meant memos were often written in diaries, on scrap pieces of papers and post-it notes. Using the memo function in NVivo helped bring some order to the chaos and enable me to link my memos directly to interview transcripts. Having paper copies of the transcripts helped with creativity and kept me close to the data. Once the interview was transcribed it was uploaded and stored safely in NVivo. The following section will outline my experience using NVivo software.

### 5.3.2 Use of Software

My aim was to find a program that could help with organization, offer flexibility and that would complement the analysis methods of grounded theory. A number of computer programmes were considered like NUD.IST or ATLAS.ti software programmes. The software QSR NVivo was chosen because it met my requirements both in its ability to organise large amounts of data and its functionality. On a more practical level the software was already provided by the university and this meant there was no cost attached to the licence. According to Gilbert (2002) the danger of novice researchers using sophisticated data analysis software is they can 'mess up' without realising they have done so. My experience with Qualitative Data Analysis (QDA) was limited and so access to training was an important factor in deciding which software to choose. Apart from the practicalities of choosing a software programme consideration was given to other factors like time required to undertake the analysis. Glaser (2005) famously describes the use of computer software to be burdensome and terribly time taking (p38). Robson (2002) echoes Glaser's (2005) concerns by adding that it is not only the time and effort it takes to become proficient in using the software but the prescriptive approaches to analysis.

Whilst time was a key consideration in making my choice the advantages of using NVivo far outweighed the supposed disadvantages. The software provided a way of managing my ideas by rapid access to memos, interviews, ideas and concepts. The software allowed me to ask

questions of the data to look at relationships between groups and to undertake comparisons of groups. Bazeley et al (2013) believes that using QDA software can add rigour to your study by providing transparency of the data analysis process. In this study the computer was only used as an adjunct to the analysis process providing a more consistent and methodical way of working.  The software cannot necessarily provide that intimate closeness to the data and therefore frequent reading of transcripts and listening to recordings of participants was done in order to keep me close to my participants' experiences. The process of initial coding remained a manual process where narrative was analysed line by line. In the following sections I will begin to elaborate on the coding process and give some real examples of how this was achieved.

### 5.3.3 Constant Comparison

The constant comparative method is an integral part of grounded theory enabling the researcher to move from description to conceptualisation (Strauss and Corbin 1998). Charmaz (2014) defines constant comparison as "a method of analysis that generates successively more abstract concepts and theories through inductive processes of comparing data with data, data with code, code with code, code with category, category with category and category with concept" (p342). The aim of this study was to gain a greater understanding of the lived experience of healthcare professionals and patients when considering end of life decision making. By engaging with constant comparison at each stage of coding I could a) compare people's beliefs, actions and experiences b) compare relationships between groups c) compare incident with incident d) compare categories with codes e) compare categories with my memos and f) gain a greater understanding of the social processes of my participants During each coding stage theoretical memos were written to focus questions and further data collection as well as inform and refine the developing theoretical analysis.

### 5.3.4 Theoretical Sensitivity

Theoretical sensitivity is a multidimensional concept that includes the researcher's level of insight into the research area, how attuned they are to the nuances and complexities of the participants' words and actions, their ability to reconstruct meaning from the data generated (Strauss and Corbin 1998). The researcher should be "sufficiently theoretical sensitive so that he/she can conceptualise and formulate a theory as it emerges "(Glaser and Strauss 1967, p46). To enhance theoretical sensitivity researchers' are told that "they must enter the field with as fewer preconceptions as possible" (Glaser 1978, p3). In many cases this is not always possible as often individual's will come to a study with their own beliefs, culture, experiences and values (Charmaz 2014). Certainly, my knowledge and experience in critical care nursing could have potentially led me to force data and apply extant theories. According to Charmaz (2014) engaging in reflexivity helps you to become more aware of your preconceptions and can enhance the iterative process of coding, memo writing and collecting data. Having an intimate familiarity with my data meant I could dig deeper and ask questions of the participants' which may have got overlooked by someone not as familiar with the subject area. The art of constantly writing and comparing gave me a vantage point in which to look down and see my data from different angles and perspectives. This was written into a reflective diary and was used as a source to inform my data collection.

### 5.3.5 Theoretical Memos

Memos are a crucial part of the grounded theory method allowing the space to explore data and emerging categories (Charmaz 2014). Memos can form part of the grounded theory "*in short memo writing provides a space to become actively engaged in your materials, to develop your ideas, to fine tune your subsequent data gathering and to engage in critical reflexivity*" (Charmaz 2014, p163). Memoing was undertaken throughout this study to actively interact with the data, speed analytical momentum, question and clarify what was emerging from the data,

see data and codes in new ways and increase the level of abstraction. Memos were written after the first interview in a notebook which was convenient in quickly capturing ideas. The second phase 'focus coding' the memos was written using the memo and annotation function in NVivo. The process of writing helped to raise ideas from the descriptive to a more conceptual level. By continually comparing my memos with my transcripts, field notes and informal observations I was assured that the emerging categories were representative of my participants' views. As Glaser (1992, p4) explains "a concept is the naming of an emergent social pattern grounded in research data". To assist with the organisation of memos they were cross referenced at source to the coded and categorised data. This meant that I was able to trace emergent categories and show any changes in analytical direction.

The following example (fig 3.0) relates to an early memo written after interviewing two qualified nurses on a respiratory ward. My memo indicates my surprise at nurses' perception of their role in 'giving information'. A further interview with a doctor (fig 4.0) implied that information was given to a patient on a need to know basis for fear of not wanting to upset the patient. By comparing participant interviews and memos the concept '*giving information*' was raised to a more theoretical level. Raising my sensitivity to this concept enabled me to explore further the literature around the category 'giving information'.

| Name | Transcript | Memo |
|---|---|---|
| *Staff Nurse Ella* *Qualified 30 years* *Care of Elderly ward* | *"I don't think that the nurses especially us on the ward are confident to have this type of conversation its mostly the doctors refer them to the doctors to have a chat with the relatives or with the patients"* | *The interviews today raised some interesting views on information giving to patients. Both nurses discussed the importance of being honest. However, both agreed it was the doctor's role to have end of life conversations. The nurse's role was considered to be 'mopping up' and clarifying information given to the patient what had been said by the doctor. There is a general* |
| *Staff Nurse Danielle* *Qualified 2 years* *Respiratory Ward* | *"you can ....they just sit there and they just nod and you can see the mind wandering and* | |

| | | |
|---|---|---|
| | *then afterwards they go...so...what do they mean and then I say do you want them to discuss it again with you... no no its fine....but I get them to relay the information...but sometimes it too much information for the patient".* | *consensus that the topic of end of life is not always delivered at the most appropriate time in the illness trajectory and this leaves the patient or families no opportunity to make decisions about their care. Information appears to be given on a need to know basis. Doctor's seem to have the power over how; when, where this is done...nurses do not feel empowered. Why?* |

Memo 1 written after interviewing two qualified nurses on a medical ward

| Name | Transcript | Memo |
|---|---|---|
| **Doctor Shabib**<br>**FY1 Cardiology** | *"but usually when I tell the patient about the results I tell them step by step and then I tell them what they need for that moment and leave it for the next time....really it's a problem to be honest we should tell them everything at that time but we just don't want to upset them all in one go and then go you're going to die......."* | *The information for patients seems to be given in stages. I think this confirms what I have already observed on the ward rounds. Patients are given information on a need to know basis. There isn't time to ask questions and so the patient waits to clarify this information with the nurse. This process is not allowing patients to make fully informed decisions about their care. I do think that the doctor believes he is acting in the best interest by not upsetting his patient.*<br>*This reminds me of something I read recently about how we socially construct our identity (Vivien Burr) is this going on here? ....the patient identity, the doctor identity....and how we construct these realities in our everyday contact with each other. I am also thinking of position, power and motives (Hester) and the patient having a voice.* |

| | | *'Parsons and Sick Role'* |
| | | *'Characteristics of the medical profession'* |

Memo 2 Memo following interview with Doctor Shabib

## 5.3.6 Diagramming

Diagrams can offer concrete images of our ideas and provide visual representation of categories and their relationships (Charmaz 2014). In this study diagrams provided a way of seeing the relationships between categories, the direction and connection between those categories. Having a large amount of data the diagrams assisted in making the conceptual connections between my memos, transcripts, field notes and reflections and clarifying how these linked back to my research question. (Bazeley et al 2014) argues that diagrams can be helpful in helping you get across your ideas. I found diagrams were particularly useful when member checking my findings with clinical colleagues.

## 5.4 Stages of Coding

Charmaz (2014) defines coding "*as the pivotal link between collecting data and developing an emergent theory to explain the data*" (p113). The act of coding helps to make sense of the data and informs further data gathering (Charmaz 2006). Coding moves the data from the descriptive into generalizable theoretical statements and contextual analyses of actions and events (Charmaz 2014). The process of analysis in a constructivist grounded theory has two very distinct stages:

1) An initial phase which involves coding each word, line or segment of data.

2) A focused, selective phase that uses the most significant or frequent initial codes to sort synthesize, integrate, and organise large amounts of data.

Charmaz (2014) in her book '*Constructing Grounded Theory'* discusses a potential third phase and that is axial coding (Strauss and Corbin 1990, 1998, 2008, 2015). Strauss and Corbin (1998)

define axial coding as *"the act of relating categories to subcategories along the lines of properties and dimensions"* (p124). The purpose of axial coding is to sort, synthesise and organise large amounts of data and reassemble them in new way after coding (Creswell 1998). The use of axial coding according to Charmaz (2014) is down to individual choice and whether researchers' can tolerate ambiguity or they prefer to use a framework or structure (Charmaz 2014). In this study axial coding was adopted to begin the process of moving from the descriptive to the conceptual in developing concepts and categorising the data.

### 5.4.1 Initial Coding

The first step in the coding process is initial coding. This step allows the researcher to begin to understand the participants' views. It also allows the researcher to remain open to what participants' perceive to be important (Charmaz 2014). During this phase Charmaz (2014) encourages the researcher to ask four questions of the data:

What is the study of? (Glaser,1978, p57, Glaser and Strauss 1967)

What do the data suggest? Pronounce? Leave unsaid?

From whose point of view?

What theoretical category does this specific datum indicate? (Glaser 1978)

In this study the transcripts were analysed and initially coded using line by line coding. By adopting this process it allowed me to remain close to the data. Charmaz (2014) advocates when coding to use words that reflect actions. In this study it included phrases like *"resigning to fate"* and *"feeling vulnerable"*. By adopting this way of coding it curbed the tendency to make conceptual leaps and develop theory before the process of analysis was complete (Charmaz 2014). The idea of initial coding is to remain open to what the data is saying (Charmaz 2014, Glaser 1978, 1992). In this study, being open to my data meant having to acknowledge that my own nursing experiences may affect my interpretation of the data. Dey (1999, p251) states "There is a difference between an open mind and an empty head". By coding the data line by

line and staying close to what participants' were saying gave me confidence that I was presenting their views and not my own.

During this initial coding process 'in vivo' codes were used to capture participants' meaning, views and actions. Charmaz (2014) believes that using 'in vivo' codes can be particularly helpful and can act as symbolic markers when harnessing the true meaning of participants' speech. Examples of this were phrases like "*just plodding on*", "*cracking on*" and "*you don't quite see the forests for the trees*". To further enhance the process of coding 'gerunds' were used. Glaser (1978) describes 'gerunds' as the 'doing' words so for example; experiencing versus experience and recognising versus recognise. The use of gerunds promotes a sense of action, promotes fluidity and gives a strong sense of what the data is about (Charmaz 2006). In this study using gerunds gave fresh insights into the phenomenon 'decision making' and how this related to 'end of life care'. During the process of initial coding data was constantly compared (appendix 9 and 10). From these initial codes ideas were generated and gaps in knowledge identified which would then inform further questioning. The following is an example of how the data were coded line by line.

| Interview Transcript | Initial Coding line by line coding |
|---|---|
| ***Patient Heather*** | |
| *Yes I did smoke ...but to be truthful I don't think it was smoke related. I have not touched one since and I never will do but I don't think it was smoke related. I think it is hereditary from my Dad. My Dad had a lot of heart problem and I did lung function tests and was told basically you would never have thought I was a smoker because my lungs were good so I really don't put it down to smoking. I have never been a drinker so it's nothing to do with alcohol and I eat healthy. I am not overweight so I kept myself fit and healthy……….* | *Defining the truth* *Defining the cause of heart failure* *Coming to terms with diagnosis* *Seeking confirmation from past events* *Seeking reassurance from diagnostic tests* *Denying contributing factors* *Maintaining a healthy lifestyle* |
| ***Debbie Ward Manager*** | |
| *I think some of it is that some of the nurses and some of the doctors are worried about* | *Expressing concerns* |

| | |
|---|---|
| *putting the patient on a pathway....have we reached that crucial time and some of them are like I say junior nurses they are a little bit apprehensive. Because unless it is documented and the observations are being done and when we do actually stop doing them and I think what worries a lot of the nurses especially those who don't have a lot of experience with end of life and particularly those who are junior is they worry about their registration………..* | *Recognising dying*<br><br>*Professional responsibilities*<br><br>*Understanding the process*<br>*Defining the start and end points*<br><br>*Acknowledging lack of experience*<br><br>*Professional accountability* |
| **Dr Amina**<br>*I always tell my patients when they get to that point that they are quite concerned that why there quality of life is deteriorating. I tell them that heart failure can be worse than some cancers for example bowel cancer. But to approach palliative care team we don't have a policy of guidelines to recommend co-operation with the palliative care and to prevent....so you know if a patient is going to die very soon with severe LV Dysfunction 20 or below or an ejection fraction 20 or below with lots of symptoms would be beneficial if the palliative team were involved and the heart failure nurses……….* | *Giving reassurance*<br>*Acknowledging concern*<br><br>*Comparing heart failure with other terminal disease*<br>*Acknowledging the need for guidance*<br><br>*Seeking collaboration with experts*<br><br>*Identifying the symptoms*<br><br>*Recognising the need for expert help* |

Figure 5 Example of how the data was coded line by line

### 5.4.3 Focussed Coding

The next step was to conduct what is termed focussed coding. Focussed codes are more directed, selective and conceptual than the initial word by word line by line coding (Glaser 1978). Charmaz (2014) describes the process of focussed coding as sifting, sorting, synthesising and analysing large amounts of data. In this study the process of focussed coding began by manually sifting through my initial codes. This involved analysing my codes and identifying those which had theoretical reach, centrality and direction. This process often meant changing and renaming initial codes which Charmaz (2014) refers to as 'trimming away the excess'. Moving across and comparing the data enabled me to check my own preconceptions and confirm that what was emerging was in fact the experiences of the participants'. It was during this second phase of

analysis that the transcripts were uploaded into NVivo. NVivo provided a way of structuring my initial codes (nodes) into 'a branching tree system' with categories and sub categories. Bazeley et al (2014) believes this process brings organisation to chaos and can help bring conceptual clarity. The process of focus coding took sometime but once complete fourteen categories emerged; examples of these '*recognising dying*', '*signposting symptoms*', '*organising care*', '*seeking knowledge*' and '*giving information*'. The table below gives some examples of how the data was fractured, initially coded and then categorised using focussed coding.

| Interview Transcript | Initial coding | Focused Coding |
|---|---|---|
| *Andrew* <br> *Spec Reg Cardiology* <br> *"the only thing that I will say is and I don't speak for everyone but I speak from experience but I think as cardiologists we are particularly poor at identifying that stage in people. Like from my experience they come in acute and chronic heart failure and then they get to a level you don't 'quite see the forest for the tree' so we think alright this person has this baseline but we aim for that baseline, but sometimes we don't take into account that that may be their new baseline. So what we are doing we are not treating someone we are giving them a new place for them to handle their last days".* | *Speaking from experience* <br><br> *Identifying end stage* <br><br> *getting to a level* <br><br> *'see the forest the tree'* <br><br> *aiming for a new baseline* <br><br> *giving them a new place* | *'Recognising Dying'* |
| *Jane, Specialist Nurse Cardiology* <br><br> *"I don't particularly want to diagnose dying in* | *Diagnosing dying* | *'Recognising dying'* |

| | | |
|---|---|---|
| *someone with heart failure because I don't know enough about it and if we were to see patient s with heart failure we would have to see patient with COPD and various others and lots of other illnesses and I wouldn't know enough about those illness to step in at that time and support that decision making. I like that to be made before I get involved.* | *Having the right knowledge and skills*<br><br>*Seeing other patients*<br><br>*Stepping in at the right time*<br><br>*Making the decision* | |
| ***Steve, Heart Failure Nurse*** | | |
| *"plenty of people come back into the clinic and they are getting signs and symptoms and there is always a tipping point with every patient and they will ring 999 because they will get fluid on the lung and there is not a lot that can stop that happening in this patient group"* | *Getting signs and symptoms*<br><br><br>*'Tipping point'*<br><br>*Devastating symptoms* | ***'Signposting symptoms'*** |
| ***Patient Fred*** | | |
| *"because my legs were swelled up again so when I say swelled up I would say they were twice that size and it was one of them where if you leaned on it when you came up it left a big groove where you had been"* | *Worsening symptoms*<br><br><br><br>*Markers of deterioration* | ***'Signposting symptoms'*** |

Figure 6 Examples of how the data was fractured, initially coded and then categorised using focussed coding.

### 5.4.4 Axial Coding

Axial coding is defined by Strauss and Corbin (1990) as a "set of procedures whereby data are put back together in new ways after open coding by making connections between categories" (p96). The process of axial coding involves using coding paradigm which includes conditions, context, action/interactional strategies and consequences. Asking questions of the data like who, when, where, how and with what consequences relationships can be made between the categories and subcategories (Charmaz 2014). In this study axial coding began once my initial codes had been identified and my focussed coding began. Using the iterative process of constantly comparing data and writing memos I was able to identify categories or what Strauss and Corbin (1998) label as a 'phenomenon'. A phenomenon is a term that answers the "What is going on here"? (Strauss and Corbin 1998). There were a number of different frameworks to assist me with the process of axial coding. Strauss and Corbin (1998) propose two illustrative diagrams to use when axial coding; the mini framework or conceptual diagrams. However, on further exploration these frameworks appeared a bit too vague. Scott (2008) framework the 'conditional relationship guide' applies the principals of grounded theory (Glaser 1967, Strauss and Corbin 1998) and provides a link during the process of constant comparative analysis when moving between focussed and axial coding. This framework was helpful in identifying relationships between my categories and later in identifying my theoretical categories. The following table gives an example of how the guide was used to identify relationships between my categories.

| Conditional Relationship Guide | | | | | |
|---|---|---|---|---|---|
| Category | What | When | Where | Why | How | Consequence |
| Finding the right time | Decisions by HCP on when was the right time to have end of life conversations with the patient. | During face to face interactions between the HCP and the patient. | Takes place on the ward round or in the OPD Providing a safe environment | Because HCP recognised the need to be honest with the patient and provide an opportunity for patients to make decisions about their end of life care | Patient information leaflets Face to face conversation with HCP. Formally on ward round (decision made by HCP on how much information to give patient) | HCP would be relieved/feel satisfied information had been given at the right time. Patient knows the relevant information. 'Being honest' 'Information Giving' |
| 'Aiming for the baseline' | 'Providing a new place or another 'space and place' for the patient to manage symptoms. | During the physical examination and interventions on admission | Patient is admitted to the Emergency Department or Medical Assessment Unit. | The emergency doctors will treat the patient symptomatically but recognise they do not have cardiology expertise. The limited resource means patients are signposted to a different place to manage their symptoms. | Intervention involves treating the symptoms of decompensation and monitoring the patient. | The patients' symptoms are treated. The patient is either discharged home or transferred to the MAU. 'Signposting the journey' 'Signposting symptoms' |

Figure 7 Scott (2008) Conditional Relationship Guide

## 5.4.5 Theoretical Coding

Theoretical coding follows the codes you develop during focussed coding and begins to develop these codes into theoretical categories in which you can begin to formulate a theory or hypotheses (Glaser 1978). Developing theoretical codes allows you to show relationships between the focused categories. It brings back together the fractured data to make a comprehensible story (Charmaz 2014). Glaser (1978) in his book 'Theoretical Sensitivity' offers 18 sociological constructs known as coding families to assist with theoretical coding. These coding families according to Charmaz (2014) can provide a structure which can add

precision and clarity to your analysis. Glaser (1978) cautions that over reliance on the coding families' results in researchers assigning theoretical codes which participants' may not recognise. By staying close to my substantial analysis and codes and continually comparing data I was able to avoid imposing a forced framework. Involving my participants' in checking my data gave me the confidence in knowing that the theoretical codes which emerged were in fact relevant and meaningful. In this study the process of theoretical coding involved going back to my focussed codes and comparing codes with categories, codes with theoretical memo's and codes with field notes. This constant comparing data and rechecking was a way of making sure that my categories reflected the views and experiences of my participants. The theoretical code '*Being informed'* is used to demonstrate how analytical theoretical coding was applied.

Early substantive analysis began to raise some concepts around '*being honest'*, *knowing diagnosis,* and *'avoiding medical jargon'*. For the patient '*being honest'* and '*telling it like it is'* was important in order to make an informed decision about their care. The healthcare professionals saw a *'reason not to tell'* as a way of protecting the patient from emotional distress or *'losing hope'*. These initial codes which are situated in the outer circle of the Venn diagram (fig 4.0) informed my theoretical sampling and directed my questions. Further focussed coding led to the codes '*seeking information, 'telling the truth', 'knowing the right time'* and *'using medical jargon'*.

Knowing whats coming

Being honest

Reason not to tell

Telling them not going to tell

Seeking information

Telling the truth

**Being Informed**

Using Medical Jargon

Knowing the right time

Tell it like it is

Avoiding technical jargon

Familial relationships

Knowing diagnosis

Knowing the process
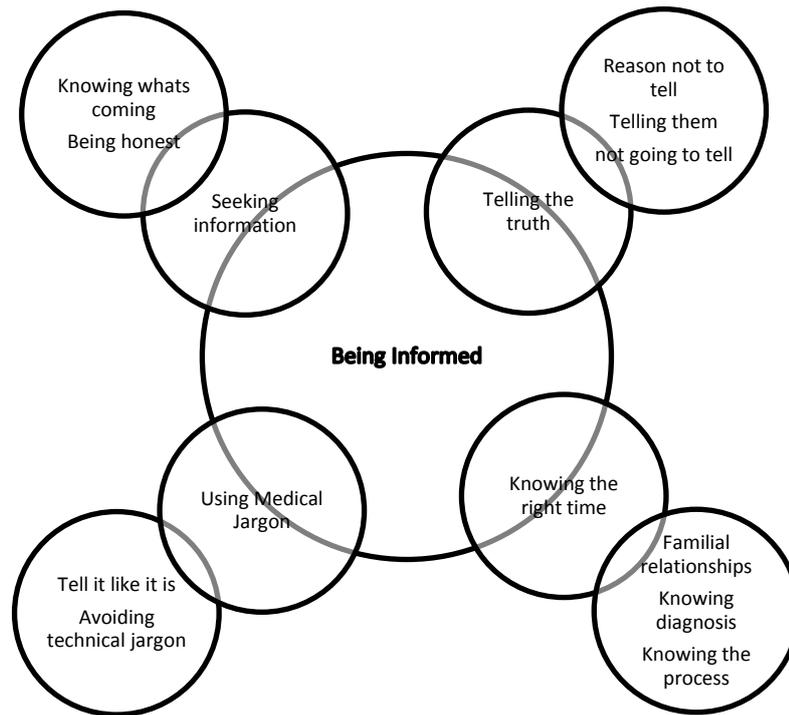
Figure 8 Venn diagram to demonstrate the relationships between initial codes, focussed codes and the theoretical category 'Being informed'

A memo (fig 5.0) written following an interview with a patient demonstrates my move away from descriptive to a more conceptual way of thinking. The theoretical category '*being informed'* begins to emerge as a theoretical category.

| Memo |
| --- |
| *My patients talk about 'being stuck' neither moving forward or backwards. There is little opportunity for these patients to move backwards or forwards because they do not have the right information to make a decision. Information is only given when it is perceived to be the right time so patients are 'stuck' in the middle or centre. To cope with this reality patients often talk about their past but never their future. It is clear that patients value a close relationship with their doctor 'being known' is important and enabling the patient to trust the information given by the healthcare professional.* |

Memo 3 written following an interview with a patient

Exploring relationships between categories began to move some of my earlier lower level concepts to higher level concepts. By doing this it helped in constructing a 'storyline; which would later explain my grounded theory. Birks et al (2013) believes writing a 'storyline' helps

to explain the relationships between concepts that will later make up your theory. Following theoretical coding four codes were identified which gave explanatory power to the phenomenon decision making and end of life care in heart failure. These four theoretical codes were as follows; ***recognising dying, signposting symptoms, organising care and being informed.*** The following paragraph will give a brief overview of my theoretical model however this will be discussed in more detail in the following chapter.

The transition for end stage heart failure patients to palliative care involves healthcare professionals being able to recognise the right time to have end of life conversations. In order to decide on when is the right time healthcare professionals' have to negotiate and navigate their way through a 'vicious cycle of care'; this included uncertainty around end of life care planning, and an unpredictable disease trajectory. As a consequence, this had created a nervousness and lack of clarity in recognising dying. To try and navigate this 'vicious cycle of care healthcare professionals would use clinical symptoms as a way of signposting a clinical route during the acute phase of care. Often this route of care for the patient was 'cyclical' and would involve a number of readmissions to the Emergency Department, Short Stay Unit and Medical Admissions Unit. This 'vicious cycle of care' led to patients' 'being stuck' and not able to access the right services like cardiology. The consequence of this 'vicious cycle of care' led to healthcare professional and the patient missing opportunities to make decisions about end of life care. The diagram below (fig 6.0) illustrates the evolution of my core category.

Core Category     Theoretical Codes     Focussed Codes     Initial Codes
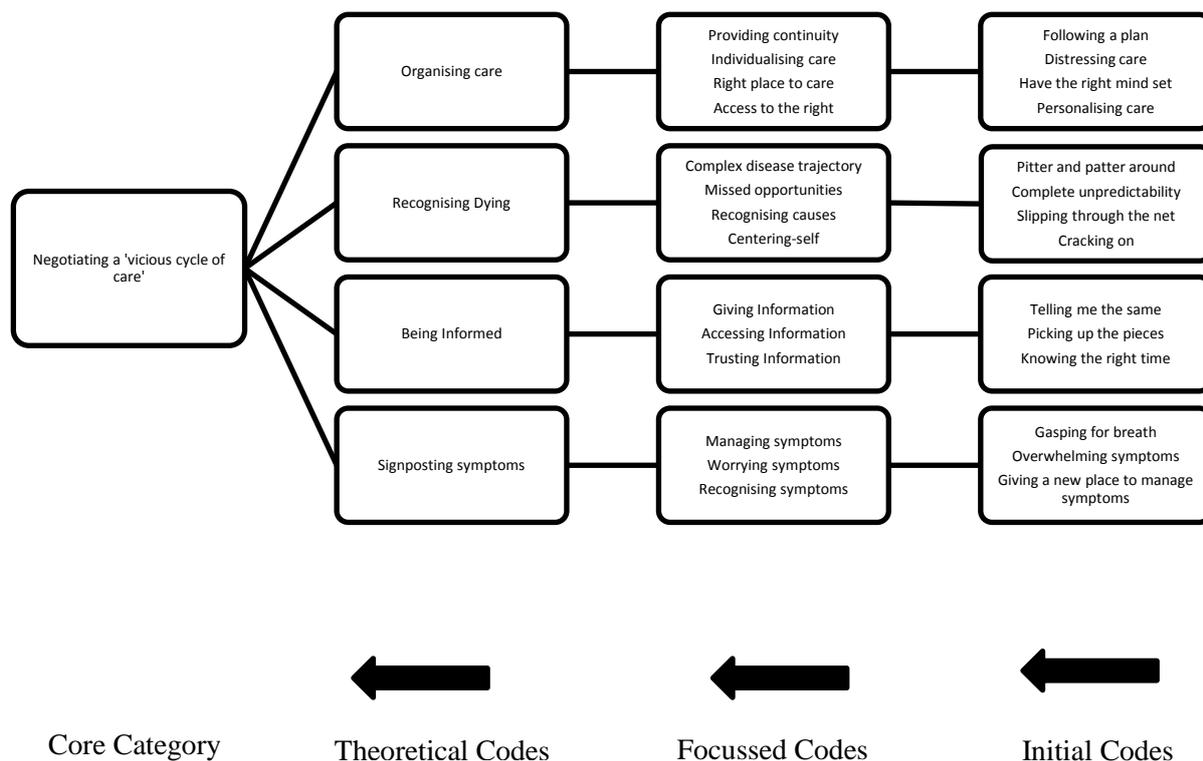
Figure 9 The Evolution of my Core Category 'Negotiating a vicious cycle of care'

### 5.4.6 Theoretical Saturation

Theoretical saturation is the term introduced by Glaser and Strauss (1967) to describe the criteria for when to stop theoretically sampling. Straus and Corbin (1998) define theoretical saturation when no new or relevant data seem to emerge from a category and the category is well developed in terms of its properties and dimensions. Charmaz (2014) adds further clarity by stating that a category is saturated only when it can no longer trigger any new theoretical insights. One criticism of theoretical saturation is that it is imprecise as the coding relies on researcher conjecture that categories are all saturated (Dey 1999). Glaser (2001) argues that if constant comparison of data is applied to data in each category then a rich conceptual dense theory can be developed. Charmaz (2014) solution to avoid constructing superficial analysis is to remain open and when new concepts emerge go back to the data and recode.

After 32 interviews (2 focus groups) with 47 participants' the core category '**negotiating a vicious cycle of care**' emerged. To fully saturate my categories, it involved going back and interviewing a palliative care consultant and a palliative care nurse. Transcripts were also recoded against the four theoretical categories as part of theoretical saturation. Constantly comparing codes and categories with theoretical memos lifted some of my lower level concepts to higher level concepts. This iterative process of more focused data gathering continued until my theoretical categories were saturated with theoretical codes. Only when there were no new themes emerging from my interview transcripts and each of my four categories was sufficiently saturated did the process of data collection end.

**5.5 Conclusion**

Grounded theory uses a systematic set of data collection and analysis procedures to develop an inductively derived theory from the data (Strauss and Corbin 1998, Charmaz 2014). In this study data was analysed to explore the social processes and experiences of healthcare professionals when making decisions about patients diagnosed with end stage heart failure. The aim of this chapter was to make clear the process of my data analysis using constructivist grounded theory principles of data analysis; initial coding, focussed coding, axial coding and theoretical coding (Charmaz 2014). To develop a greater theoretical sensitivity to the data Scott (2004) Conditional Relationship Guide was adopted to assist in recognising relationships between categories and saturating theoretical concepts. The use of constant comparison and memos were illustrated and discussed and examples given of how these methods have assisted in guiding theoretical sampling towards theoretical saturation and the emergence of the core category '**negotiating a vicious cycle of care**'. The following chapter I will begin to discuss my findings.

# Chapter 6 The Findings

## 6.1 Introduction

The process of decision making by healthcare professionals when managing end of life care for patients diagnosed with heart failure is revealed in this constructivist grounded theory study. Constructivist grounded theory has been described as an excellent method when wanting to understand the real lived experiences and views of participants (Charmaz 2014). In this study, it was important not only to capture the experiences of healthcare professionals but those of patients whom were part of this decision-making process. The literature suggests that patients may not always be included in decisions about end of life care and as a result may not have the opportunity to contribute to their end of life care planning (Costello 2006, Goodlin 2009, Gott 2011, Watts 2012). This chapter will provide an opportunity to present the results of my analysis, its relevance to the phenomenon 'decision making' in end of life care' for patients diagnosed with heart failure.

To navigate around the different themes and concepts the data will be presented under my four theoretical categories; 'organising care', 'being informed', 'signposting symptoms' and 'recognising dying.' Throughout this chapter my own informal observations, memos, excerpts from interviews and the literature will be provided. It is recognised that the words of the participants and their experiences, of which I was privileged to be a part, remain of the utmost importance and what makes this study grounded in the data. It is therefore necessary to make sure that their voice is heard and so every effort has been made to ensure that their experiences are presented as accurately as possible. The discussion that now follows relates to the phenomenon studied, in particular decision making by healthcare professionals when managing end stage heart failure.

## 6.2 The phenomenon- decision making in end stage heart failure

This section presents my account of how healthcare professionals and patients constructed meaning and actions in their situations. This is from a position as close as possible to the participants' lived experience recognising that it is not possible to fully replicate the experiences of nurses, doctors and patients (Charmaz 2014). The phenomenon 'decision making' was explored using open-ended questions. The healthcare professionals and patients who participated in this study actively engaged and spoke honestly about their own experiences. It was clear from my interviews and observational data that there were a number of factors which influenced healthcare professionals' 'decision making' when considering end of life care which included: professional boundaries, professional accountability and individuals' own experience of dying. The patient's experience of decision making was one of contrasts which often had both emotional and psychosocial affects. For the patient these emotions were often expressed as feelings of anxiety and depression. My interactions with healthcare professionals and patients led me to believe that end of life decision making is both multifaceted and complex. The disease trajectory for heart failure does not make prognostication easy and so doctors often felt morally and ethically obliged to continue what were likely to be futile treatments (Willmott et al 2016). On the whole decisions were made sensitively and with compassion often taking into consideration the patient's wellbeing. However, information given to patients in order to make decisions was often given on a 'need to know basis' as defined by the healthcare professionals. This did not allow patients to make informed decisions about their care. Whilst the intention of this study was to explore 'decision making' when considering end of life care for heart failure, it soon became clear when transcribing and initially coding my data that there were many different strands to this phenomenon. Each of these strands inter-connected so making the process of end of life decision making challenging for both healthcare professionals and their patients. For my findings to emerge an iterative process was adopted to allow for the continuous

analysis and comparing of my data. This dynamic relationship between data collection, data analysis and theory generation is well recognised in grounded theory and is often referred to as 'analytical induction' (Charmaz 2016, Hesse-Biber 2007). The following diagram illustrates this fluid research process which was often cyclical in nature moving backwards and forwards as questions emerged and new leads were followed.
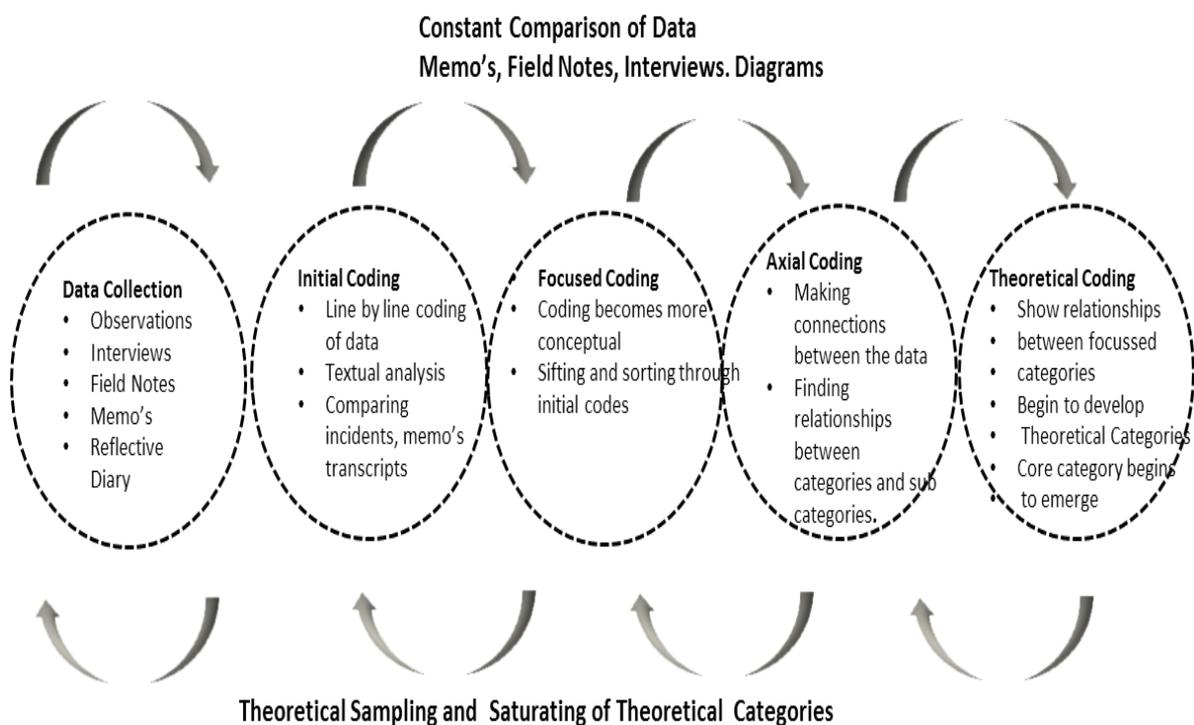


Figure 10  Process of Data Generation and Data Analysis

## 6.3 Theoretical Category One: Organising Care

### 6.3.1 Access to the right care

The first theoretical category 'organising care' recognised healthcare professionals' challenges when caring for patients diagnosed with end stage heart failure. Initial coding of my data revealed that these challenges were multifactorial and included; *"providing the right care environment" (Steve, Heart Failure Nurse) "developing therapeutic relationships" (Debbie,*

*Ward Manager, end of life link nurse), "having the right knowledge" (Jane, Cardiology Specialist Nurse) and "having a proper heart failure pathway" (Dr Ahmed, Consultant Cardiologist).* Healthcare professionals accepted that patients did not always have access to the right care. There was a general consensus amongst the doctors and nurses that not having a clearly defined heart failure pathway meant that patients were not always admitted to the 'right care environment'. The in vivo code *'vicious cycle of care'* was used frequently by the participants to describe this cycle of heart failure care.  In this study patients were observed being admitted to the emergency department, medical assessment unit and care of elderly wards. Very few patients were admitted directly to a cardiology ward.  This 'vicious cycle of care' meant that patients had to try and navigate both primary and acute care health care systems. This involved multiple visits to the General Practitioner (GP) in crisis when experiencing symptoms of decompensation (breathlessness and fluid overload). Patients would frequently describe to me *'I wasn't right with my breath' (Allan, patient)* or '*gasping for breath' (Paul, patient)* as a way of grabbing healthcare professionals' attention to the futility of their situation. Patients did not always have access to a community heart failure nurse so relied on the GP or practice nurse for advice and support. If symptoms did not improve the GP would refer the patient to the on-call physician or the emergency department. When experiencing these symptoms patients often spoke about '*feeling frightened' (Heather, patient) so* would frequently self-refer to the emergency department.

The diagram below (Figure 11) is a visual representation of this cycle of care; the outer circle representing the cycle of care that patients would typically experience on admission to hospital. This cycle of care is what the healthcare professionals would often refer to as being the *'vicious cycle'.* The inner dotted circle represents access to the 'right care' which for the patient was difficult to navigate and depended on the healthcare professionals recognising the need for specialist intervention.
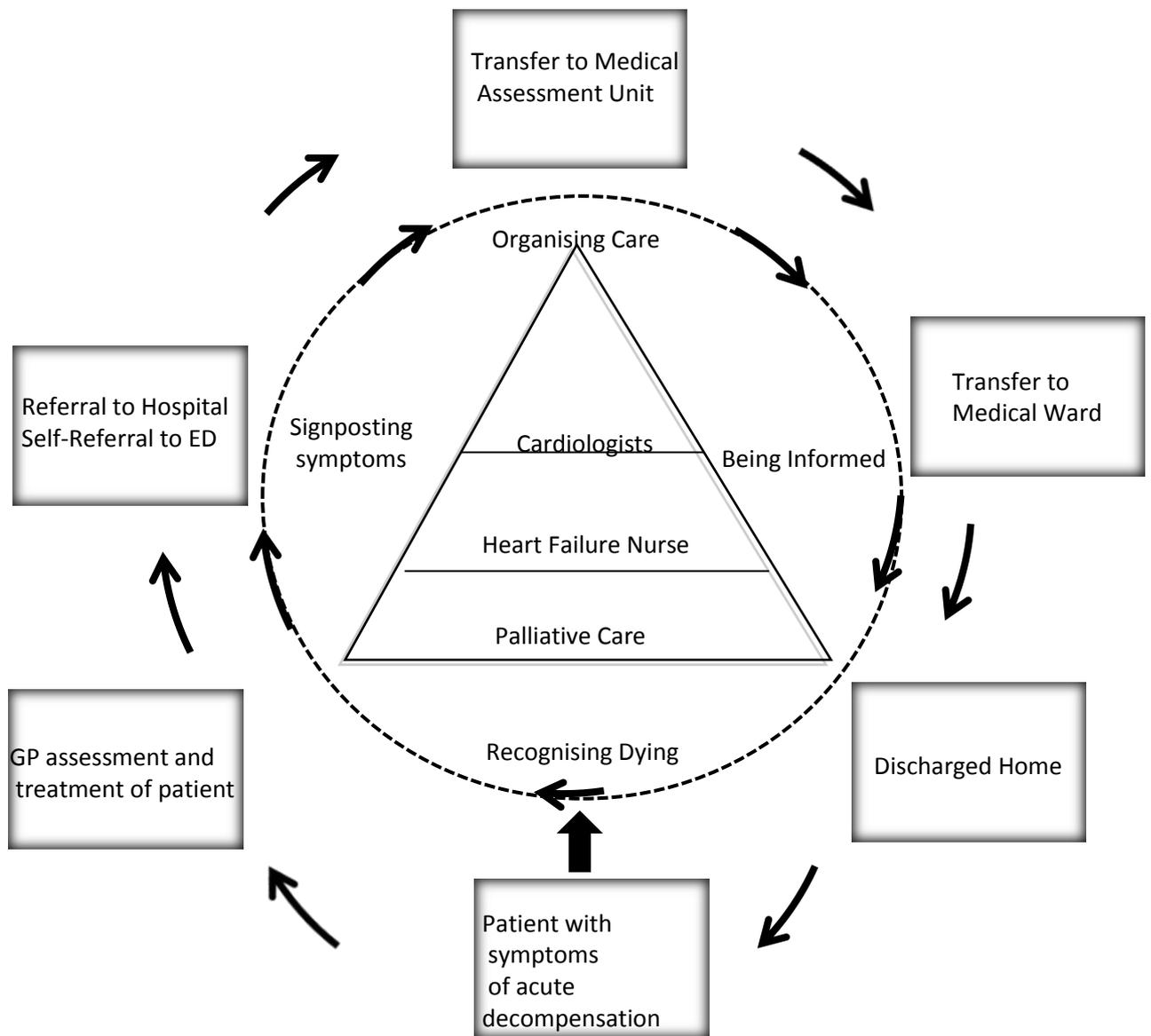
Figure 11 Cycle of Care for Heart Failure Patients

On admission to the emergency department (ED) patients would receive the '*standard treatment of diuretics and nitrates' (Geoff, ED, Consultant).* This consultant described this intervention as '*sticky plaster medicine*' recognising that many stage 4 heart failure patients would '*bounce back into hospital*' once they became breathless and oedematous. The emergency department was considered by healthcare professionals to be the lowest common denominator when it came

to patients being readmitted back into hospital. This consultant commented that the department was often used to provide '*crisis intervention*' for patients which were seen as unsatisfactory.

*……………"In the acute phase it's just sticky plaster medicine you get them over the hump and discharge them home but there is not much in the way of follow up, what's the long term plan, is palliation an option?" (Geoff, Consultant, Emergency Department)*

The ethos of care on the medical assessment unit was found to be similar to that of the emergency department. The patient was rapidly assessed, treated and monitored and would either be transferred to a ward or discharged home. Referral to a heart failure nurse or cardiologist rarely happened unless the patient was identified as requiring specialist intervention. The nurses believed that the job of referring the patient was down to the ward nurse. In many cases the patient would be discharged home from MAU without seeing a cardiologist or heart failure nurse. The memo below was written shortly after interviewing Anne the senior nurse who managed the department.

---

Memo

*Met with Anne this afternoon to discuss admission of heart failure patients to MAU. I was interested to know a bit more about the nurses' role in managing this group of patients. Anne stated that the nurses tended to <u>follow the doctors instructions.</u> There was a quick turnover of patients in the department so once treated the patients were either transferred to a ward or discharged home. I asked if the nurses raised any concerns about those patients diagnosed with end stage heart failure who were frequent attenders to the department. Anne hesitated and then replied that this never happens. She said 'to be honest 'the nurses follow the doctor's instructions'. I asked if the nurses would consider referring the patient to the heart failure*

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> *nurse or the community heart failure team. Anne seemed to think this was the job of the nurses on the ward. I wonder if not referring is symptomatic of how under resourced and busy the department is. Anne then looked at me and replied "I guess it is something we should do"....*
>
> *Anne acknowledged that maybe not referring to the heart failure nurses was a missed opportunity....I get the impression that the nurses know it is the right thing to do for the patient but being so busy it just gets forgotten. I wonder how the referral process could be improved....There is something about professional responsibility and accountability.*
>
> *Anne told me that the introduction of 'Board Rounds' has helped identify patients with heart failure. She enthusiastically tells me that having the palliative care consultant visit the unit twice a week has also helped with this process. I can't help feeling that there is a real disconnect between departments and little collaboration between disciplines. Everyone seems to be working in their own professional bubble. I can now appreciate the heart failure nurse's frustration when talking about some of the initiatives he has tried to implement to improve referrals rates to cardiology. A brief conversation with the MAU consultant confirms that decisions about end of life care are not always planned but left 'to the last minute'. The rationale given was that the doctors find it difficult to break bad news and do not want to give up hope on the patient. Interestingly, giving up hope seems to be a common theme which I will need to explore further with the doctors.*

Memo 4 following interview with Senior Nurse

On a number of occasions patients were observed being readmitted back to the MAU; often within weeks of their discharge. Patrick, a 70-year-old gentleman diagnosed with NYHA stage 3 heart failure was discharged home with swollen legs. He knew he didn't *'feel right'* but decided to go with medical opinion that he was fit for discharge. He was discharged home to the care of his elderly brother who lived in the family home. There was no referral to the heart

failure team just a letter to his GP explaining the reasons for Patrick's admission. Within days Patrick's legs became progressively more swollen and he had difficulty breathing. On arrival to the cardiology ward an echocardiogram revealed he had an ejection fraction of <30. Like many patients Patrick did not want to make a fuss and complain.

*"Oh I had swollen legs a bit then but they still sent me home and I went downhill a bit I was sick like. Before I had my breakfast this morning I was heaving and bringing up all different sorts of stuff so I knew I was going down really as I said to them "I am not blaming anybody" because it's bad enough report to higher authority here and they want to know why I was sent home in the first place and why I have come back again". (Patrick, Patient)*

Initiatives like the 'link nurse role' were introduced by the heart failure nurse to try and improve referrals across all medical wards. Link nurses have been traditionally defined as practicing nurses with an expressed interest in a speciality and a formal link to specialist areas (MacArthur 1998). Early studies undertaken demonstrated that these link roles improved patient safety, education, surveillance and standard setting (Teare and Peacock 1996, Cooper 2004, Roberts and Casey 2004). It therefore came as a surprise that engagement by the ward nurses with this new initiative was poor. Many nurses saw it is as extra responsibility on top of what was already perceived to be a demanding role. There were no real incentives by the ward managers for nurses to get involved in this role. Nurses were expected to attend study sessions in their own time; occasionally time was given in lieu. Often the role was given to a newly qualified staff nurse to supposedly enhance their professional development. The lack of knowledge in the specialism accompanied by an uncertainty of professional leadership meant that patients were often not referred. For the patient this meant continuing on a merry go round of readmission with no decisions being made about further interventions or palliation. The following is an excerpt from an interview with a newly qualified staff nurse 'Bob' who was volunteered by his manager for the link nurse role.

*"to be honest no it wasn't erm ...we had a list of the link nurse but the sister said that I would enjoy it and it is difficult we don't get many heart failure patients on the ward .... I don't know how often I am going to actually use it... I didn't feel like I had enough knowledge on the subject anyway so I thought I would just give it a go and see how it is"* (Bob, Staff Nurse, Acute Medical Ward-Respiratory)

The lack of engagement from the nurses led to very few referrals being made to the heart failure nurse. The reason given by the nurses were they *'were just too busy'*.

*"I have had a few referrals maybe a handful of referrals in the last few weeks. Not enough because I have still found patients even on the cardiology ward where they haven't referred to me but I have them through the echo system. This week when I asked a couple of the staff that I know really well they just say "Steve it is just too busy we are just swamped" ...so you can't .....unfortunately you can't rely on the staff"* (Steve, Heart Failure Nurse)

For the specialist nurses the advantages of having the patient on a cardiology ward meant reviews of care could be undertaken daily. The doctors made regular visits to the cardiology ward every day so concerns could be raised and dealt with quickly. Often a patient would be observed moving from ward to ward due to bed crisis in the hospital. This meant early identification of the patient by the heart failure nurse was almost impossible.

*"He came back onto another ward and then was transferred to an elderly ward which I could not understand the reasons for, and then I saw him again and specified that he be listed for the cardiology ward and now he is up there and so it is his fourth ward in three weeks. Now when I see him today he looks a lot better, because he has been seen by a cardiologist and been given appropriate IV diuretics and now being switched over to oral and he is being managed better so he looks better than he did three weeks ago"* (Jane, Specialist Nurse, Cardiology)

### 6.3.2 Individualising Care

Understandably, concerns raised by bereaved families about the Liverpool Care Pathway (LCP) had created a lot of confusion and nervousness for healthcare professionals around initiating end of life conversations (NHS England 2014). Both nurses and doctors recognised the need to 'get it right' but weren't entirely sure what that meant in terms of end of life care planning. The publication by NHS England (2014) '*Actions for End of Life Care: 2014-2016*' provided a strategy for healthcare professionals under the umbrella term 'House of Care' which outlined good end of life practice. Guidance like 'Leadership Alliance for the Care of Dying People' (2014) was considered good benchmarks of practice by the palliative care team.

*"That is what has come from the review from the leadership alliances these are the guidelines that we should be setting as a country to set our standards for nursing people who are dying at the end of life. So as part of a strategic group Greater Manchester, Lancashire and Cumbria we are looking at formulating a new end of life care plan which will supersede these guidelines. So once that's come in we are going to focus on that and once we start getting people talking about end of life care planning" (Sarah, End of Life Nurse)*

A number of the nurses and doctors had lost faith in 'pathways' and found the terminology confusing.

"because *people have lost faith in pathways at the minute because of the LCP" (Sarah, End of Life Nurse).*

*"I think I have come across it not sort of sat there and read it and took it in, I think when I was training I have come across it the GSF somewhere" (Bob Staff Nurse, respiratory ward).*

Interestingly, doctors tended to view a pathway more as a prescription or a set of instructions. Some doctors believed that the withdrawal of the LCP had led to *"a real mess"* (*John, Registrar Care of Elderly),* and that professionally we had '*taken steps back'* in providing end of life care.

*"I feel that there is a huge ambiguity where your patient is…When they were on the LCP everyone knew that this was symptomatic management and if things changed then they should be reviewed. We maybe weren't as good as that on the LCP. It would often be this patient had died a quick look in the ward round have they got symptoms and leave. For most patients 99.9% that might be adequate. There may be a small number who might not get as much medical attention than they would if they were on the pathway, but now we are in a situation of just fear of admitting. You will get patients on Tazocin and Midazolam and things like symptomatic management in the notes, but things are still going but nobody knows and nobody will take responsibility and we are paralysed with it (John, Registrar, Care of Elderly)*

Surprisingly, only one doctor believed that the LCP was still being used but in a different format *"We are still doing the same as the LCP but calling it something different"* (Paul, Registrar, Care of Elderly).

There was a general consensus amongst the palliative care nurses that the LCP may have been perceived by some healthcare professionals to be a 'tick box' exercise. Venkatasalu et al (2015) argued the LCP took nurses away from their normal practice of individualised care planning and has led to a depersonalised paper exercise. The palliative care team were keen to move towards 'individualised care planning' and this seemed to be filtering to the wards *"better term is individualised end of life care plan"* (Dr Siddiqui, Consultant, Care of Elderly)

*"The problem with the LCP when I think back now on when I used to teach people how to use the pathway you spent so long looking at the document itself and how to complete it. I don't know if you have seen one but they are so complicated lots of questions and lots of tick boxes. We used to talk about how to complete the document and not about the care. So now it's going to be more free script if you like so nurses can write the old fashioned care plans we used to do years ago what we going to do this patient and how we are going to do it…..I don't know if this*

*is still a draft form…we are going to pilot this in December on two wards in the hospital…..”(Rebecca, Palliative Care Nurse.)*

Opposing paradigms of care made it difficult for medical doctors to know the right time to refer the patient for palliation. The ethos amongst doctors was to treat the patient and so they would often describe feeling '*duty bound*' to treat symptoms of decompensation. This frequently resulted in interventions being prescribed which would probably prove futile.

*"Yes we are good at that and the trick is the thing is when people come into hospital it is very easy to say that they have decompensated heart failure but often they have got symptoms of that episode of heart failure which is treatable so you come in with poor LV function and a pneumonia and the fact they have come into hospital you are <u>duty bound to act upon that</u> and these things should come later rather than end of life.." (David, Registrar, Care of Elderly)*

Euphemisms like '*cracking on*' or '*cracking the whip*' were spoken of by medical doctors as a way to illuminate how care was managed in the acute phase. The delivery of care focussed on managing the acute symptoms rather than considering palliation.

*"What we're good at is limiting their care. If we know someone has a poor baseline physiological function it is rare that they will be intubated, it is rare that they will be admitted to level 2 maybe a bit of CPAP often we give them a crack of the whip when they are in hospital" (David, Registrar, Care of Elderly)[6]*

The medical 'philosophy of care' was seen by the palliative care nurses as getting in the way of end of life conversations. The conversations were often found to happen too late for the patient and so there was little opportunity for shared decision making and advanced care planning with

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[6] Continuous Positive Airway Pressure (CPAP) can be used for the primary treatment of patients with acute hypoxemic respiratory failure. The use of a tight fitting mask allows the application of CPAP without the need for endotracheal intubation or tracheostomy. (Hinds and Watson 2008).

the patient. The philosophy of palliative care in contrast was found to differ with the focus primarily being on alleviating suffering and improving quality of life.

*"so our doctors don't think like that and also when someone comes into hospital they are thinking about how we treat then and how can we do to help. So it is a completely different ethos to know that they don't think about managing somebody end of life care as they approaching that time perhaps the last 3 or 6 months of life. They only think about it when it is happening". (Rebecca, Palliative Care Nurse)*

The introduction of two palliative care sessions a week for the acute medical wards was observed to help break down professional barriers amongst the cardiologists and care of the elderly doctors. These barriers were identified into three main categories; unpredictable disease trajectory which did not make identification easy, healthcare professionals' lack of appreciation of what was meant by the term palliative care and lack of co-ordination of care between healthcare professionals and palliative care team. Gott et al (2011) explored barriers to palliation and found that physicians were less likely to discuss prognosis with their patient so preventing transition from medicine to palliative care. There was little evidence that prognosticator tools such as the Seattle Heart Failure Model (Levy et al 2006), or New York Heart Association (NYHA 1994) functionality score were being used to assist decision making. For a number of the care of elderly doctors this was down to unfamiliarity of the scoring systems not an unwillingness to use them *"No I have not come across that but it would be useful but heart failure and COPD are notoriously difficult to prognosticate on. It's not like a cancer where you have x amount of time" (Steve, Registrar, Care of Elderly).* The appointment of 'Simon' the palliative care consultant was instrumental in providing an expert link between the hospice and acute care; something which had not been introduced before.

*"Palliative care is very relevant for heart failure patients but it is getting around some of the prejudices and ways of working of some of the cardiologists…some are better than others"(Simon, Palliative Care Doctor)*

The family was viewed by doctors as a 'safe option' when it came to initiating end of life conversations. A family member would tentatively 'hint' at knowing something was wrong and would ask the nurse questions. The nurse would pass this information onto the doctor signalling the time was right to initiate end of life conversation with the patient. There were barriers observed to 'telling' which delayed transition to palliative care and these included; avoiding breaking bad news and the concept 'giving up hope'.

**"***Suppose you have someone NYHA stage 4 and is on maximum medication and maximum heart failure treatment still coming in and out and can hardly walk. Then I think that is the thing really, that is when you need to start discussing with the family that this is the maximum medications. These things and obviously all the investigations have been done. I have not seen the NICE guidelines but definitely this stage you need to explain to the patient and the family who maybe not aware" (Dr Patel, Consultant, Care of Elderly).*

The delay in 'telling' the patient caused irritation amongst the nurses who believed the patient was disabled in making a timely decision about their care. Words like '*pitter patter around'* were frequently used to express what they perceived to be '*dancing around the topic'* of end of life care. A number of nurses expressed feeling confident 'telling' the patient but believed it was the responsibility of the consultant to have the initial conversation.

*"….they pitter and patter around leave it to the last minute……where if it was more controlled and patients were more informed it could be more smooth. They could get the end they wanted. Patients if they wanted to go back home to a palliative unit or wherever" (Danielle, Staff Nurse, Respiratory Ward)*

A number of different strategies of telling were adopted by different health care professionals in gauging when to approach end of life conversations with patients. One strategy was to 'treat people as individual' and see 'where the conversation goes'. By using this strategy, it protected the healthcare professional from any awkward interaction with the patient. Cardiology nurses frequently spoke about being the 'best person' to have end of life discussions because of the close relationship they had with both the patient and their families.

*"No obviously it's got to be hard for a patient because they get frustrated because they are not getting the answers I can understand that from a patients perspective but for me personally it doesn't make my job harder I approach every patient individually and you see where each conversation goes with them".(Jane, Cardiology, Specialist Nurse)*

So far the findings suggest that organisation of end of life care was multifaceted and at times challenging for both the healthcare professional and the patient. There were a number of reasons for this; clarity on when to transition a patient to palliative care, recognising when to initiate end of life conversations with the patient, confusion around end of life pathways and opposing paradigms of care. It was clear that care was fragmented and delivered in isolation consequently the patient was not referred to palliative care. The following section explores my second theoretical category 'Being Informed.'

## 6.4 Theoretical Category 2: Being Informed

The second theoretical category was about patient, nurse and doctor 'being informed' and having access to the right information in order to make informed decisions. It was clear from analysing and constantly comparing my data that 'being informed' was multi-factorial and revealed different emotions in both the patient and the healthcare professional. For example, it was important for the patient to be informed about what was *'going on'* by a healthcare professional whom they considered to be trustworthy. For the healthcare professional 'being

informed' was about balancing the risks and being able to deliver safe and effective care. The diagram below gives an example of how my initial coding led to my focussed codes. The process of comparing interviews with interviews and interviews with memos led to the emergence of my theoretical category 'being informed'.
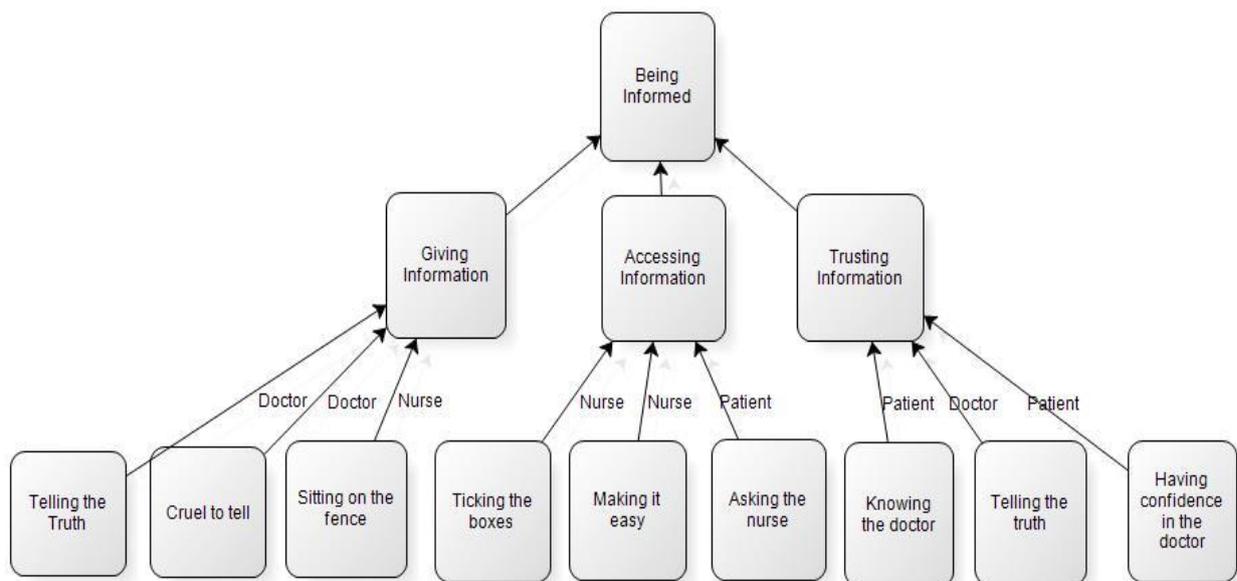


Figure 12 Example of a concept map illustrating my initial codes, focussed codes and theoretical category 'being informed'

The 'giving information' to patients about their end of life care was dependent on a number of factors; the expertise of the person giving the information, professional status, suitability of the information and how the information would be received by the patient and their families. Nurses described patients falling into two categories; '*those who could handle*' the information and those who '*couldn't handle the information*'. Occasionally nurses would refer to this 'intuitive knowing' which was described as '*a gut feeling*' that patients were ready to receive information. Benner and Tanner (1987) define intuitive knowing as 'understanding without rationale' indeed Tanner et al (1993) later went on to refine the definition by incorporating 'judgement without rationale'.

*"I think you can come across some patients who you would get the feeling who you know can handle the information you are going to give them and they are to handle it well and they are going to take it on board but there are other patients how are they going to respond to this" (Bob, Staff Nurse, Respiratory Ward)*

To avoid upsetting the patient nurses would initially use the family as a 'sound board' to test the patient's understanding about their terminal condition. This technique was well rehearsed and meant nurses could avoid unintentionally upsetting the patient. It was not clear what nurses considered to be the accepted or the right time to give information to the patient. Generally, information was observed to be given on a need to know basis. The only time nurses would deviate from this practice was when a direct question was asked by the patient. The rationale given for not giving end of life information was patients would 'not want to know', it would be to upsetting or 'they couldn't handle it'. This practice was observed amongst the more senior nurses who took a gatekeeper role in keeping the patient emotionally safe. Hjelmfors et al's (2014) survey of heart failure nurses found 84% of nurses would be worried about having end of life discussions with the patient and 55% of nurses were concerned about the patient becoming upset.

"Yes *probably more so I think with spouses than with the patients themselves I think somebody who is very close to somebody can see that they are not getting better and they want to know the answers and they want to know what is coming. They don't always want to discuss that in front of the patient but they want to know the answers and I think sometimes possibly the fear with patients they almost don't want to know they won't ask the question because they don't want to know the answer. I think there is a slight element of that sometimes" (Jane, Specialist Nurse, Cardiology)*

In contrast palliative care nurses took a different tactic to information giving; there was an understanding that the patient had a right to know their fate. It was accepted 'being sad' and 'being upset' was part of a normal response to being given a terminal diagnosis.

*"I have seen over a thousand patients…I must have done…most people yes they are sad but they are ok …..they are ok….yes of course they are sad they approaching the end of their life….but they are ok"(Rebecca, Palliative Care Nurse)*

The ward nurses saw the palliative care nurses as 'good facilitators' of dying and so were happy to accept their support, advice and intervention. The palliative care nurses on the other hand believed that the introduction of specialist nurses had de -skilled the ward nurses in delivering *'basic palliative care'*. The boundaries of professional responsibility often became blurred once the patient entered into the end of life phase. It was during this time that decisions were often delayed or were not considered when considering advance care planning and referral to palliative care.

*"The nurses should be able to give good general nursing care without aggressively treating him……  You know what I think, I think sometimes when specialisms come along they almost de -skill nurses and it can sometimes be a case of "I don't have to talk" or "I don't have to do that if there is a specialist nurse to do it for me" …I am going to tell you a tale now that which made me go cold. A couple of years ago we were hoping to start a patient on a Liverpool Care Pathway. A patient who was clearly dying, and all that meant was we were getting rid of anything that wasn't helpful to that patient, so we were not going to do blood pressures blood tests and all the rest of it we were just going to do good nursing care. The nurse said to me "Oh God" I am going to have to talk to the family. I don't think it wasn't that she didn't want to talk to the family but it was just because she was just too busy" (Rebecca, Palliative Care Nurse)*

A consensus amongst some healthcare professionals was that information was not given because of a 'lack of confidence'. This was observed in non-speciality areas like care of elderly and respiratory medicine where healthcare professionals were considered 'not the experts'.

*"I think it is a confidence thing with the person who is giving that information because sometimes you see it yourself people sitting on the fence a bit and sort of what you think well this is .....they need to know the facts" (Jenny, Trainee Advanced Nurse Practitioner, Acute Medicine)*

In this study both nurses and doctors were honest and stated they found the task of explaining the diagnosis and prognosis to the patient very challenging. They spoke about the 'need to be honest' about the seriousness of the condition and were mindful that this could raise patient anxiety. To avoid giving information to patients about their terminal condition emotional blockers would be used like '*I don't want the patient 'to lose hope.' (Dr Amina, Specialist Registrar, Cardiology)* This left many patients in a situation of 'not knowing' and having 'false hope'.

*"Really it's a problem to be honest we should tell them everything at that time but we just don't want to upset them all in one go and then go you're going to die"....... (Dr Shabib, FY1 Cardiology)*

These sentiments were echoed by 'Jane' a cardiology specialist nurse who believed the Liverpool Care Pathway had added to healthcare professionals' nervousness in informing patients.

*"I think it's difficult because obviously there has been a lot of bad publicity as well recently around the Liverpool Care Pathway. I think it's almost that fear factor saying you are giving up on somebody" (Jane, Specialist Nurse, Cardiology).*

For the patient 'being honest' meant having access to the right information in order to make informed choices. In order to receive this information some patients would be happy for their next of kin to be told first. One patient 'Barry' was happy that his wife Elsie was given the information first by the healthcare professionals in order that he could get to the truth about his prognosis.

*"I would rather be at home but if it gets to that stage they can't do anything and nothing I can and nothing they can do. They are doing their best to keep me going. I appreciate that I would like them to be honest and come and tell me. If they don't want to tell me then tell Elsie (wife)"*
*………….. (Barry, patient)*

Glaser and Strauss's (1967) '*Awareness of Dying'* book describes this phenomenon as 'closed awareness' where the patient who is terminal may not be aware because the physician chooses to withhold information for fear of the patient' 'going to pieces'. Interestingly, more recent studies seem to suggest that medical ideology of 'delivering curative treatments' has led to this 'not wanting to give up hope' phenomenon. (Gadoud et al 2013, Granek et al 2013, Willmott et al 2016). The following memo illustrates my informal observations during a ward round with one of the cardiology teams.

> Memo
>
> *Just interviewed a junior doctor who made an interesting comment about giving information to the patient. During the interview he said "I think we give them what they need" referring to the patient. This statement made me think how does this doctor know how much information to give the patient? What is telling him that the patient has had the right amount of information? I have heard many doctors talk about the importance of the patient 'not*

> *losing hope'. However, it is clear we are not being honest. Went on a ward round today and observed patients who were not being encouraged to participate in the discussion. The information was passed to colleagues across the bed or chair where the patient was sitting. One patient looked particularly bemused and wasn't sure what was happening. There was no opportunity for the patient to ask a question. In fact the junior doctor after the ward round went back and asked the patient if he had any questions. There was lots of medical jargon being used which the patient did not understand. The relationship between the patient and the doctor is one of 'power' which is described in Ivan Illich's book, Medical Nemesis. How we construct our relationships and play different roles; nurse, patient, doctor all play a part in how much information is given to the patient. Healthcare professionals have the power to withhold or give information……this needs further exploration in my interviews with participants.*

Memo 5 My observations and reflections following the ward round


It was evident once analysis of data was complete that 'giving information' to patients about their end of life care posed both a moral (principles of doing right and wrong) and ethical dilemma (choice to be made between two courses of action) for the healthcare professional. The conflict of roles and having to manage 'professional boundaries' led to healthcare professionals giving patients information on a 'need to know basis'. Consequently, patients were not fully informed of their terminal status and so could not plan or make decisions with their families regarding their end of life care. My initial coding and later more focussed coding led to the discovery of my third theoretical category 'signposting symptoms'.

## 6.5 Theoretical Category 3: Signposting Symptoms

The third category 'signposting symptoms' recognised the importance of symptoms as a way for the patient and the healthcare professional to navigate the uncertainties of heart failure. The

patient would use symptoms as a way of grabbing the healthcare professionals' attention to the

futility of their situation. The healthcare professional would use symptoms to inform decisions

and to navigate the next steps in the care planning. To progress focussed coding and to heighten

my theoretical sensitivity a concept map was used to visually interpret some of my initial and

then focussed codes (see diagram below)
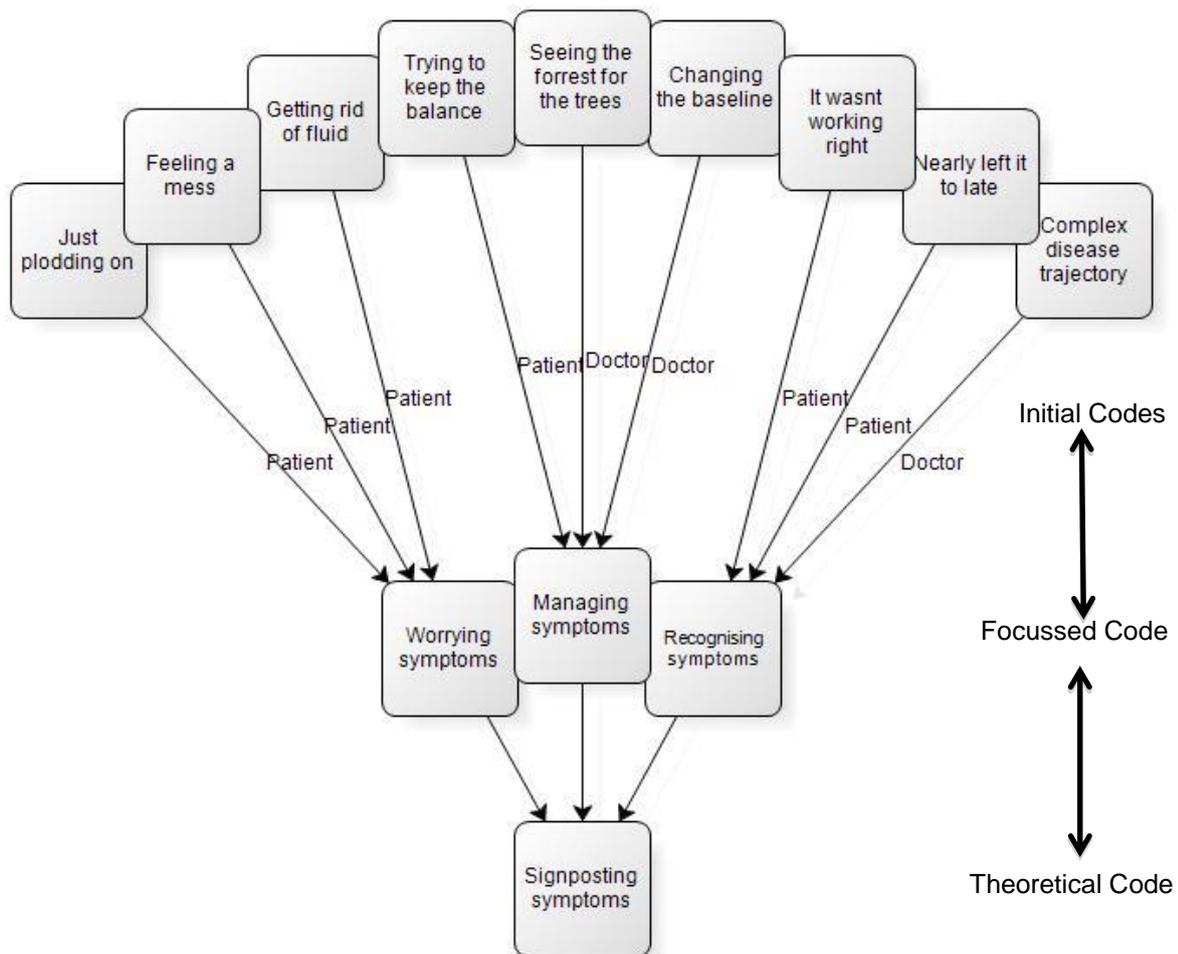


Figure 13 Example of a concept map to illustrate a sample of my initial codes, focussed codes
and theoretical code 'signposting symptoms'.

A high proportion of patients with end stage heart failure suffer with refractory symptoms such

as pain, breathlessness, persistent cough, fatigue, anxiety, depression, constipation, sleep

disturbances and limitation of physical activity (Jaarsma et al 2009). In this study it was

common for patients to present initially to the GP with acute symptoms of decompensation. These symptoms included breathlessness, fatigue, pulmonary oedema and loss of appetite. Patients spoke about making multiple visits to their GP where their medications would be reviewed and then being sent home. There were common 'markers' or 'signposts' which the patient would describe. Often these markers or signposts would be described '*gasping for breath', 'swollen legs', 'loss of appetite' and 'lack of sleep'*. These symptoms would often signpost the GP to refer the patient onto secondary care to be reviewed by an emergency care consultant. Sometimes these markers or signposts were missed because they were masked by other symptoms or co-morbidities. It was not uncommon for a patient to present with pneumonia to then be admitted to hospital and have their heart failure diagnosed. Patients would talk about self-referral to the emergency department when symptoms became progressively worse and the markers or symptoms were not picked up by the GP.

"*I went to doctors because I couldn't breathe. At times they gave me some tablets which they said take for 10 days so I took them for 10 days. They worked to an extent because it all settled down. Once I stopped taking them it went back up again, so it weren't that were it started. I went back to doctors they gave me the same again only for longer and they didn't seem to do anything at all. Next thing I know 2 more weeks down the line I'm going back getting another load of tablets twice as strong as the last lot and I mean you have seen my legs*" ( Patrick, Patient)

"*I went to doctor I had a blood tests but I got that way that the slightest bit of exertion walking I became breathless. I had a do and I rang my sister and she rang the paramedics and they brought me in here…they gave me an injection in my stomach. They said it was to stop me having a heart attack. They kept me in 2 or 3 days and then they said right everything is normal so they sent me home. It was a few weeks later when I began gasping for my breath*" (Paul, Patient)

There were a number of occasions where patients reported feeling ignored despite numerous attempts to grab attention by 'signposting symptoms' like feeling '*short of breath'* and *'gasping for breath'*. On these visits to the GP medications would be re-prescribed, doses altered or new drugs added. It would take a number of visits before the GP would refer to a specialist cardiologist, emergency care consultant or on-call physician. On one occasion 'Allan' a 74 year old gentleman with NYHA stage 4 heart failure told me the only way he could find out any information about his 'heart condition' was to ask his wife to search on the internet.

*"The only thing that annoyed us and this weren't these doctors up here it was our own doctors. I was getting short of breath and I was going down to the doctors and saying "I was short of breath". They say what is your medications and they would say take another half a tablet and this and that. I have been going up and down short of breath for months and then they give us a little pamphlet. I am not the best of readers...so we sat in at night and the wife said just listen to this short of breath ...you've got heart failure she told me from a little pamphlet they have given us...... don't they know"(Allan, Patient)*

For the care of elderly doctors 'signposting symptoms' involved treating the acute episode of decompensation. It involved controlling symptoms rather than acknowledging or trying to change the patient's prognosis or refer to palliative care. In many cases patient's symptoms would improve to allow discharge home. For many patients it was common to be readmitted with worsening symptoms only weeks after being discharged back home. This '*vicious cycle of care'* would then be repeated over and over again; treatment, review, discharge and readmission.

*"If patients are stage 3 and 4 they are usually on maximal medical therapy and are never going to get any better so it's about symptom control as opposed to like making their  prognosis any better. They are  probably going to die in the next six months but they continue to come back into hospital because they become more breathless. We tinker around with the diuretics and*

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*then they go home and then they come back with acute kidney infection because the Frusemide has been upped so it is a recognition that the person is probably dying and that it is symptom control" (Fiona, ST2, Care of Elderly)*

This type of medical model of managing heart failure patients was considered by doctors to be *'sticky plaster medicine' (Geoff, ED, Consultant)* and that often it was just a case of "*cracking on until the end" (Dr Shabib, FY1, Cardiology).* It was unanimously agreed amongst the doctors that conversations about end of life should already have been initiated with the patient before reaching the end stages of the disease. This was felt to be the responsibility of the heart failure team. A barrier to end of life conversations observed on the wards was recognising or diagnosing dying. In the following section I will share my findings under my fourth and last theoretical category 'recognising dying'

## 6.6 Theoretical Category 4: Recognising Dying

The unpredictable disease trajectory of heart failure meant for healthcare professionals recognising dying was considered a challenge. "*Heart failure and Chronic Obstructive Airways are notoriously difficult to prognosticate on it's not like a cancer where you have x amount of time" (Tim, ST2, Care of Elderly).* The healthcare professionals were often resigned to the fact that heart failure was difficult to prognosticate and that the unpredictability of the disease could lead to unexpected deaths.

*They will just try everything they can medically off-loading the fluid you know to the point where the renal function is impaired probably because the disease trajectory is so unpredictable. Even the cardiologists don't like to commit to days or weeks. I know people who I have seen in the clinic on Tuesday and they sadly passed away on the Thursday. I would be thinking what's*

*wrong with them but they are either going to die from pump failure or an arrhythmia so it's what gets you first unfortunately" (Steve, Heart Failure Nurse)*

Despite the availability of prognostic indicators, like the New York Heart Association functional classification, there were very few doctors observed recording the patient NYHA classification in the medical notes. The reason given for this was *'it isn't very helpful'*, *'patients find it difficult to understand'* and *'not always as reliable as blood tests and echocardiogram' (Dr Ahmed, Consultant, Cardiology).* There were very few nurses both on the cardiology and acute medical wards who understood NYHA or knew about the classification.

*"No I never see that on the ward but I think the nurses do ask some of the questions but maybe not all of them. For me they are either out of breath or not out of breath they are either breathless when walking or not out of breath when walking." ....(Liz, Sister, Cardiology)*

The 'bad press' around the Liverpool Care Pathway had made doctors nervous about diagnosing dying and so there was a tendency to prescribe potentially futile treatments for the patients.

*"I think that is our failing I think it is the medics failing I think that is permanently at the moment it is failing like from my point of view. This patient in particular we really have to be sensible about this and how long do we sensibly have to continue doing things for this gentleman which is inappropriate and we have to bear in mind what he wants. Does he want to spend his last days in a hospital or does he want his symptoms looked at in an appropriate setting and I think yeah and I think other than that we can all reflect and improve." (Liam, Registrar, Cardiology).*

The continuation of these futile treatments occasionally led to patients' lives being unnecessarily prolonged; this was distressing for the patient and their families. I witnessed this first-hand when a patient recruited to my study 'Frank' was admitted to an acute respiratory ward with symptoms of acute decompensation.  Frank was a 75-year-old gentleman diagnosed

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with NYHA stage 4 heart failure. Frank until his diagnosis had led a full and active life and in his words *'had never smoked'*. The diagnosis of heart failure came as a real blow and he found it particularly difficult to deal with his loss of independence. He knew he was deteriorating but was upset because in his words *'I am just deteriorating but no one said why it's happening …I am just lost…"* During the 12 months of my study Frank was admitted to a number of different wards including care of elderly, medical admissions unit, cardiology ward and lastly a respiratory ward. Each time we met it was evident that Franks' symptoms were getting progressively worse...*"I think if I see someone else will they be able to help but it seems like they can't really you know" …….* The last time we spoke Frank had been admitted to a respiratory ward with symptoms of acute decompensation. The following memo is my own reflections following this meeting.

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Memo

*Visited ward … today by chance…… more Heart Failure patients to recruit to my study. I was told by the ward sister that there was a gentleman who met the criteria for my study. I asked if I could read the medical notes and she agreed. On reading the medical notes it became apparent that the patient who had been admitted was a patient I had interviewed on ward only a few months back. Reading the medical notes it transpired that Frank had been admitted to the medical admissions unit on the 29th October with severe shortness of breath. He had remained on the medical admissions unit where he was managed by the medical team until being transferred to ward….. I was surprised that he had been on medical assessment unit for so long without a cardiology referral …. or not having been seen by heart failure nurse.*

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*Approaching Frank it was clear he was having difficulty breathing. He lifted his head and smiled and said "hello". I said "do you remember me"? He replied" yes you're the nice nurse whom I chatted to on ward ..." I was pleased he recognised me and that I didn't have to explain who I was-I felt a bit awkward because I knew he was unwell and didn't want him to talk too much as he was breathless. The Bi PAP (breathing assistance) machine was noisy and so it was making it difficult for me to understand what he was saying. Frank's eyes looked very sore due to the high flow oxygen and the leak around the mask. Frank stated "my mouth is dry as hell-they won't let me have a drink.-well I can't drink because I can't take this mask off or I wouldn't be able to breathe". A drip was running into his hand which was keeping him hydrated.*

*Frank took hold of my hand and gave it a squeeze. He said "will I survive do you think". I didn't know how to answer this one. I replied "the heart is a complex organ and when it starts to fail it can affect your lungs and kidneys which is why you are having problems with your breathing". Frank looked at me and said "Oh so will I get better"? I said that the doctors were doing everything they could but these things take time". I wasn't sure if I had reassured Frank. I got the feeling that he knew his condition was terminal and that this could be it... (He had an advance care plan and there was a DNAR (do not resuscitate order) in his notes which the family had agreed). Frank told me that he had had a great holiday in Greece recently with his son and his wife. He had paid –it was as if it was his last treat giving the family a good holiday. Frank stated "it was so warm my breathing was good"*

*I tried to be as upbeat as possible but deep down I knew that this might be the last time I spoke with Frank. I promised on my next visit to the ward I would bring him some E45 for his dry skin. I sat with Frank for a while longer-we didn't speak he just squeezed my hand. He did tell me that he had tried to contact the heart failure nurses in the community but*

*without success "bloody useless". I promised Frank that I would let heart failure team know*

*he was on the ward.  ………………*

Memo 6 Reflections following my meeting with Frank


The fear of 'getting it wrong' and 'diagnosing dying' too early in the disease trajectory often meant that referrals to palliative came too late. In Franks' case his referral to palliative care came 24 hours prior to his death. Ironically, it was on inspection of Frank's medical notes by the palliative care nurse that an advance care plan was found. To my knowledge there had been no discussions with Frank regarding his advance care plan (ACP) despite his multiple admissions to the hospital. Certainly, he had not raised during our conversations the existence of an advance care plan.  According to NHS End of Life Care guidance (2008) the ACP can be instigated by the individual or care provider at any time. However, it is recommended that consideration is given to the following key points in the individual's life: these include a significant shift in treatment focus and multiple hospital admissions (NHS End of Life Care 2008). Often healthcare professionals would say that they were *'too busy', 'understaffed'* (*Liz, Sister, Cardiology Ward)* or there *'isn't enough time to find information '(Jane, Specialist Nurse, Cardiology)* in the medical notes. Often this information was not clearly documented or clearly visible which resulted in the advance care directive being missed.

*"Because it isn't clearly documented and identified that they are end of life as an acute nurse you have to treat something you feel like you have to do something about the heart failure....how far do you leave the patient before you say they are dying" .....(Kelly, Trainee Advanced Nurse Practitioner).*

Similarly, the legacy of the Liverpool Care Pathway had left nurses feeling overly cautious and fearful of recognising dying. There was a culture of *'just carrying on'* rather than being

pragmatic and making sensible end of life decisions. Many nurses feared complaints from families' particularly if they got the 'recognising dying' wrong and the patient recovered.

*"I think it's fear……and possibly we know the patient is dying but what if the patient doesn't die or linger and then the relatives said this patient is dying but he has picked up….and religious beliefs….and I think some nurses are just frightened. You know that this patient is dying but you don't want to tell the relative but we can't say the patient is going to die in 24 hours as it might be even longer" (Debbie, ward manager).*

One doctor suggested that dying was still viewed amongst some of his medical colleagues as a taboo subject and that admitting your patient was dying was associated with failure as a doctor. *"There is a certain sort of feeling amongst the medical profession that to admit that your patient's going to die is you have failed (Geoff, ED, Consultant).* This culture of actively treating the patient and not wanting to fail was viewed by the nurses as a barrier to delivering end of life care.

*"I think from my understanding what the palliative care nurses told me are that they got resistance from the consultants because it was almost they didn't want to accept that these patients were end of life. The emphasis is on treatment rather than long term planning and that is obviously a culture change that we are going to have to address but now that …….here he can target the doctors (Sarah, End of Life Nurse)*

Ivan Illich (1976) in his book *'Limits to medicine, Medical Nemesis: The Expropriation of Health'* refers to this phenomenon as "modern fear of unhygienic death "(pg. 102) where there is a refusal amongst doctors to recognise the point at which they cease to become a useful healer. In this study being a useful healer often precluded doctors' decision making about end of life care. This resulted in many patients not having the opportunity to plan with their families their own end of life care.

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Other barriers to recognising dying involved healthcare professionals having to negotiate their own professional responsibilities and accountabilities. For example, if the patient had access to expert care from the cardiologist it was likely that they would be referred to the palliative care consultant.

*"For example here as you know we have the monthly MDT with everybody from palliative care and physio everybody comes to that and we can discuss cases quite openly. The problem here is that if you are under a cardiologist with an interest who uses that service people get a good deal but the vast majority of people don't get that" (Dr Ahmed, Cardiology Consultant)*

Access to this expert care for the patient was a lottery depending on who was the admitting consultant and the route of admission into the hospital. For those patients admitted to the emergency care areas the likelihood of seeing a cardiologist was doubtful unless a referral had been made directly to the heart failure nurse. There were a number of care of the elderly doctors who were uncertain about their claim to expertise in this area and whether it was a core responsibility of their role.

*You would hope that by the point they are reaching that element of heart failure someone has already said to them that they have a disease that is going to kill them in the coming months and or years. It's all about managing the symptoms because you know like the cardiac decompensation and they get better and go home again you would hope that somewhere along the heart failure clinic or the heart failure follow up that someone has said that this is never going to get any better"…..(Fiona ST2, Care of the Elderly)*

The 'nurse specialist' roles were seen by some nurses to hinder the process of recognising dying and subsequently referral of the patient for palliation. The palliative care nurses believed that ward nurses should be able to recognise dying and be able to confidently deliver care to the dying patient and their families. Conversely, ward nurses were hesitant in making decisions

recognise dying and believed this was in the domain of the specialist nurse. This lack of clarity of whose professional responsibility it was to recognise dying meant there were unnecessary delays in referring the patient onto palliative care services.

*"I would expect the heart failure nurses because they are the specialist nurses to offer that support. ....and if they are not going to and this patient is towards the end of life and they don't see that as their role then maybe they need to link in with the palliative care nurse here". (Sarah, End of Life Nurse).*

The perceived barriers to the lack of expert care by some doctors involved the lack of clear guidance around end of life care. For many doctors having defined guidance provided the necessary support and assurance to know when to refer onto the palliative care team. This lack of uncertainty around recognising dying and referral often delayed the patients transfer and consequently the patient died in a hospital bed. The cardiology doctors often referred to this as being the *'vicious cycle'*

*"To approach palliative care team we don't have a policy of guidelines to recommend co-operation with the palliative are team and to prevent....so you know if a patient is going to die very soon with severe LV dysfunction 20 or below of ejection fraction 20 or below with lots of symptoms would be beneficial if the palliative team were involved and the heart failure nurses"………. One patient was here for 6 months she was in the side ward and we were not doing anything…......we hardly made any changes….it is a vicious cycle…..and it was difficult to get her out of the hospital… these patients are very costly". (Amina, Specialist Registrar, Cardiology*

### 6.6.1 The patient perspective on dying

It was apparent during my conversations with patients that they made very little reference to the topic of death or dying. Conversations seemed to focus on the hope of getting better and getting

back to a normal life. This way of thinking was encouraged by healthcare professionals by reaffirming their own beliefs in not wanting to 'give up hope' on the patient "*not making people lose hope*" "*(Dr Ahmed, Consultant Cardiologist)*. The unpredictable disease trajectory of heart failure meant that medications and tests were constantly being reviewed and changed; this gave patients a sense of renewed optimism and hope. One example of this was during an interview with Heather a 50 year old lady who was stage NYHA stage 3 heart failure. Heather had been seen by the heart failure nurse to be told her results following an[7] echocardiogram. It was clear from the conversation that Heather saw the increase in numbers as a positive despite the fact she was on maximum medication therapy.

"*What he said was it has gone up from 20 to 25 % .....but that could be that it just has been done in a different hospital but no one mentioned that it had gone up....it made me feel better that it has gone up to 25%......you know because that then gives you hope that it will carry on going up which is a good thing and then I can hopefully lead a normal life".(Heather, Patient)*

A way for patients to cope with the uncertainty of death was to use metaphors to describe how they were feeling; for example, *"going out with a blaze" (Peter, Patient)* suggesting a triumphant finale and *"getting to that stage" (Jo, patient)* suggesting a final acceptance of one's fate. For some patient's death was inevitability; a fact of life and something not to be concerned about *"I just can't worry about things somebody says I'm dying. I just say am I?  That's how I am (Paul, patient).* There were patients who wanted to fight the disease all the way and took a stoical stance "*I am not giving up why I should give up. I want to keep on going and enjoy....well I haven't got much left but it is better than lying in a hospital bed all the time" (Jo, Patient).* For some patients nearing death provided an opportunity to make amends with their past.

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[7] Echocardiogram is a type of ultrasound test that uses high pitched sound waves that are sent through a device called a transducer. The device picks up echoes of the sound waves as they bounce of the different parts of the heart. (Olson 2014).

Graham had been estranged from his children for over 20 years. He didn't go into detail about why but it was clear by his nonverbal cues he was finding it difficult to talk about past events. "*I mean they haven't been the best family in the world but by the same token they haven't been the worst neither and neither have I been the best father in the world but I haven't been the worst. I was always there for them in my own way. My wife is a very nice person. I'm not sometimes which is not very good but I have been there for them" …"Anyway that were that it seems that's all rectified. I thought it were time because at the time when it was all going and I thought I might not make it and I wouldn't like to leave it as it is and that's why I said what I said. (Graham, Patient).*

By bringing closure to a past life it meant that Graham could move forward and somehow come to terms with an uncertain future. It was clear from interviewing Graham and other patients that 'centering- self' was an important strategy in dealing with the past and coping with the present. Kreiger (1979) defines centering- self as a state of inner being; a place of quietude within oneself where one can feel integrated unified and focused. Initially, my first thoughts were that patients were behaving passively and that there was an almost accepting of their fate. However, I observed that by 'centering- self' this seemed to provide patients with a way of dealing with the ups and downs of the unpredictable disease trajectory. The following memo illustrates my thinking at the time.

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**Memo**

*The act of 'centering- self seems to be important strategy for patients to enable them to cope with the terminal diagnosis of heart failure. It seems that talking about the past paradoxically helps them to deal with the present. This strategy seems to help in distracting any thoughts about the future and what it may hold. By constructing their own reality of dying there is*

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> *almost a self-validation and acceptance of the situation. By centering their thoughts and*
> *emotions it seems to help patient in dealing with the present and an uncertain future.*

Memo 7 Centering-Self


## 6.7 Conclusion

The writing of this findings chapter has been both rewarding and challenging. The rewards have been seeing the analysis of the data finally coming together to tell the participants' stories. The challenges have been making sure that each word or phrase from each participant is written and represented in context as accurately as possible.

My research journey began by asking the question 'How do healthcare professionals facilitate end of life decision making when considering end of life care for patients diagnosed with NYHA stage 3 and stage 4 heart failure'? The method constructivist grounded theory was applied to guide the gathering and analysis of data. Four theoretical categories emerged; organising care, being informed, signposting symptoms and recognising dying. It is clear from my findings that decision making is not an entity which stands alone but is multifaceted, fluid and requires collaboration and teamwork. A number of barriers appear to prevent healthcare professionals making end of life decisions and these were observed to be; lack of clarity around end of life pathways, professional boundaries, silos of care and opposing paradigms. For the patient this meant having to 'negotiate a vicious cycle of care' which moved between the GP, emergency department, medical admissions unit and the acute medical ward. In healthcare 'cycles of care' are often used for process mapping from a patient perspective with the objective of reducing unnecessary variations in patient care and outcomes (Verbeek et al 2004). In this study the 'vicious cycle of care' for heart failure patients was observed to have a number of access points to healthcare professionals. However, these access points to care did not always provide the patient with the opportunity to receive expert care from either a cardiologist or heart failure

nurse. Neither did this cycle of care allow the patient the opportunity to make informed decisions about their care. Consequently, this 'vicious cycle of care' for the patient was self – perpetuating, exhausting and anxiety provoking leading to missed opportunities for the patient to transition to palliative care. In the next chapter my findings will be discussed making clear the links between existing literature, relevant practice and theory.

# Chapter 7 Emerging Theory and Discussion

## 7.1 Introduction

The primary aim of this study was to explore how healthcare professionals made decisions when considering end of life care for heart failure patients. The theoretical lens of symbolic interactionism provided a way of understanding how participants constructed their own reality of heart failure and end of life care. The method of constructivist grounded theory provided the analytical tools in which to gather and analyse rich and meaningful data. To facilitate the exploration of this phenomenon a number of specific questions were posited:

1)      To explore how health care professionals make the decision to place a patient on an individualised End of Life Care Pathway.

2)      To explore how decision making at end of life by healthcare professionals could affect patients experience.

3)      To explore healthcare professionals perceptions and understanding of end of life for patients diagnosed with end stage heart failure.

The findings outlined in Chapter 6 suggest that the subject of decision making in patients with end stage heart failure is both complex and challenging. In this study the in vivo code 'vicious cycle of care' emerged as a theory to describe how participants met the daily challenges of decision making in end stages of heart failure. It is important to mention here that the in vivo code 'vicious cycle' came from my participants during their interviews where they would describe the care of heart failure as a 'vicious cycle'. Like many cycles of care in health, this cycle was fast paced, turbulent and time limiting therefore was observed to disable the process of end of life decision -making. The data from participant interviews identified that a number of factors influenced this cycle of care. These were categorised into four themes which were

organising care, being informed, signposting symptoms and recognising dying. In this chapter these four theoretical categories will be explored in depth along with the supporting wider body of literature. Following on from this discussion the limitations and strengths of this study will be presented; Chapter 8 will conclude with recommendations for practice, policy, guidelines and future research. To begin this chapter the emerging theory negotiating a 'vicious cycle of care' will now be discussed and its fit with decision making when managing patients with end stage heart failure.

## 7.2 The Substantive Theory - Negotiating the 'Vicious Cycle of Care'

The theory 'negotiating the vicious cycle of care' (Figure 14) was an in vivo code which emerged to explain how participants in my study negotiated decision making within the cycle of end stage heart failure. The theory suggests that this turbulent 'vicious cycle' of care for heart failure patients disabled the shared decision-making process between healthcare professionals and the patient resulting in a delay in transitioning patients to palliative care. To try and negotiate this cycle of care participants were found to adopt a number of different strategies which were neatly packaged within the four theoretical categories; signposting symptoms, organising care, being informed and recognising dying. These themes identified by the participants and grounded in data were found to be important landmarks in the negotiation process and assisted participants in making sense of each stage of the cycle. To trigger this cycle of care required the patient or the family to recognise or 'signpost symptoms' of acute decompensation and seek medical intervention from the GP. In this first stage of the cycle patients commonly adopt a passive role in decision making relying on the GP to medicate and treat symptoms. In this stage the patient requires multiple visits and reviews by the GP in order to optimise drug dosages. The denial by the patient of the futility of the situation and the time constraints enforced on the GP mean that information on the terminal phase of heart failure is limited. This can leave the patient moving back and forth trapped in this stage of the cycle

indefinitely only moving to the next stage if the patient cannot legitimise the GP in this role and symptoms become progressively worse. The patient uses symptoms to bargain with the family and the GP to signpost a self-referral to the emergency department where standard medical intervention is given. The emergency cycle is chaotic and disruptive and like the GP cycle is limited in the time allowed to treat symptoms before the patient is either discharged or moved to the next stage of the cycle; the Medical Assessment Unit. In the Medical Assessment Unit patients and families continually negotiate their position with the healthcare professionals seeking expert opinion (being informed) and asking questions. The negotiations are limited in this stage of the cycle; the healthcare professional avoids 'telling' to avoid the awkwardness of addressing the patient's terminal phase of the disease. There is little opportunity in this stage of the cycle to determine the patient's holistic needs. Meeting organisational demands means the opportunity for the healthcare professional to refer the patient to the cardiologist or heart failure nurse is missed resulting in the patient either being moved onto the last stage of the cycle, the ward, or discharged back to GP care. In the final stage of the cycle changes in functional status prompt the patient to renegotiate relationships with both their families and the healthcare professionals managing their care. These physical and functional changes experienced by the patient act as a catalyst to review their current status within the illness trajectory and to develop strategies like 'centering self' in order to cope with an uncertain future. The ability of the healthcare professionals to recognise this stage and initiate end of life discussions is hampered by role legitimacy, professional boundaries and hierarchies of care. It is during this stage that missed opportunities to refer the patient to palliative care lead to the triggering of the vicious cycle of care; the patient is discharged from the ward only to begin a self-perpetuating, self-limiting cycle of heart failure care.

Transfer to Medical Assessment Unit

Referral to Hospital Self-Referral to ED

Transfer to Medical Ward

Organising Care

Signposting symptoms

Cardiologists

Being Informed

Heart Failure Nurse

Palliative Care

Recognising Dying

GP assessment and treatment of patient

Discharged Home

Patient with symptoms of acute decompensation
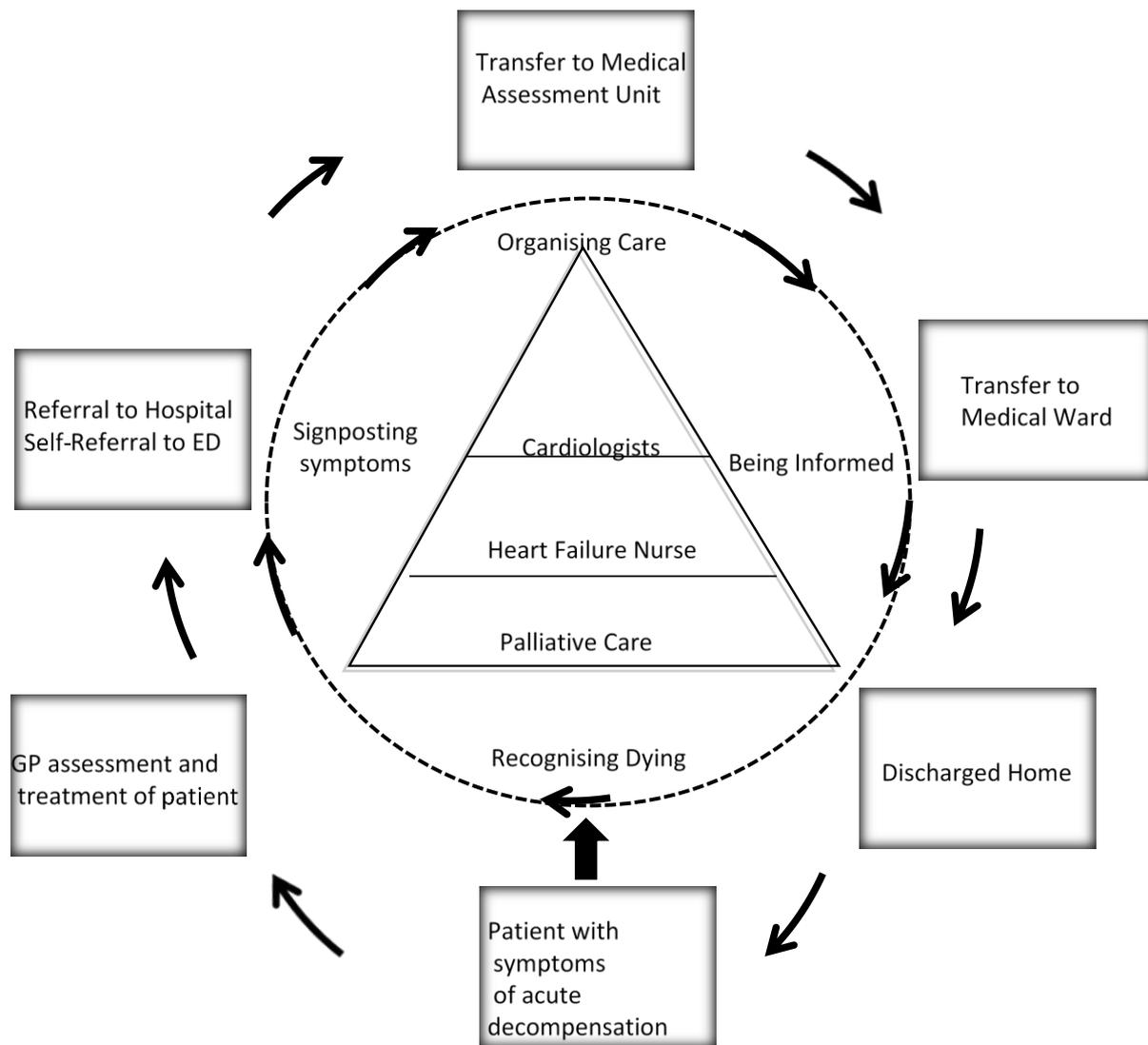
Figure 14 Cycle of Care for Heart Failure Patients

## 7.2.1 Negotiated Order Theory

The constructivist grounded theory methodology and the theoretical framework of 'negotiated order' theory (Strauss et al 1963, Strauss and Bucher 1964, Strauss 1978) assisted in providing an in depth understanding of the participants' social processes when considering decision making in end stage heart failure. The term 'negotiated order' was first introduced into the

literature by Strauss et al (1963) as a way of conceptualising "ordered flux" they found in their study of two psychiatric hospitals. The conceptualisation recognised the stable features of an organisation and how rules, hierarchies, boundaries and ideologies became the organisational backdrop through which people would interact and attempt to get their work done (Maines 1982). The authors recognised that through negotiation the organisational structure is able to operate and so negotiation was seen as important for understanding stability as well as change (Strauss et al 1963). In this study participants' use of negotiation helped them to bargain and broker the decision-making process when it came to transitioning each stage of the vicious cycle of care. Strauss (1978) argues that all social order is negotiated, not accidental, but follows the lines of existing communications and structural conditions of the organisation. The turbulent nature of the vicious cycle of care meant that negotiations were often dependent on organisational rules and for healthcare professionals this became a barrier to engaging with patients in end of life conversations. The negotiated order theory provided a way to explain what was happening to my participants and how these outside influences like organisational demands impact on the processes of decision making.

**7.2.2 Situating the substantive theory and study findings within the context of the existing literature**

Conceptually navigating the 'vicious cycle of care' differs from existing cycles of care because it focuses on the patient's ability at each stage of the cycle to make informed choices about their care. The cycle points to key transition points that the patient moves through which become important in either enabling or disabling the process of informed decision making. The findings reveal some important concepts which contextualise the participants' experiences and provide a more in depth understanding of the phenomenon end of life decision making in heart failure.

The following sections will now discuss in more detail the four theoretical categories which make up the 'vicious cycle' of heart failure care and presents the literature which underpins the study findings.

## 7.3 Theoretical Category 1 -Organising Care

### 7.3.1 Emergency Care

The theoretical category 'organising care' emerged to explain how the participants navigated the cycle of heart failure care. The findings identified that 'organising care' was often multifaceted and involved healthcare professionals having to balance professional rules with organisation policy. For example, one doctor in the emergency department (ED) described the challenge of meeting a four hour wait target and as a consequence only having time to treat patient's symptoms; he referred to this as '*sticky plaster medicine*'. The decision making was based on clinical judgement alone rather than in depth cardiological assessment and therefore if symptoms improved patients would be considered for discharge home. There was a general acceptance in the department that the patient would either be re- referred by the GP or readmitted to an acute medical ward with symptoms of acute decompensation. These findings are consistent with Lee et al (2010) who after reviewing patients' medical notes found a total of 4.5% patients died within 30 days from admission and 1.3 % patients died within 7 days of discharge from ED. The patients' narratives suggested that attendance to ED happened when symptoms of acute decompensation were not improving despite frequent reviews by their GP. A number of patients described '*losing confidence in the GP*' and gave this as a reason for attending the ED. Such findings are significant because they highlight the challenges for the patient in not gaining access to the right care. Hancock et al (2014) and Smeets et al (2016) suggest that multiple attendances to the ED were often due to the GP's lack of confidence around the titration of beta blockers, ACE inhibitors and the time required to follow up and monitor the patient.

**7.3.2 Ward Care**

The healthcare professionals working on the general medical wards had a strong view that the patients admitted with heart failure were often not admitted to the right care environment and this hampered the delivery of good care (NICOR 2013). At interview a number of nurses voiced concern regarding the daily demand for medical beds and believed this contributed to the displacement of patients into acute medical beds. Nevertheless, the ward nurses described a commitment to delivering a good standard of care despite having to negotiate challenging organisational demands. The doctors in this study shared a similar view to that of the nurses and agreed that they were good at managing the acute phase of decompensation and '*tinkering around with the diuretics'* but more expert intervention was seen to be in the domain of the cardiologist. In the focus group care of the elderly doctors raised a concern that limited access to some reporting systems meant that decision making around management plans was often delayed. These findings are consistent with Parmar et al (2015) who found that a greater percentage of patients admitted to the cardiology ward underwent in-patient echocardiography suggesting poorer access to specialist investigations for care of elderly doctors. Healthcare professionals described not having access to the right skills and knowledge as a barrier to having end of life conversations with patients (Whellan et a 2014, Charnock 2014, Glogowska et al 2015). To navigate this problem the 'link nurse' role had been introduced to the wards by the heart failure nurse to try and increase knowledge and improve referral rates to the heart failure service. The nurses initially were keen to embrace this role but described having '*not enough time'* and '*lack of senior nurse support'* as barriers to engaging with this initiative (McKeeney 2003, Hasson et al 2008). Interview data suggested that education around end of life care for doctors was brief, inadequate and delivered primarily in the medical school focussing on

protocols like 'SPIKES' breaking bad news.[8] A general consensus amongst the junior doctors in this study was that using a protocol provided a structure to end of life conversations but the majority agreed it was observing senior medical colleagues where they had gained the most experience. These findings concur with a UK qualitative study undertaken by Price and Schofield (2015) who found that out of 11 FY1 doctors interviewed 7 reported no specific end of life training in any undergraduate programmes. Similarly, Schmit et al (2016) in a survey of 787 American residents and fellows in one academic institution found residents had very little training or no training on end of life discussions in both medical school and residency (54.3% and 88.1 % respectively). Physicians who reported having end of life training whilst at medical school reported a greater confidence in having end of life conversations (OR=3.3(95% CI:1.2-8.9); p=0.0017, and (OR=2.1(95% CI:1.1-4.1); p=0.003 respectively. Likewise, the medical students who had received end of life training before leaving medical school felt adequately prepared to have end of life conversations (OR=2.1(95%CI:1.1-4.1); p=0.030). In this study doctors unanimously agreed that end of life training programmes should be part of the existing post graduate training programme. Furthermore, the doctors agreed that the specialist palliative care team were vital in playing a role in this training programme as well as providing expert advice to healthcare professionals on end of life care.

### 7.3.3 Healthcare professionals experience of decision making

Consistent with findings from other studies a number of ward nurses believed the overall responsibility for initiating end of life conversations with patients and families was with the doctor responsible for the patient's care (Larson and Tobin 2000, Tobler et al 2012, Ho et al 2016). This view was not shared by the senior ward nurses or specialist nurses who believed

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[8] SPIKES is a six-stage protocol used by doctors to provide a structured way to deliver bad news to a patient. The stages of the protocol are as follows: Setting up the interview, assessing the patient's perception, obtaining the patient's invitation, giving knowledge and information to the patient, addressing the patient's emotions with empathetic response and strategy and summary (Baile et al 2000)

they had the autonomy to engage in shared decision making based on their expertise and knowledge of the patient, a view echoed by Beckstrand et al (2009). The specialist nurses in this study described having a positive working relationship with the doctors which they believed allowed them to build on their own knowledge and increase their confidence in making autonomous decisions (Nieminen et al 2011, Ramis et al 2013). In contrast the junior nurses perceived a lack of autonomy and role legitimacy when it came to 'being heard' and voicing their concern about end of life care planning. The challenges around 'role legitimacy' would often manifest in tensions between the junior nurses and doctors particularly when medical care plans had been changed or potentially futile interventions had been prescribed without prior knowledge. In this context nurses would describe feelings of uncertainty, frustration and anger which led to dissatisfaction and disengagement from ward culture. The phenomenon of 'tension' has been explored by Hopkinson et al (2003) who found that when a nurses experience of a patient dying does not meet the personal ideal then she (sic) may experience tension that could manifest itself in negative emotions. In this study nurses talked about seeking out supportive collegial relationships amongst their own peer group as a way of trying to diffuse professional and personal tensions.

Underlying many of the ward nurses' concerns was the sense of powerlessness in the end of life decision making process. In this study the ward nurses' sense of powerlessness was described as 'limiting' made worse by a perceived 'hierarchy' which got in the way of patient referrals to the specialist nurses' and palliative care team. In Stein's (1967) seminal work on interpersonal dynamics between nurses and doctors, he describes the nurse-doctor relationship as an interprofessional game in which the power of the physician is maintained at the expense of the nurse's intellectual contribution to care. A follow up paper some years later seems to suggest that social change was a catalyst which shifted nurses from doctor's 'handmaiden' to autonomous decision maker and this in turn had begun to challenge the hierarchical structure of

medicine (Stein et al 1990). In this study nurses found ways to overcome 'powerlessness' by seeking support and advice from more experienced nurses or using information-based cognition to negotiate care with medical colleagues on behalf of the patient. Nurses described how the inability to impact on end of life decisions occasionally led to 'moral dilemma' and a concern that they could not always reduce the patients suffering.

Hierarchy emerged as a different theme for doctors who described being morally responsible for making the right end of life decisions but were aware that on occasion their decisions may conflict with the nurses. These findings are congruent with Oberle et al (2000) who found nurses' and doctors' end of life decision making engendered a 'moral distress' in both groups which led to a degree of uncertainty in knowing what was the right course of action for the patient. Problems for both groups in this study appeared to rest primarily on the nature of their responses to the patient and the process by which decisions were made. Interview data suggested that the issues centred around the moral obligation to respond to suffering and the nature of that response. These findings highlight the need for further exploration of how moral and ethical dilemmas impact on end of life decision making in the acute care setting. Furthermore, these findings indicate a common moral ground that nurses and doctors share which may go some way to redesigning a cycle of care.

### 7.3.4 The patient's experience of decision making

Generally, the patients' narratives suggested that a passive role was the preferred model of choice when it came to making decisions about treatments and care planning. The rationale given by patients for this choice was 'trusting' the doctors' decision and the 'nurses and doctors knowing best'. In contrast there were a few patients who deviated from this position of passivity to a more active role in the decision making. These patients were observed to have an already established relationship with the cardiologist and were frequent attenders to the cardiology

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ward. Patients who favoured a passive role generally viewed any decisions made by the doctors regarding therapies as positive. A number of patients expressed the opinion that if a doctor was suggesting a therapy then there must be a degree of 'hope' that a cure was available to treat their heart failure. The highly complex set of factors nudging patients towards passivity were further magnified in that cognitive impairment, low health literacy and depression (Gazmararian et al 1999, Beckelman et al 2007, Dickson et al 2007) were present in over half of the patients in this study. One explanation for these distinct passive and active coping strategies was the need for some patients to construct a coping style to help manage the anxieties of an uncertain future. Charmaz (1997) in her seminal text 'Good Days, Bad Days' refers to this strategy as 'constructing denial' where an individual will deny they have a chronic illness in order to preserve their individuality and 'self-identify'. In this study patients' 'denial' manifested itself during interviews when there was a reluctance to discuss the terminal stages of 'heart failure' or engage in conversations about the present or future. Instead patients would focus on their past identity, the 'past self', as a way of restabilising and reconnecting with who they were. Charmaz (1987) believes 'denial 'can be a risky strategy for the patient stating "When professionals believe certain patients deny their illness, they deny them partnership in treatment planning" (p17). The literature suggests that preferences around decision making for patients is a dynamic process (Thorne et al 2001, Doherty et al 2005). A Cochrane review of decision aid trials demonstrated that patients preferred more involvement in decision making when they were better informed (O' Connor et al 2003, O'Connor et al 2009, Stacey et al 2011, Stacey et al 2014, Stacey et al 2017). Furthermore, some studies have suggested that patients who are more involved in their decision making have better outcomes (Greenfield et al 1988, Anderson et al 2009, Matlock et al 2010). The finding in this study suggests that patients to avoid the reality of their prognosis take on a past identity to help cope with the future and the burden of heart failure. It is therefore important that healthcare professionals recognise in 'passive' patients these

strategies of coping in order to facilitate better ways of enabling the decision-making process. Further work needs to be undertaken to understand and test communication techniques to help passive patients make decisions.

**7.3.5 Blurring of Professional Boundaries**

In this study professional boundaries were found to have a strong impact on how healthcare professionals influenced the transition of patients to end of life care. This made it much more challenging for the palliative care team to influence and change routine ward practice. Efforts by the palliative care nurses to improve care for heart failure patients were hindered by the reluctance of some healthcare professionals to acknowledge their legitimate role in care of the dying. A finding which emerged from this study was that intra-professional boundaries existed between the different medical specialities which were often subtle but led to independent working and doctors competing for 'professional territory', resource and recognition. Similarly, intra-professional boundaries were observed between the ward nurses and specialist palliative care nurses where uncertainty existed around the professional responsibility for the dying. Consequently, the blurring of boundaries was found to disable the shared decision-making process between the patient and the healthcare professional often resulting in the continuation of futile treatments and delaying the patient's transition to palliative care services (Goodlin et al 2008, Gadoud et al 2013, Beattie 2014). To negotiate 'role blurring' ward nurses frequently had to 'step out' of the ward's organisational structure to negotiate and bargain with the doctor on behalf of the patient. A number of nurses described this act of negotiation as part of their role and legitimized their actions by claiming a moral and professional duty towards the patient. According to Bucher and Stelling (1977) organisational rules can be fudged or even broken by persons or groups pursuing their own vested interests. In this study ward nurses 'fudging of rules' was viewed more as championing the patient's cause rather than pursuing any personnel

glorification or professional gain. Strauss et al (1963) refer to this process as the "ruled" and "unruled" behaviour:

*"Except for a few legal rules, which stem from state and professional prescription, and for some rulings pertaining to all of (a hospital), almost all of these house rules are much less like commands, and much more like general understandings: not even their punishments are spelled out; and mostly they can be stretched, negotiated, argued, as well as ignored or applied at convenient moments"* (p,153)

These findings support the work of Sanders and Harrison (2008) who explored healthcare professionals experiences of occupational boundaries when managing the care of heart failure patients in a medical setting. The authors found that different multi -disciplines caring for the heart failure patient entered into a discursive rhetorical battlefield in which multiple discourses would compete in order to legitimise occupations, work patterns and codes of practice. More recently Liberati's (2017) study exploring nursing -medical boundaries found that patients' state of awareness, the type of clinical approach adopted by nurses and doctors and the level of acuity on the ward significantly affected the construction of medical and nursing boundaries.

**7.3.6 End of Life Care Plans**

A number of doctors expressed disappointment in the demise of the Liverpool Care Pathway stating it had provided a vehicle for shared decision making and planning of end of life care (Chinthapalli, 2013). In contrast, nurses described the LCP as a 'tick box' exercise and therefore were happy to return back to what they believed was 'individualised care planning' (Venkatasalu et al 2015). The doctors in this study believed that the confusing terminology and guidance around end of life 'pathway' and 'care plan' did not help the decision-making process and as a consequence had led to what they described as 'professional paralysis'. This finding is consistent with Twigger et al (2016) who found that doctors' lack of confidence in identifying

end of life had led to the persistence of a 'cure culture' and the continuation of futile treatments. Overall, the doctors main concern was placing a patient on an end of life care plan and 'getting it wrong' or being criticised by the families (Rivera et al 2001, Palda et al 2005, Kadooka et al 2012). The bad publicity around the Liverpool Care Pathway had left many of the doctors in this study feeling apprehensive about making end of life decisions. Tensions arose when the prognostication tools did not provide the medical certainty or there was concern that delaying the pathway could lead to poor end of life care. Willmott et al (2016) found that prognostic uncertainty contributed to the provision of futile treatment because of the difficulty in assessing futility. In this study doctors' commented on the continuation of futile treatment and how it was difficult to stop when patient and families' expectations around treatments had been raised. The issue of medical futility, social power and authority of medicine was identified by Ivan Illich (1976) in his seminal text 'Limits to Medicine'. According to Illich (1976) "*The doctor's refusal to recognise the point at which he has ceased to be a useful healer and to withdraw when death shows on his patient's face has made him into an agent of evasion or outright dissimulation. The patient's unwillingness to die on his own makes him pathetically dependent*" (p103). The doctors in this study acknowledged the continuation of treatment could potentially prolong the final stages of the dying process but felt ethically and morally obliged to continue with futile treatments. The findings confirmed that there was persistence of a cure culture amongst the doctors who reported a profound fear of getting it wrong, causing harm or being criticised by patients' families. Further exploration of this phenomena is indicated in order to address existing barriers to end of life care planning and to prevent the unnecessary prolongation of life.

## 7.4 Theoretical Category 2-Being Informed

The category 'being informed' was complex because it highlighted a number of different strategies healthcare professionals and patients would use to either seek or avoid information within the 'vicious cycle of care'. For the healthcare professional 'being informed' often meant

grappling with personal values and professional ethical codes to avoid causing any upset or harm to the patient. For the patient 'being informed' involved making decisions to seek information at the risk of having to live with the present and come to terms with an uncertain future. In the section below these issues will now be discussed in a little more detail from both the patient and healthcare professional perspective.

**7.4.1 Healthcare Professionals' Perspective**

Healthcare professionals reported 'being informed' was challenging because of what they perceived to be the 'the revolving door' (Alspach 2014) of the heart failure patient. The crucial steps of sourcing information were often missed because the medical notes were either with another department or in some cases had been misplaced. The lack of familiarity with the patient meant that sourcing information was critical for health care professionals in being able to make informed decisions about the patients' treatment plans. This was found to be a particular issue for the emergency department doctors who described having to provide treatment in an urgent situation without knowing the patient's past medical history. Doctors' views on how much information to give to a patient varied depending on a number of factors; a) if they were familiar with the patient b) if they believed that the information was going to benefit the patient. A general consensus amongst the doctors was that any prognostic information should be delivered sensitively so as not to cause undue distress to the patient. In fact, a number of doctors were of the view that withholding information or choosing what information to give was a good thing if it meant that the patient didn't give up hope. These findings supplement those of Hancock et al (2007) and Clayton et al (2005) who found that doctors were reluctant to disclose prognosis because they wanted to preserve hope and avoid harm to the patient. The principles of non-maleficence and beneficence (Beauchamp and Childress, 2008) were important to the doctors in this study who described the giving of information as a careful balancing act between meeting patient expectation and avoiding harm. Gordon et al (2003) argue that these principles may be

misguided and that beneficence would ideally still entail full disclosure of prognosis without necessarily causing harm. Likewise, nurses were of the opinion they would be more comfortable raising discussions and giving prognostic information if it was perceived to benefit the patient and their families. Peculiar to the nurses was this assumed role of 'gatekeeper' which was assigned to the most senior nurse on the ward and whose function was to act as a conduit between the doctor, patient and the families. The purpose of this role was to buffer any unwanted or upsetting information and soften any of the unnecessary medical jargon. Such findings collaborate with Kars et al (2015) who following s systemic review found that nurses tended to assume the role of 'gatekeeper' when it was felt that the patient was vulnerable. There was a perception by healthcare professionals that some patients may not be able to understand and accept information and this dictated the level of prognostic disclosure. Notably, this practice was observed on daily ward rounds where information would be given to the patient based on their ability to cope (Barnes et al 2006). By adopting this strategy, it isolated patients from asking questions and often resulted in a second party having to translate the consultant care plans. Similar findings were reported by Swenne et al (2013) who found patients wanted to be part of the ward round and ask questions but were met by a paternalistic attitude which did not encourage questions.  The data seems to suggest that 'being informed' for the patient was guided by a number of unsaid rules which were fashioned by healthcare professionals to avoid awkward conversations and upsetting the status quo. This finding is important because it highlights how despite the reverence to patient centeredness there are still pockets of practice which foster a paternalistic style of care and so may disable the decision-making process.

**7.4.2 Intuitive Knowing**

The concept of 'intuitive knowing' is how nurses described the process of deciding when was the right time to give the patient information about their heart failure condition. This process of intuitive knowing was seen by the nurses as a way of protecting the patient from any information

which could potentially cause any harm or distress. Equally, intuitive knowing was what the nurses used to decide the patients' readiness to receive information. This process was carefully orchestrated to allow the nurses time to flag any concerns to the doctor and supress what may be perceived unwanted information. Interview data suggested that the recipe for 'intuitive knowing' appeared to have two main ingredients: 'knowing the patient' and 'knowing the family'. Carper (1978) in her seminal text described four patterns of 'knowing' that nurses use to develop knowledge and beliefs about their practice and patient care. These included: 1) empirics, the science of nursing, 2) aesthetics, the art of nursing, 3) the component of personal knowledge in nursing and 4) ethics, the component of moral knowledge in nursing. According to Calder (1978) these patterns of knowing are not mutually exclusive and nurses use attributes of all four patterns to successfully care for the patient. Following Calder's (1978) study, a number of theories were posited to try to explain the concept of knowing and caring in nursing. Watsons Transpersonal Caring theory (1979) focus on creating a mutual caring relationship between the patient and the nurse based on three main principles of respect, compassion and support. The theory advocates nurturing the spiritual and preserving human dignity resulting in a deeper connection with the patient and the nurses 'knowing' (Watson 1985). Swanson's (1991) Middle Range Theory of caring further defines 'knowing' by saying it is "*when one is operating from a basis of knowing, the care provider works to avoid a prior assumption about the meaning of an event; centres on the one cared for and conducts a thorough, ongoing cue-seeking assessment of the experience of the one cared for*" (p163). A clear example of this was in this study where families were observed to play a crucial role in the patient 'being informed' Nurses described how families would often provide essential nonverbal and verbal cues signalling the patients' readiness to receive information. These nonverbal cues or triggers provided a clear signal to the nurse that it was the right time to engage in end of life discussions with the patient. This finding is consistent with Manusov et al's (2015) research which following

interviews with 55 family members identified a number of nonverbal communicative functions which were categorised in to five themes; relational messages, emotional expression, interaction management, social support and transitioning.  The importance of these functional categories was to provide the families with a way of understanding and making sense of some of the nonverbal cues when it came to end of life care (Manusov et al 2015). Similarly, in the study nurses described how the use of nonverbal cues provided a way of making sense of the patients' and families' need for information when it came to end of life decision making. It is clear from this study's findings that interpretation of these nonverbal cues is important in helping nurses decipher patients and family's needs for information. The issue of how healthcare professionals may use nonverbal and verbal cues in end of life care planning needs further exploration to elicit how we can best serve the information needs of both the patient and their families

### 7.4.3 Patients' Perspective

Overall, the patients considered 'being informed' part of the role of the healthcare professional and believed there was no reason to question the information being given. The general consensus amongst most patients was '*no news is good news'* and so they were happy to avoid seeking information. For the majority of patients, a sense of connectedness with the healthcare professional was cited as being important particularly if the 'being informed' involved giving bad news (Kuhl et al 2010). Despite access to information using technology platforms like 'Google'™ were avoided by most patients preferring the information to come from a 'real person' they could trust. Only one patient in this study sourced information from undertaking a Google search giving the rationale that no one during his visits to hospital had explained his heart failure condition. Interestingly, in this study very few patients were observed proactively seeking out information from healthcare professionals preferring to take a more backstage passive role in the process of being informed. Literature around the topic of health information seeking behaviour seems to suggest that avoiding information is a common strategy used to

protect oneself from the burden of knowledge (Klindtworth et al 2015). Lambert et al (2007) noted that many individuals choose to cope with a health-related threat by seeking information, others are found purposefully to avoid such information. Information avoidance, also referred broadly as "denial, blunting or repression emphasises that some choose to divert attention from the perceived threat" (Lambert et al 2007, p1009). Other factors observed to influence patients' information seeking were found to be the physical symptoms of heart failure, for example breathlessness, which made it difficult for many patients to engage in questioning or conversation. A number of patients in this study had cognitive impairment due to the heart failure and so their attention to detail and ability to assimilate facts was poor. It is well documented that decreased cardiac output, reduction in cerebral blood flow, and modifications of blood pressure lead to cognitive impairment of the brain (Leto et al 2014). Klindtworth et al (2015) believes that patients who are elderly may not perceive heart failure as a life limiting disease. The mean age of patients in this study was 70 years and so this may explain why some patients declined to seek information about their heart condition. The recent government publications on end of life care has stressed the importance of health care professionals being open and transparent when it comes to the giving and sharing of information with patients and their families (DH 2008, DH 2009, DH 2010, DH 2012). This finding is important because it highlights the need to recognise those individuals who may require a different strategy or a different approach to being informed by healthcare professionals. Certainly, future research needs to consider the impact cognitive impairment may have on the giving and receiving of information for patients and their families. This should be a consideration for future policy making.

**7.5 Theoretical Category 3-Signposting symptoms**

The third category 'signposting symptoms' describes how patients and healthcare professionals used symptoms to navigate their way through the 'vicious cycle of care'. For the patient

symptoms would signpost the need to seek treatment by either attending the GP surgery or in many cases the local emergency department. In the case of healthcare professionals symptoms of decompensation would signpost the need for urgent intervention. The turbulent and fast paced nature of the vicious cycle of care meant that once patients' symptoms were treated they were often discharged home without follow-up from a cardiologist or heart failure nurse. The pattern of 'signposting symptoms' would then become a continuous vicious cycle where the patient and healthcare professional felt powerless to intervene. The majority of studies undertaken to date have focussed mainly on the delays in patients seeking medical attention for their symptom burden (Friedman et al 2008, Gravely-Witte et al 2010). The finding in this study is unique as its brings to the fore the problem of cycles of care which do not facilitate the timely intervention and treatment of symptoms in heart failure. The following sections will now discuss 'signposting symptoms' from the healthcare professional and patient perspective.

### 7.5.1 The HealthCare Perspective

According to Parsons (1951) the primary definition of the physician's responsibility is to do everything possible to forward and complete, early, and painless recovery of the patient (p450). In the present study the physical 'symptoms' of illness were what doctors in this study treated to relieve symptoms, improve exercise capacity, reduce hospitalisations and prolong life. The concern for a number of doctors was that elderly patients admitted with heart failure were less likely to receive the appropriate care and investigations if they were admitted acutely. The care of elderly doctors reported that the older frailer patients presented a challenge when it came to managing symptoms because they usually had other significant co-morbidities that could mask or take precedence over the heart failure (McMurray et al 2012). Furthermore, doctors commented that elderly patients did not always tolerate or comply with the standard heart failure treatment regime making the symptoms of decompensation difficult to manage (Johansson et al 2001, Rutten et al 2003). The doctors' descriptions of how symptoms were managed suggested

an initial primary focus on alleviating patient symptoms and trying to optimize functional capacity. A number of doctors commented on how there was very little time to spend on goal setting and once symptoms improved this then signposted the doctor to discharge the patient back into the community. Evidence suggests that the journey of elderly heart failure patients is often one of repeated exacerbations and progressive functional decline   due to a lack of early identification and referral to a heart failure team (Heckman et a 2014). In this study doctors referred to the constant demand for medical beds and the lack of clinical resource as possible reasons for missed opportunities to refer the patient to the heart failure team. This finding is consistent with a recent audit which found that despite government recommendations mortality remained high in care of elderly wards (16%), followed by non-specialist input wards (14.7%) and general medicine (10.4%) (National Heart Failure Audit 2014-2015). Following this report NICE (2014) issued the following guidance (CG 187) on the management of acute heart failure advising that all patients being admitted to hospital with suspected acute heart failure should have early and continuing input from a dedicated specialist heart failure team. It is clear that work needs to be undertaken with the geriatricians and generalist physicians to support the development of 'specialist roles' within their service to support the ongoing care of heart failure patients.

### 7.5.2 The Patient Perspective

In this study breathlessness (dyspnoea) was identified by the patients as the most common symptom and was given as a reason for multiple visits to the GP and emergency department. (Parshall et al 2001). The second most commonly mentioned symptom by patients was oedema or 'fluid retention' often leading to restrictions in mobility and poor quality of life due to the high dose of diuretics. In this study patients described the families as being instrumental in 'signposting symptoms' and advising to seek help from the GP when it was evident that the heart failure was not improving (Friedman et al 2008). Counterintuitively, some patients in this

study described using diversional tactics like self-medicating, reducing dietary intake or reducing activity as a way of ignoring worsening symptoms and avoiding medical intervention (Bennett 2000). In many cases this tactic was found to be employed by patients who were reluctant to acknowledge that their symptoms may be getting worse. Patients' narratives suggested that 'symptoms' were not how they wanted to be defined and so avoidance in seeking support or advice from the GP was common place until experiencing crisis in their heart failure condition. Glogowska et al (2016) argues that by their very nature personal health decisions can be uncertain and risky because outcomes are unknown and patients often have limited knowledge, information and experience on which to base their decisions. In this study patients were frequently found to base their decisions on past symptom experience and so the process of decision-making became more iterative based on a repetitive vicious cycle of care.

## 7.6 Theoretical Category 4-Recognising Dying

The findings in this study seem to suggest that there is still a degree of uncertainty amongst healthcare professionals when it comes to recognising dying. The demise of the Liverpool Care Pathway along with an unpredictable disease trajectory were reasons given by the doctors in delaying or avoiding end of life discussions with their patients.  There was a belief held amongst some of the doctors that recognising dying was equivalent to failure and so they felt morally justified in continuing to provide medical intervention. A number of doctors recognised that prolongation of life was not right but at times felt obliged to meet the treatment expectations of both the patient and their families. The difficulties in recognising end of life have been demonstrated in the literature where doctors have failed to recognise dying and been overly optimistic with treatment plans (O'Leary et al 2009, Willard and Luker 2006, Momen et al 2011).  In the focus groups doctors agreed that the dominant bio medical culture was something which dictated and often got in the way of initiating end of life conversations and engaging in decision making with the patient. The topic of bio medical culture and how this has led to a

medicalisation of dying has been expounded and debated in the literature. In Philippe Arieś (1981) text on dying he offers a critique of the medicalisation of dying by saying "hospital personnel have defined an acceptable style of facing death. This is the death of the man who pretends he is not going to die. He will be better if at this deception he does not know the truth himself" (p587) Furthermore, Ivan Illich's (1970) critique of the medicalisation of dying launches a powerful attack on the medical profession by criticising what he believes to be a form of social control in which the rejection of 'patient hood' by dying or bereaved people is labelled as a form of deviance. Clark (2002) argues that in speaking about the medicalising of death we may have gone too far in explicating its effects on modern society and the term has now become synonymous with a profession reaching too far into "the body, mind and soul". (p905). It is noteworthy that the nurses in this study reported on finding 'recognising dying' equally as difficult stating the legacy of the LCP had also made them fearful of making the wrong clinical decisions. Despite these concerns nurses were observed to be the chief negotiators in enabling the transition of patients from the care of the medial team to palliative care. The findings illustrate the ongoing issue and complexities for doctors and nurses in recognising dying and the impact it has on patients with end stage heart failure. The professional cultures within medicine appears to be a significant barrier in making end of life decisions and one that needs further exploration.

**7.6.1 Prognostication in Heart Failure**

The findings in this study suggested that the use of prognostic tools in heart failure is complex and that there is no perfect predictor of outcome making recognising dying more challenging (Jaarsma et al 2009). In this study the NYHA functional classification was very rarely recorded in the patient medical notes. Doctors' narratives suggested that recording the NYHA score was something only done in an out-patient setting as part of the patients' initial assessment. It seemed very little notice was taken of the NYHA functional score with neurohormonal markers

being the cardiologists' preferred way of assessing the patient's heart failure status. The cardiology doctors described clinical tests like B Type natriuretic peptide (BNP), N-terminal pro- BNP, chest x-ray and echocardiogram as being more confident predictors of the patient's heart failure (Metra et al 2007, Rothenburger et al 2004). As previously stated for the care of the elderly doctors they did not have access to the full suite of investigations making diagnosis and prognostication challenging. The 'Gold Standard Framework' (GSF, 2011) meant very little to the doctors, in fact many did not really know what it was or how it applied to the care of a patient with end stage heart failure. When asked 'Would you be surprised if this patient were to die in the next few months, weeks, days? (GSF, 2011) some doctors replied that they would find the surprise question helpful but would prefer to use clinical investigations to determine if the patient was nearing the end of life. Similarly, the nurses when asked about the GSF (2011) were uncertain how this prognostication tool would apply to the end of life decision making. Nurses voiced concern that there was no clear guidance in practice for them to follow and so it would be difficult to apply the principles to their clinical practice. Recent evidence suggests that the use of the '12-month question' may not be appropriate for the patient diagnosed with a non - cancer illness (Gott et al 2011, Murray et al 2011).

Certainly, it was viewed by some healthcare professionals that complex scoring systems were not required and signs of deterioration like the patient's frequent admissions to hospital, recurrent episodes of decompensation, and poor quality of life would indicate a need to consider advance care planning and or an end of life care pathway. In this study there was no mention or discussion with the patients about prognostication fuelling the 'not wanting the patient to give up hope' belief. Giving the opportunity for the patient to discuss prognostication may provide the healthcare professional with a gateway to beginning end of life conversations with the patient. For the patient and their families this would provide an opportunity to begin to make plans around their future care.

**7.6.2 Transitioning to Palliative Care**

The difficulty healthcare professionals had in recognising dying meant that for many patients in this study the transition to palliative care was either delayed or the referral was not made. In this study only one patient had an end of life care plan and this was not instigated until the last few days of life. In 2010 the GMC published guidance on the end of life care which stated that doctors must ensure that death becomes an explicit discussion point when patients are likely to die within 12 months. In this study the difficult disease trajectory along with the uncertainty of prognostication meant actually pinpointing when to have an explicit end of life discussions was difficult. The appointment of a palliative care consultant to the hospital for two sessions per week was observed to make a significant difference in navigating some of the professional barriers; attendance at medical board rounds in the MAU and Emergency Department had slowly begun to increase the number of referrals to palliative care. Despite this appointment the narratives suggested that healthcare professionals still found the identification of patients who required palliative care a challenge. Recent policy recommends that healthcare professionals should be educated and trained to identify patients approaching the end of life and to recognise when someone is dying. (NHS England 2015). According to Gardiner et al (2012) a lack of recognition of palliative care need can lead to inappropriate interventions, hospitalisation, inappropriate treatment and reduced patient quality of life. In this study the healthcare professions agreed that clear definition and guidance would help but were sceptical that resources required and time needed would be given to attend training. Further discussion revealed that healthcare professionals found defining 'a good death' difficult offering a number of possible options based on both personnel and professional experiences of dying. This finding is similar to Cipolletta et al's (2014) grounded theory study which found healthcare professionals were ambivalent when it came to defining 'a good death' describing the physical context, maintaining body integrity and respect of the dying persons will as being important

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factors. They concluded the discomfort in defining 'a good death' was due to health care professionals own experience of death, and the everyday constraints of a healthcare system that does not allow time to reflect on practice. The findings in this study highlight some of the barriers which continue to exist in clinical practice and what appeared to prevent patients transitioning to palliative care. Future policy and guidelines need to take into account these barriers and provide recommendations which acknowledge the healthcare professionals position in identifying and supporting the patient who requires end of life care.

**7.7 Summary**

The vicious cycle of care for heart failure patients is a product of a health care system where organisational demands and organisational rules do not facilitate the delivery of care. The cycle allows the patient to enter and exit the cycle randomly without any barriers leading to the patient moving back and forth within the cycle until the patient's untimely death. The findings seem to suggest that professional boundaries, hierarchies of care and role legitimacy add to the complex nature of this cycle making it impossible for the patient to break this cycle of care (Oberle et al 2000, Hopkinson et al 2003). Healthcare professionals are left powerless to break this cycle because of the need to meet organisational targets and the care needs of a diverse and increasing ageing population. There is very little opportunity for the patient within the cycle to make end of life decisions with families or healthcare professionals. The opportunity for the patient to transition to palliative care is lost. In the following section a reflection of the research process will be discussed followed by the limitations of this study.

**7.8 Reflecting on the Research Process**

The process of recruiting patients to this study initially was quite slow and this came as a surprise since prior to commencing my study time had been invested in engaging with the healthcare professionals in wards and clinical meetings. The initial plan was for the ward

managers to act as a gatekeeper agreeing to contact me if a patient was happy to participate in the study. However, it became clear in the early stages of recruitment that the ward managers did not always have time to alert me to potential recruits. On a number of occasions there were missed opportunities despite leaving study protocols, making my contact details available and daily phone calls to the wards. Interestingly, where patients were found to be frequent attenders to a ward nurses tended to adopt a more 'paternalistic' stance being reluctant to engage in the information giving to the patient. This made it difficult to recruit those patients as trying to persuade the nurses may have been viewed as being coercive. After meeting with the ward managers and discussing my dilemma with the heart failure nurse it was agreed that in the first instance the heart failure nurse would inform me of patients who met the study inclusion criteria. It was already part of the heart failure nurse's role to check the echocardiogram of patients admitted with heart failure on a daily basis. The plan was to meet the heart failure nurse in the echocardiogram department or if I was not on site to receive a phone call or text. The patient would be visited on the ward by the heart failure nurse and during the health promotion would be given an information leaflet. After 24-48 hours the patient would then be asked by the heart failure nurse or ward manager if they were happy to be interviewed. Of course, this recruitment strategy worked well for those patients the heart failure nurse was aware of and who had been admitted to an acute medical ward. For those departments like the medical emergency unit regular visits each week meant patients admitted directly from the GP or the emergency department could be identified. By adopting this new recruitment strategy, the numbers identified who met the study inclusion began to steadily increase.

### 7.8.1 Researcher's Perspective

Birks et al (2013) suggests it is better to acknowledge your existing assumptions, knowledge and experience in order to establish where you stand in relation to your study. As someone who has been a qualified nurse for 28 years my initial concerns were that my prior knowledge and

experience would influence the co-construction of data and subsequent analysis of my interview transcripts. It was important therefore before commencing my study to acknowledge these experiences as well as my own beliefs and assumptions. Charmaz (2014) puts this into perspective by saying "We are not scientific observers who can dismiss scrutiny of our values by claiming scientific neutrality and authority. Neither observer nor observed come to the scene untouched by the world "(p27). It therefore became important on a daily basis to capture my thoughts and feelings in my field notes and reflective diary and compare these notes with my memos. By adopting a more reflective and reflexive position to my study it provided a more in-depth understanding of my participants' behaviours and their experiences of heart failure. The physical act of writing gave me the time and space to reflect on what was an intense and highly emotional topic 'end of life care' and then to develop strategies to cope with some of the more personal stories and experiences of the participants in this study.

### 7.8.2 Relations in the field

The time spent establishing good relationships with healthcare professionals in this study allowed access to what Gubruim and Holstein (1997) refer to as the 'social reality' of healthcare and this allowed me to see it as 'it really is'. This overt access to healthcare professionals was based on a willingness to provide information about my study and being available to meet with the 'gatekeepers' who could facilitate access to the ward setting. According to Hammersley and Atkinson (2000) "they will try to gauge how far he or she can be trusted, what he or she might be able to offer as an acquaintance or friend, and perhaps also how easily he or she can easily be manipulated or exploited "(p83). Sharing my nursing skills and expertise became an important bargaining tool in this relationship and involved delivering the occasional teaching sessions for the ward staff, working the odd clinical shift at a weekend or quite simply just offering advice. Of course, it could be argued that being a nurse gave me a certain amount of legitimacy and privilege in being able to access insider information. Dwyer et al (2009) believes

this insider role status allows researchers more rapid and more complete acceptance by their participants. In this study the common ground, healthcare, shared between myself and the healthcare professionals led to the acceptance of my role as a researcher. Branick and Coghlan (2007) argue having a dual role may lead to role conflict when confronted with "loyalty tugs" and "behavioural claims" (p70). In my study this did not present itself as a problem because staff on the wards did not know me as a co-worker but as a researcher who happened to have experience of being a nurse.

### 7.8.3 Evaluation of the Grounded Theory

The strength of using the constructivist grounded theory method in this study was it allowed an in-depth exploration of the participants' experiences. The continuous cycle of collecting data, analysing, coding and constantly comparing meant that my findings were grounded in the participants experiences and that this data would accurately represent the phenomena being studied. This was important to me because any theory generated had to make sense to my participants but also to a larger healthcare audience. Being a novice researcher with little experience of grounded theory my learning curve was huge and overwhelming at times. The data collection and coding were very time consuming and was undertaken both manually and using the database NVIVO. Using both methods meant my transcripts and initial codes had to be painstakingly uploaded into NVIVO before I could begin the process of focus coding. A secondary check of my transcripts had to take place to ensure no data had been lost in translation during the upload to NVIVO. In hindsight using NVIVO to code, write memos, transcribe and store transcripts would have saved time. However, the immediate to hand diary was helpful in being able to record my immediate thoughts, feelings, concepts, ideas and memos.

### 7.**8.4 Reflection on Ethical procedures**

The recommendations given by NREC were clear in that words like 'end of life care' and 'dying' could not be used and had to be removed from any information leaflets to avoid upsetting participants. There was no reference to these words during my interviews unless the patients explicitly stated they wanted to discuss end of life or dying. The adherence to these recommendations whilst coming from a place of non -maleficence continued to add to the myth that as a society and culture we should not under any circumstance discuss death. In fact, the discussion around death and dying should be avoided at all costs. The dance around the topic of end of life meant that participants whom may have wished to discuss their death were prevented by an unspoken rule that it was not acceptable. Those patients who chose to talk about end of life, which were very few, did so on their own accord and did not come to any harm. In fact, those patients who felt they could talk about their heart failure and their impending death felt it was beneficial to talk and as one patients stated 'get it off my chest'. The need to call upon the services of the palliative care team in the event someone became upset was not required. Only on one occasion did a female patient become upset, a ward nurse was informed and the lady was offered counselling support. The use of gatekeepers avoided the accusation of coercion and gave the participants time to make an informed decision. There was only one male patient who refused to participate in this study.

### 7.8.5 Quality

### 7.8.5.1 Credibility

The intimate familiarity with the topic of heart failure came about by spending a significant amount of time in the clinical setting both prior, during and following the completion of this study. This provided a unique insider view into the world of heart failure which in turn raised my awareness and understanding of the phenomena under investigation. The total number of

participants recruited to this study was a respectable 46 (n=46) (patients, n=16, nurses, n=15, doctors, n= 15). The reasonable sample gave me the breadth and depth of data required to make constant comparisons between observations and between categories. The gathering of significant volumes of data allowed a link to be made between my study aims and objectives and the study question.

### 7.8.5.2 Originality

There is very little evidence published on cycles of care and end stage heart failure which makes this study unique. The categories which have emerged from the data bring new insight into how healthcare professionals make decisions when considering the care of patients diagnosed with end stage heart failure. The emergence of these categories along with some fresh insights into the cycle of care for end stage heart failure will complement the already existing literature. The social and theoretical significance of this study would indicate that a review of the cycle of heart failure is indicated in particular how patients transition through each stage and how healthcare professionals can be supported in developing a service which allows the early identification and referral to specialist teams.

### 7.8.5.3 Resonance

Once the categories began to emerge from my data these were shared with my clinical colleagues to see if they resonated with their own experiences and if the emerging theory made sense. This constant going back and checking with the participants confirmed that my theory in fact was grounded in the data. The constant comparing of data, field notes and memos helped in this checking process and assisted in directing my questions until all categories were theoretical saturated and there was no further exploration of the phenomena.

### 7.8.5.4 Usefulness

The vicious cycle of care represents the experiences of the participants in how they made decisions in managing the end stage of heart failure. The theory suggests that the current cycle of care disables the decision-making process and therefore does not allow opportunity for either the healthcare professional or the patient to make decisions about end of life care. The cycle highlights the current clinical practices and how organisation rules and organisational boundaries impact on the delivery of care. The disjointed and on occasion chaotic delivery of the service means the opportunity for the patient to be referred to palliative care is missed. By addressing each stage of the cycle and how patients transition the cycle from the GP to acute care we can best understand how we can redesign a service that can meet the needs of the patient. The 'vicious cycle of care' will provide an opportunity for healthcare professionals to address some of the fundamental care needs of heart failure care and redesign a cycle of care that meets the need of the heart failure patient at the end of life.

### 7.10 Limitations of the Research

A number of limitations have been identified and will now be discussed in the section below under the headings; participant sample, myself as the researcher, data collection and methodology. To enhance the reporting of this study and highlight possible imitations a Consolidated Criteria for Reporting Qualitive Research checklist (COREQ) was completed (Tong et al 2007), (appendix 13).

### 7.10.1 Limitations related to the sampling of participants

Firstly, the sample recruited to this study was limited to only one District General Hospital in the Northwest of England, therefore these findings may not be transferable to other health care organisations. However, it could be argued that the process of gathering rich and contextualised data on the human experience compliments and adds to existing literature on the topic of end stage heart failure. The aim of this study was not to provide a theory specific to one participant

but one that could be applied or compared with data across other similar settings. Therefore, it is important to consider that this substantive theory will in the future provide a platform for further research to explore cycles of care with patients diagnosed with end stage heart failure.

Secondly, the sample initially was recruited purposively from a population of healthcare professionals and patients who met this study's inclusion criteria. In hindsight it would have been advantageous to have explored the experiences of the local General Practitioners managing the care of heart failure patients. Only during participants' interviews did it become evident how significant the role of the GP was in managing heart failure in the primary care setting. Nevertheless, the aims of this study were to explore decision making in the medical setting, an area where there is a dearth of literature. A future recommendation would be to explore local GP's experiences of managing heart failure patients. This would provide an opportunity to test the substantive theory from this study.

### 7.10.2 Limitations related to myself as the researcher

The healthcare professionals in this study were cognisant of my professional background as a registered general nurse. Within the paradigm of interpretative research this may not necessarily be considered a limitation. In some cases, sharing a common ground with participants can be valuable in creating a mutual trusting relationship allowing the participants to open up and share their lived experience. However, healthcare professionals conscious of my nursing background may have felt slightly threatened and challenged by my asking questions about their experiences in managing the care of heart failure patients. This may have led to healthcare professionals offering a limited account of their experience based on what they believed to fit with my research agenda. To mitigate for these circumstances a reflexive stance congruent with constructivist grounded theory was adopted (as previously discussed in Chapter 3) which involved being open at every stage of the research process from design, data collection and analysis to producing the emergence of my grounded theory.

### 7.10.3 Limitations related to methods of data collection.

The dominance of a senior doctor in the cardiology focus group led to a number of junior colleagues feeling inhibited to share their experiences of end of life decision making. The power differentials which existed between the senior doctor and that of the junior doctors may have resulted in the junior doctors agreeing with the senior colleague's opinions to avoid perceived reprisals. Because of this power imbalance within the group there was a risk that rich contextualised data on participants experiences was lost. In hindsight it may have been useful to hold separate focus groups for the more junior doctors. However, the aim of the focus group was to create a safe environment in which all doctors could share and learn from each other their personal experiences of managing end of life care.

### 7.10.4 Limitations of the Methodology

This study lies firmly within the interpretative tradition of qualitative research 'as the analysis was contextually situated in time, place, culture and situation' (Charmaz 206, p131). Qualitative research makes no claims to generalisability, qualitative approaches recognise there is no single interpretative truth and that qualitative research approaches investigate "the real world of the participant and so can provide important insight and knowledge" (Denzin and Lincoln, 2005, p8). Therefore, the findings from this study cannot be generalised to the wider population of end stage heart failure but can provide a grounded theory which can be used as a platform to explore further this phenomenon in practice. The findings from this study can also be used to explore changes to practice; for example, the 'vicious cycle of heart failure' care and how these cycles can be improved to deliver quality care for patients diagnosed with heart failure.

## 7.11 Conclusion

This chapter has provided an opportunity to present my substantive theory 'vicious cycle of care' and to discuss my four theoretical categories; organising care, being informed, signposting symptoms and recognising dying. To date very little has been written on cycles of care in heart failure and the impact this may have had on the patient's quality of care. This study therefore is unique in providing insight into how these cycles can negatively impact on the decision-making process and the delivery of end of life care. Furthermore, this study has provided a more in depth understanding on how participants use the social process of negotiation to bargain and broker the act of decision making. On a personal level this chapter has provided an opportunity to reflect on my research journey and where things have gone well and maybe not so well. The aim of this study was to provide a grounded theory which would be useful and make sense not only to the participants in my study but to the wider healthcare community. The section on quality begins to address this issue by discussing how the study has met the criteria of quality for a grounded theory study (Charmaz 2014). Lastly, the limitations of this study have been presented and discussed. In Chapter 8 of this thesis the themes which emerged from the analysis will provide the basis for my recommendations for future practice, guidelines and policy.

# Chapter 8 Conclusion and Implications for Practice

## 8.1 Introduction

The final chapter of this thesis will summarise the study findings and will clearly outline the contribution to knowledge this study has made in the care of patients with end stage heart failure. Then conclusions will be drawn and recommendations made for clinical practice, education, research and healthcare policy.

The study began by asking the following question; How do healthcare professionals facilitate clinical decision making when considering end of life care for patients diagnosed with NYHA stage 3 and stage 4 heart failure? To answer this question a number of aims were identified; these were as follows:

- To explore how health care professionals make the decision to place a patient on an individualised End of Life Care Pathway.
- To explore how decision making at end of life by healthcare professionals could affect patient's experience.
- To explore healthcare professionals' perceptions and understanding of end of life for patients diagnosed with end stage heart failure.

## 8.2 Findings and Contribution to Knowledge

The research aims were met by exploring healthcare professionals' and patients experiences of decision making when managing end stage heart failure. A constructivist grounded theory method was used to answer the research question. Forty-two-participants were interviewed in an acute medical setting to understand their experiences of decision making when considering end of life care in heat failure. The interviews were transcribed, coded and analysed using the grounded theory constant comparative method and QSR NVivo software. The findings from

this study revealed that healthcare professionals used negotiation to bargain and broker the process of decision making in a vicious cycle of care. Often decisions were made against a backdrop of organisational rules and organisational demands which did not always facilitate the process of shared decision making; this resulted in missed opportunities for the patient to transition to palliative care. To date very few studies have explored how cycles of care may interrupt and disable the process of decision making in an acute medical setting. The findings from this study are unique in that they highlight how the cycle of heart failure care not only constrains the decision-making process but disenfranchises patients from receiving the expert care needed in the last year of life. To begin this chapter a brief reflection will be given on my professional doctoral journey and how this journey has impacted on me as a practitioner, researcher and a person. This will be followed by implications and recommendations for clinical practice, research, education and health care policy.

## 8.3 Professional and Personal Impact of the Professional Doctoral Journey

Eat, Pray Love is a novel by Elizabeth Gilbert (2016) of one women setting out on a journey of self-discovery; it's about facing adversity and reclaiming responsibility for your own life and contentment. In relation to my own research journey it has often felt like venturing into the unknown where the territory at times has felt hostile and unforgiving. Like the women in Gilbert's novel the feelings of vulnerability and anxiety as the journey begins is soon turned into feelings of excitement and euphoria as new knowledge is discovered. The start of this doctoral journey began by asking myself questions about my own ontological position; Who am I? and What do I know? What is my reality? The opportunity to reflect on these questions provided the space to consider how my own culture, beliefs and values may have influenced this study along with my twenty-eight years' experience as a registered nurse. It was important to acknowledge these experiences and to know that bringing my values and beliefs into my research was something to embrace. In the early days of my study the ontology and

epistemology were something I grappled with but soon realised that the philosophy of constructivism allowed and encouraged the co-construction of data with my participants. The diary became my best friend and it was on a daily basis accounts would be written where reflection and learning would take place. This constant reflection and being reflexive allowed me to remain subjective about my participants and the research world in which they occupied. The unfamiliarity with doctoral studies and the demands of a higher degree led to on occasions feelings of uncertainty. Having professionally come from a place of certainty these feelings of uncertainty were alien and at times felt particularly uncomfortable albeit transient. Batchelor et al (2006) talks about living with uncertainties throughout your doctoral journey and this involves going through stages of integration, disintegration and then finally reintegration. The integration stage for me came at the beginning of the professional doctoral journey where the first two years of taught modules gave the underpinning knowledge and allowed for self-reflection and critical analysis of my professional journey. The disintegration phase was the doing part of the research when out in the field things did not always go to plan and the feelings of 'being stuck' and not moving forward created moments of panic and anxiety. Finally, the reintegration phase came in the final stages of my research where following months of coding my data a number of theoretical categories began to emerge. This was my eureka moment.

There is almost an inevitability when embarking on a journey of learning and self-exploration that change is going to take place. Lyotard (1995) in his opening commentary on James Joyce's Ulysses asks the following question How can one be sure that what returns is precisely what had disappeared? Or that what returns not only appears, but is reappearing? (p192). For me the doctoral journey has brought about many positive changes in both my personal, professional and academic life. For example, I have learnt that my passion, motivation, perseverance and determination to succeed has got me through some difficult and often challenging times in my research journey. When changes have been enforced, like setbacks to my funding, then being

persistent and facing the challenge has led to feelings of empowerment when solutions have been found. There were many occasions when I needed to find space to think, reflect and to re-engage in my research which often meant sacrificing time with my family and friends. As a consequence, many of these changes led to feelings of loneliness and frustration but I came to understand that out of adversity there comes a change of self. This journey has made not only positive changes to me as an individual but has had a significant impact on how I view myself as a practitioner/ researcher.

My professional doctoral journey like my personnel journey has opened up and illuminated my clinical practice; enabling me to look at problems and find solutions in a different more meaningful way. The doctorate has allowed room for professional growth, giving me time and space to think about how my learning can be applied into practice. I am more self-aware and more confident as a practitioner and feel my research training has put me on an equal playing field with other healthcare professional colleagues. My motivation for undertaking a professional doctorate was to develop the skills of critical analysis and critical reflection to be able to identify gaps in knowledge and confidently undertake research with the aim to improve patient care. This study has achieved this aim by giving back to the patient and healthcare professionals meaningful findings which will impact both on policy, education and clinical practice. In the following section my recommendations for clinical practice, research, education and healthcare policy will now be presented.

## 8.4 Recommendations for Clinical Practice

In this study there were areas identified of good practice where healthcare professionals did engage in the process of decision making with patients diagnosed with end stage heart failure. This was observed in clinical areas like the out-patient department, heart failure clinics and palliative care. Nevertheless, the findings suggest that the current cycle of care does not

facilitate decision making between the healthcare professional and the patient. Therefore, the clinical recommendations from this study are as follows:

- There needs to be a well-structured integrated care pathway which includes, primary care, secondary care and tertiary services. This pathway needs to include a clearly defined decision-making algorithm to optimise the patients and families experience throughout the episode of care. A risk stratification tool should be developed and included in this pathway in order to identify those patients whom are end of life and who would require immediate intervention from the cardiologist, palliative care services and heart failure team. The purpose of this pathway would be to improve communication and working across all health care providers who would be involved in the patient journey.

- A flag system similar to that adopted by cancer services needs to be adopted by the electronic patient records systems for heart failure patients so healthcare professionals can identify quickly if the patient is end of life and has an advance care plan in place. This flag system could be incorporated into the integrated care pathway. The early identification and alert will prevent the patient being missed and avoid inappropriate cycles of care.

-  Exploratory work needs to be undertaken with the Care of the Elderly doctors and Generalists Physicians to explore the possibility of having an identified doctor who has a specialist interest in heart failure working alongside the clinical teams. This may include cross fertilisation of working between primary and secondary care in the guise of the GPsi role which would improve care, treatment and communication across both primary and secondary care sectors.

- Development of the Advance Practice Nurse Role across all departments to support medical colleagues in the early identification of patients diagnosed with end stage heart failure. These nurses will have the education and training to deliver first line interventions, undertake the necessary preliminary investigations and who can complete timely referral to the heart failure team.

- Access to the full suite of heart failure investigations needs to be readily available for those doctors working in non-cardiac specialisms. This would avoid unnecessary delays to the patients diagnosis, treatment and referral to a cardiologist. Access to these investigations needs to include full access to all the reporting systems.

- The ward heart failure link nurse is a vital role in being the conduit between the heart failure nurse, cardiologist, palliative care team and community services. It is essential, that this role is developed and that the link nurse is given protected time away from their clinical environment to attend away days, educational sessions and to support the heart failure nurse.

- Currently there is only one whole time equivalent (wte) heart failure nurse who currently provides a service across the Trust for patients diagnosed with heart failure. The findings suggest that in the current cycle of heart failure care this is woefully inadequate. A business plan is required alongside an integrated care plan that can fully determine a workforce that can provide 24-hour service for heart failure patients.

## 8.5 Recommendations for Education

The healthcare professionals in this study highlighted the need to have access to end of life education on site. A concern raised by healthcare professionals was the lack of clarity around

what was meant by individualised end of life care plan and the terminology surrounding this. Based on the findings the recommendations for education are as follows:

- End of life care should be compulsory for all qualified nurses and doctors and this should be made easily available as part of the post-qualifying, post graduate programmes. This educational programme needs to include topics on how to initiate end of life conversations, and how to identify when is the right time to have end of life conversations. These sessions should have an element of practice-based learning where staff across all discipline's in a safe environment can practice their conversational skills and receive feedback from their peers.

- Educational events or drop in sessions for healthcare professionals need to be regularly available on end of life care pathway, when it should be considered and the terminology used; like advance care planning. These sessions could be used to update healthcare professionals on government policy or local Trust guidelines.

- Consideration needs to be given to making available on-line e -learning modules for those healthcare professionals who are too busy to attend formal educational sessions or for part time employees. These on-line modules could be aimed at the ancillary staff who maybe involved in the end of life journey of the patient but maybe do not have direct patient contact. This would assist in demystifying death and dying and bring conversations more out into the open.

## 8.6 Recommendations for Research

The recommendations for further research based on my study findings are as follows:

- Evidence suggests in this study patients preferred to take a more passive role in their decision making. Future research needs to explore communication techniques which may help passive patients engage in the decision-making process.

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- Further studies need to be undertaken to explore how paternalism affects the decision-making process for patients nearing the end of life.

-  In this study a barrier to decision making was found to be professional boundaries and hierarchies of care. Both of these inhibited and delayed the decision making when considering end of life care. Further studies need to be undertaken to explore fully the impact this may have on the patient and family quality outcomes.

- Further studies need to be undertaken to explore how cognitive impairment as a result of end stage heart failure affects the giving and receiving of information and how this may affect the process of informed decision making.

- Findings from this study suggest that healthcare professionals use a number of verbal and nonverbal cues when communicating concerns about end of life care. Further studies need to be undertaken to explore how non-verbal and verbal cues are communicated and interpreted by healthcare professionals and how these may affect the patients transitioning to palliative.

- In this study the findings suggest that the GP knowledge and confidence in treating patients diagnosed with end stage heart failure may have resulted in avoidable admissions to hospital. Future studies need to explore the role of the GP in the management of the patient diagnosed with heart failure and the decision making when considering the different treatment pathways offered within the primary care setting.

## 8.7 Recommendations for Healthcare Policy

It was evident from the findings that healthcare professionals were not always aware of local and national policy for end of life care. More importantly it became evident on reviewing this policy and guidelines that it did to reflect the unique needs of the heart failure patient who will require palliation at the end of life. With this in mind my recommendations for healthcare policy is as follows:

- There needs to be a clear definition for healthcare professionals as to what is meant by individualised end of life care planning and then how does this translate to the patient diagnosed with end stage heart failure.

- National Policy needs to reflect the uniqueness of heart failure, the unpredictable disease trajectory and the difficulties in prognostication and provide a policy which addresses those needs and provides a tangible and recognisable document for healthcare professionals which can be easily translated into clinical practice.

- National and local policy must provide clear and appropriate guidance on palliative care for heart failure patients for healthcare professionals paying particular attention to the stages of transition from acute care into palliative care. There needs to be a clear decision-making algorithm which clearly sets out how shared decision making can be facilitated between the healthcare professional, patient and their families.

- National and local policy to recommend that all undergraduates and healthcare professionals training programmes to include palliative care education.

## 8.8 Final Conclusion

Miriam Johnson Professor of Palliative Medicine stated in the British, Heart Foundation, All Party Parliamentary Group on Heart Disease (APGG 2016):

*"If we get palliative care -problem based care-right, end of life care flows out of that naturally into care for the dying and support for the bereaved" (p18)*

Whilst government publication and policy seem to suggest that we are providing palliative end of life care for end stage heart failure; the evidence seems to suggest that we still have some way to go before we can confidently say we are making a tangible difference to the lives of patients diagnosed with heart failure and their families. It is hoped that the findings and

recommendations from this study will go some way in making a difference to this group of patients.

# APPENDICES

**Patient Information Sheet**

**Study title**

To explore decision making by health care professionals for patients diagnosed with New York Heart Association (NYHA) stage 3 and stage 4 heart failure in acute medical wards in a District General Hospital.

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Please ask 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.

**What is the purpose of the study?**

The aim of this study is to explore how health care professionals make decisions with regards to the treatment and management of care for patients with heart failure. A further aim will be to explore from the patient and family perspective how the involvement or lack of involvement in decision making process can affect quality of life and family dynamics.

**Why have I been invited?**

You have been chosen to participate in the study because you have been diagnosed by your doctor with heart failure. You will have been admitted onto a medical ward where the study is taking place.

**Do I have to take part?**

**No, it is up to you to decide whether or not  to join the study** . The researcher will describe the study and go through this information sheet. If you agree to take part, the researcher will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

**What will happen to me if I take part?**

If you agree to participate in the study you will be asked a few general questions by the researcher about your heart failure and how this has affected your life and your family. You will also be asked if you have been involved in making decisions about your care. A quiet room on the ward will be located in order to provide confidentiality. The interview will be very relaxed and informal and will be taped. You will be able to stop the interview at any time if you feel you do not wish to proceed. If there are issues or questions raised in the interview which have caused any upset or distress provision will be made to address these immediately. You can stop the interview at any time without fear of prejudice to your care or treatment on the ward.

**What will I have to do?**

Participation in the study will involve a 45-minute interview where the researcher will ask you questions about your heart failure condition. The researcher will also ask you questions about how involved you and your family have been in the decision-making process regarding your care and treatment.
.
**Data used for my study**

The interview data which has been taped will be will be given a code to prevent you personally being identified. Any information used for purposes of this study will be treated in the strictest confidence and will not be used for any other purposes without your permission.  All data will remain confidential and be locked in a cabinet only accessible by the researcher.

**What are the risks and benefits of taking part?**

The topic of discussion, heart failure, may bring to the surface some **personal anxieties** and fears for both you and your family. You may feel that you have questions unanswered about heart failure or anxieties about the future. During the interview this may make you feel upset. If this happens the interview will be stopped immediately and expert help and support sought from the counselling team and heart failure nurses.

There will be no initial benefits to you but the research will help patients in the future being identified by health care professionals as requiring palliative care. This will mean

for patients being able to access more readily the care, support and benefits they or their families may require.

**Who is organising and funding the research?**

This research is being undertaken as part of Professional Doctorate in Nursing and is sponsored by the University of Salford

**Who has reviewed this study?**

The study has been reviewed by University of Salford Ethics committee **and National Research Ethics Service-Greater Manchester West.**

**What if there is a problem?**

If you have a concern about any aspect of this study you should ask to speak to the researcher Mrs Karen Higginbotham who will do her best to answer your questions (mobile 0781 491 4851). If you remain unhappy and wish to complain formally via NHS Complaints you can do this by contacting the hospitals Patient Advisory Liaison Service (PALS) on tel: 0161-922-4466 ex 4466. The team are located in Base Accommodation, Darnton Site off Darnton Road

I would like to take this opportunity to thank you for taking part in this study.

Contact for Further Information

Karen Higginbotham

Professional Doctorate Student

University of Salford

Mobile 07814914851

Email k.higginbotham@edu.salford.ac.uk

**University of**
**Salford**
MANCHESTER

**Healthcare Professional Information Sheet**

**Study title**

To explore decision making by health care professionals for patients diagnosed with New York Heart Association (NYHA) stage 3 and stage 4 heart failure in acute medical wards in a District General Hospital.

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and colleagues if you wish. Please ask 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.

**What is the purpose of the study?**

Using Grounded Theory, the aim of this study is to explore how health care professionals make decisions with regards to the treatment and management of care for patients with NYHA stage 3 and stage 4 heart failure. A further aim will be to explore from the patient and family perspective how the involvement or lack of involvement in decision making process can affect quality of life and family dynamics.

**Why have I been invited?**

You have been chosen to participate in the study because you are directly involved in the care or management of patients diagnosed with NYHA stage 3 and stage 4 heart failure.

**Do I have to take part?**

**No, it is up to you to decide whether or not to join the study**. The researcher will describe the study and go through this information sheet. If you agree to take part, the researcher will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

**What will happen to me if I take part?**

If you agree to participate in the study you will be asked a few general questions by the researcher about your involvement in the management/care of NYHA stage 3 and stage 4 heart failure patients. You will also be asked how you involve this group of patients and their family in decision making with regards their future treatment and care planning. The interview will be conducted in a place of your convenience situated on hospital grounds. The interview will be very relaxed and informal and will be taped. You will be able to stop the interview at any time if you feel you do not wish to proceed.

**What will I have to do?**

Participation in the study will involve a 45-minute interview where the researcher who will ask you questions about your decision-making process in the care and management of patients with NYHA stage 3 and stage 4 heart failure patients.

**Data used for my study**

The interview data which has been taped will be will be given a code to prevent you personally being identified. Any information used for purposes of this study will be treated in the strictest confidence and will not be used for any other purposes without your permission. All data will remain confidential and be locked in a cabinet only accessible by the researcher.

**What are the risks and benefits of taking part?**

There will be no initial benefits to you personally but the research will help patients in the future being identified by health care professionals as requiring palliative care. This will mean for patients being able to access more readily the care, support and benefits they or their families may require. The research will hopefully result in a clinical decision-making model which will complement the already existing prognostic indictor tool (GSF 2010) to support this decision-making process.

**Who is organising and funding the research?**

This research is being undertaken as part of Professional Doctorate in Nursing and is sponsored by the University of Salford

**Who has reviewed this study?**

The study has been reviewed by University of Salford Ethics committee and National Research Ethics Service-Greater Manchester West.

**What if there is a problem?**

If you have a concern about any aspect of this study please feel free to contact me on my mobile 0781 491 4851. Or if you wish to discuss the study further with my Supervisors you can contact Professor Martin Johnson tel: 0161-295-2733 or Dr Ian Jones Senior Lecturer in Cardiac Nursing 0161-295-7278

I would like to take this opportunity to thank you for taking part in this study.

Contact for Further Information

Karen Higginbotham

Professional Doctorate Student

University of Salford

Mobile 07814914851


Email k.higginbotham@edu.salford.ac.uk

University of
**Salford**
MANCHESTER

Centre Number:        13/NW/0483

Study Number: 130957

Patient Identification Number this study:

---

**CONSENT FORM**

---

Title of Project: To explore the decision-making process by health care professionals for patients diagnosed with New York Association (NYHA) stage 3 and stage 4 heart failure in acute medical wards in a District General Hospital

Name of Researcher: Mrs Karen Higginbotham

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 28th July 2013 (version 2) for the above study.  I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from University of Salford, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research.  I give permission for these individuals to have access to my records.

4. I agree to my GP being informed of my participation in the study.

5. I agree to take part in the above study.

6. I agree to my interview being audio recorded

7.  I agree to the use of anonymised direct quotations as appropriate to the study

        □

_____    _____    _____

Name of Participant               Date                       Signature

_____    _____    _____

Name of Person                Date                       Signature

Taking consent.

University of
**Salford**
MANCHESTER

Centre Number:         13/NW/0483

Study Number: 130957

Participant Identification Number for this study:

---

**CONSENT FORM (Health Care Professionals)**

---

Title of Project: To explore the decision-making process by health care professionals for patients diagnosed with New York Association (NYHA) stage 3 and stage 4 heart failure in acute medical wards in a District General Hospital

Name of Researcher: Mrs Karen Higginbotham

Please initial all boxes

8.  I confirm that I have read and understand the information sheet dated 13th August 2013 (version 2) for the above study.  I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

9.  I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

3. I agree to take part in the above study.

☐

10. I agree to my interview being audio recorded

☐

11. I agree to the use of anonymised direct quotations as appropriate to the study

☐

12. **I understand that relevant sections of data collected during the study may be looked at by individuals from University of Salford, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.**

☐

| | | |
|---|---|---|
| _____ | _____ | _____ |
| Name of Participant | Date | Signature |

| | | |
|---|---|---|
| _____ | _____ | _____ |
| Name of Person | Date | Signature |

Taking consent.

# Appendix 5: NRES Committee North West Ethical Approval Letter

**NHS**

**Health Research Authority**
**National Research Ethics Service**

**NRES Committee North West - Greater Manchester West**

3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ
Tel: 0161 625 7817
Fax: 0161 625 7299
Email: nrescommittee.northwest-gmwest@nhs.net

Mrs Karen Higginbotham
Professional Doctorate Student
BMI Alexandra Hospital
Mill Lane
Cheadle
SK8 2PX

16 August 2013

Dear Mrs Higginbotham

| | |
|---|---|
| **Study title:** | **To explore the decision making process by health care professionals when considering end of life care for patients diagnosed with New York Heart Association (NYHA)stage 3 and stage 4 heart failure in acute medical wards in a District General Hospital** |
| **REC reference:** | 13/NW/0483 |
| **IRAS project ID:** | 130957 |

Thank you for your letter of 13 August 2013, 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 the Vice Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Ms Cynthia Carter, nrescommittee.northwest-gmwest@nhs.net.

## 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).

A Research Ethics Committee established by the Health Research Authority

**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 | Response | 06 August 2013 |
| Covering Letter | 2 | 13 August 2013 |
| Evidence of insurance or indemnity | UMAL | 15 July 2013 |
| Evidence of insurance or indemnity | QBE | 01 August 2013 |
| Interview Schedules/Topic Guides | 1 | 22 April 2013 |
| Investigator CV | Higginbotham | |
| Letter of invitation to participant | 1 - Patient | 27 May 2013 |
| Letter of invitation to participant | 1 - Professional | 27 May 2013 |
| Other: CV Academic Supervisor | Johnson | |
| Other: Email regarding Interpreter Service | Yvonne Cox | 06 August 2013 |
| Other: Guideline for the Use of Interpreters Including those with Communication Impairments | 3.0 | 01 July 2013 |
| Participant Consent Form: Patient | 3 | 13 August 2013 |
| Participant Consent Form: Healthcare Professional | 2 | 13 August 2013 |
| Participant Information Sheet: Patient | 3 | 13 August 2013 |
| Participant Information Sheet: Healthcare Professional | 2 | 13 August 2013 |
| Protocol | 4 | 28 July 2013 |
| REC application | 3.5 | 27 May 2013 |
| Response to Request for Further Information | 1 | 09 August 2013 |
| Response to Request for Further Information | 2 | 13 August 2013 |

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees 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

| 13/NW/0483 | Please quote this number on all correspondence |
|---|---|

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Lorraine Lighton
Chair

This letter has been signed electronically. If you require a wet ink version please request one from the Committee Co-ordinator by email and it will be sent in the post.

Enclosures:           "After ethical review – guidance for researchers" SL-AR2

Copy to:     Professor Martin Johnson, Academic Supervisor, University of Salford
              m.johnson2@salford.ac.uk

              Professor Tony Warne, Lead Sponsor, University of Salford
              a.r.warne@salford.ac.uk

              Mrs  Rebecca Roberts, R&D office for Tameside NHS Foundation Trust
              rd@tgh.nhs.uk

# Appendix 6: University of Salford Ethics Committee Approval Letter

**University of Salford**
**MANCHESTER**

Innovation and Academic Research

**Engagement Ethical Approval Panel**

College of Health & Social Care
AD 101 Allerton Building
University of Salford
M6 6PU

T +44(0)161 295 7016
r.shuttleworth@salford.ac.uk

www.salford.ac.uk/

28 October 2013

Dear Karen,

**<u>RE: ETHICS APPLICATION HSCR13/28</u> – To explore the decision making process by health care professionals when considering end of life care for patients diagnosed with NYHA stage 3 and stage 4 heart failure in acute medical wards in a District General Hospital**

Based on the information you provided, I am pleased to inform you that application HSCR13/28 has now been approved.

If there are any changes to the project and/ or its methodology, please inform the Panel as soon as possible.

Yours sincerely,

*Rachel Shuttleworth*

Rachel Shuttleworth
College Support Officer (R&I)

University of
**Salford**
MANCHESTER

Mrs Karen Higginbotham

D Prof Student

College of Health and Social Care

University of Salford

Salford

M5 4WT

Title of Project: To explore the decision-making process by health care professionals when considering end of life care for patients diagnosed with New York Heart Association (NYHA) stage 3 and stage 4 heart failure in acute medical wards in a District General Hospital.

Dear

I am writing to say thank you for support and for giving up your time to be interviewed for my research project. I understand the pressures of working in a busy acute hospital so have really appreciated it when staff has taken time out of their busy schedules to support my study.

So far, I have interviewed approximately 25 healthcare professionals and 25 patients with end stage heart failure. I feel now in consultation with my supervisors I have a large enough sample to begin the task of data analysis. My plan will be once I completed my analysis to present the findings back to yourself and to the wider healthcare community within the Trust. I am hoping that the findings will support some small step change in the care and management of patients diagnosed with end stage heart failure.

I would just like to say it has been a real pleasure working in the Trust over the last 12 months. I have met some wonderful people. Everyone I have met (including yourself) has been incredibly supportive –so thank you.

I look forward to presenting my findings in the New Year. Please do not hesitate to contact me if you have any questions about the study

Very best wishes

Mrs Karen Higginbotham

Prof Doc student

University of Salford

Mobile 07814914851

**Interview Questions (draft 5)**

**Health Care Professionals**

- What would you consider to be the challenges in managing the care for this group of patients?
- Have you found DH Policy, Guidance, and Policy helpful in managing this group of patients? (GSF, Prognostic Indicator tools, NICE Guidance)
- What may prevent you from having an end of life discussions?
- How would you approach end of life discussions?
- How do you involve the patient and families in those discussions?
- How are you developing your heart failure service? Do you actively engage patients in user groups?
- What do understand about advance care planning and GSF? Would you consider the tool to be easy to use and to navigate? Do you think it is relevant to patients diagnosed with heart failure?
- When would you consider it to be appropriate to have EOL conversations?
- What would you consider to be the signs that you would tell you need to be thinking about having EOL conversations with patients?
- What is the optimum end of life care package? When should this be started?
- What would you consider to be the ideal palliative care pathway for heart failure patients?
- I have noticed that the participants recruited are predominantly white and aged between 50-90 years of age. Considering the diverse ethnic groups within Tameside Conurbation I have not been able to recruit for example any Asian Male or Females to the study-Interestingly the heart failure nurse does not see any in HF clinics. Do you know why this may be the case?  Do you think it may be due to access issues? Do you think they are being well managed by their GP?
- Do you think that the bad press around the LCP has made clinical staff reluctant to begin EOL discussions and decision making with HF patient and their families?
- How difficult is it to optimise these patients on admission?
- Do you think being admitted to a cardiology bed improves outcomes?

**Patient Questions**

- Would you want to know if your condition was terminal? How aggressive would you want to be treated?
- What do you understand about the term long term condition?
- What do you understand about the term heart failure?
- Did you have the opportunity to discuss what was important to you in the management of your heart failure?
- Have you been involved as much as you wanted in the decision about your care and treatment?
  How would you describe the amount of information you received to help you make a decision about your heart failure but also managed your care?

- Do you feel you have had the right support in the hospital and in the community?
- Do you think the care you are receiving is joined up and working for you?
- How confident are you that you can manage your own health?
- Have you heard about an advanced care plan? Has this ever been discussed with yourself either with GP or hospital doctor?

# Appendix 9: Example of initial coding one of my interview transcripts

activities, concepts, actions
list categories (utilise)

open code.
list of all codes.
reduce the number of codes by taking categories

KH Thank you for your time and thank you for agreeing to be interviewed. The study is about exploring how doctors and nurses make decisions when managing the care of patients diagnosed with end stage heart failure. I am interested to explore from the patent perspective if they feel they have been involved in the decision making at the end of life care. So it would be really helpful to begin with what have been your experiences managing the care of this group of patients.

JE I think from a nurses point of view i think the patients depending on whose is nursing them do feel involved in the care I do sometimes get the impression that the doctors don't tend to explain things maybe as much and don't take the time to explain things as much as what nurses are so they will ask me something and will get quite frustrated because the doctor has not explained it and I am left as the person who has to explain that to them. I know frustrations that way. Families and I know me personally I always try and involve the family because at the end of the day they are not going to be here at some point that might go home whether it be palliative or whatever they will go home and i want them to be informed so they can continue with the treatment they have been getting here and that they get the same level of care but i want them to understand why we are doing things. Families can get frustrated and take those frustrations out on me.

reaffirming position depending on the nurse
taking time to explain

becoming frustrated
leaving it to explain
understanding frustration.
personal care
involving the family
[?] woman living
[?] involve of treatment
Standards of care.
Understanding care.
Vulnerability

KH Have you got a examples of where that might of happened

JE Not so much on this ward but i have in a previous job where the patient was long term and the family seemed to think that it was because of what ....like we would omit .....the blood pressure was low so we are not going to give them the anti-hypertensive drugs were not going to give it to them ....this one turned around and said you can't make this decision you are not a doctor you are the one who is making her ill because you are not giving her these tablets so there was a lot of education

Perception of doctor and nurse role.
Lack of Understanding of Roles.
Conflict of Roles — creating conflict
Educating patients and families

is it repeated — reminds of the if theory or content
surprises me — explains states — read published reports

·1

234

**Appendix 10: Examples of using paper and post it notes to capture initial concepts and themes.**
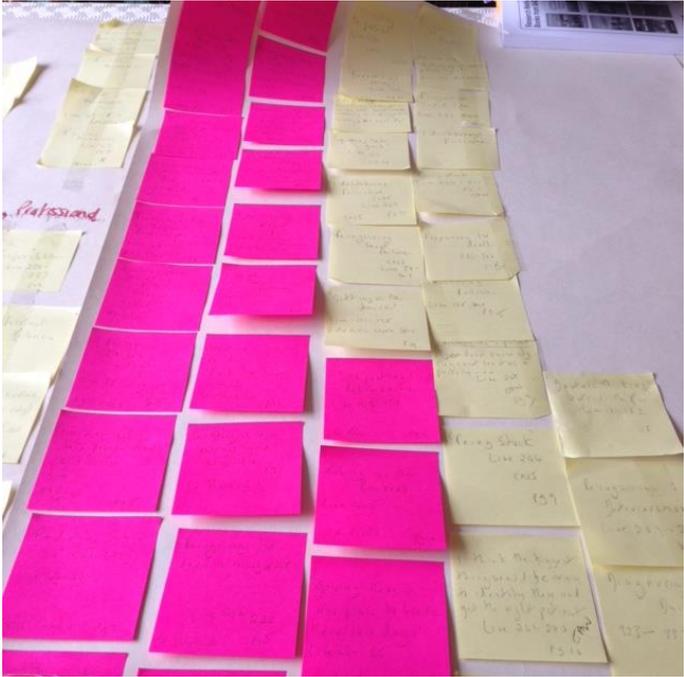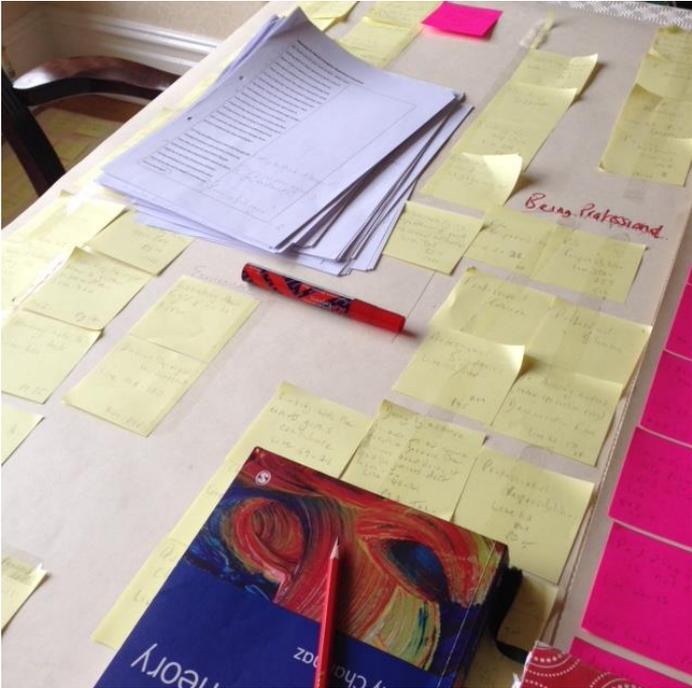
**Appendix 11 -Scoping Review- Data Extraction Form**

| | Author, Year, Title | Aim of the study | Sample | Study design | Key Findings | Conclusion | Limitations |
|---|---|---|---|---|---|---|---|
| 1 | Ahluwalia, C, S, Levin, J, R, Lorenz, K, A, Gordon, H, S (2013).<br><br>"There's no cure for this condition" How Physicians discuss advance care planning in heart failure | To explore the extent to which physicians engage in recommended elements of advance care planning during communications with HF patients during out-patient visits. | 52 patients<br>44 physicians | Qualitative content analysis | Identified 25 instances of ACP related communication over 15 of the 71 visits, in 17 instances physicians explained the nature of HF but only once was the life limiting potential of HF mentioned. Physicians discussed goals of care in 6 instances but elicited their patient's preferences in only 2 instances. | Despite recommendations for early ACP with HF patient physicians rarely engage in fundamental discussions about ACP in the out-patient department. | Only examined a cross section of clinics so were unable to determine if ACP conversations had already taken place with patients prior to the OPD visit.<br><br>Were unable to measure the non-verbal cues between the patient and the physician. |
| 2 | Allen, L, A, Yager, J, E, Funk, M, J, Levy, W,C, Tulsky, J,A, Bowers, M,T, Dodson, G,C, O'Connor, C,M, Felker, G,M (2008) | To quantify expectations for survival in heart failure patients, compare expectations to predictive models and identify factors associated | 122 heart failure patients (mean age of 62 years, 47% African -American, 42% NYHA 111 or1V | Prospective face to face survey | On average patients overestimated their life expectancy relative to model predicted life expectancy. Younger age, ischemic aetiology, | Ambulatory patients diagnosed with heart failure tended to overestimate their life expectancy compared with model -based | The sample size was relatively small and HF patients were only recruited from a single site. The study was undertaken in an ambulatory centre |

| | | | | | | |
|---|---|---|---|---|---|---|
| | Discordance between patient-predicted and model predicted life expectancy among ambulatory heart failure patients. | with optimistic prognosis. | | | lower ejection fraction, less depression and increased NYHA class were the most significant indicators of optimism. | predictions for survival. | where patient perceptions of life expectancy could be different during hospitalisation for heart failure. |
| 3 | **Apatira, L, Boyd, E, A, Malvar, G, Evans, L, R, Luce, J, M, Lo, B, White, D, B (2008)**<br><br>Hope, Truth and Preparing for Death: Perspectives of Surrogate Decision Makers | To determine surrogate decision makers' attitudes towards balancing hope and telling the truth when discussing prognosis | A total of 179 surrogate decision makers were recruited From 4 ICU; 2 medical – surgical ICU, a neurologic ICU, and a cardiac ICU | Prospective, mixed-methods cohort study.<br><br>Semi structured interviews were conducted with surrogate decision makers in a prospectively defined cohort of critically ill patients at high risk of death. | Overall, 93% (166 of 179) of surrogates felt that avoiding discussions about prognosis is an unacceptable way to maintain hope. The main explanatory theme was that timely discussion of prognosis is essential to allow family members to prepare emotionally and logistically for the possibility of the patients death. | A number of surrogates in this study believed that withholding prognostic information was not an acceptable way of 'maintaining hope'. Being giving the right information enabled the families to prepare emotionally, existentially and practically for the possibility that the patient may die. | The authors did not longitudinally assess whether early disclosure about prognosis predict fewer adverse bereavement outcomes. |
| 4 | **Atwal, A, Caldwell, K (2002)**<br><br>Do multidisciplinary | The project aimed to analyse and improve multidisciplinary teamwork in discharge planning | Second stage research involved<br><br>Auditing11case notes | Action Research | 10 cases out of the 11 an OT assessment was not documented in the medical notes. | The findings seem to suggest that although integrated care pathways led to improved outcomes there | The sample size recruited to this study was small. There was no patient or carer perspective sought |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | integrated care pathways improve interprofessional collaboration? | for #NOF. There were multiple steps involved including a Delphi Survey. | Six interviews; four nurses, one OT, and one care manager. | | The introduction of the MDT assessment did facilitate early discharge planning. The social history was found to be recorded in 36% of cases, cognition zero %, and functional status in 18%. | was little evidence to suggest they improved interprofessional relationships and communication. Time was the biggest factor in preventing HCP from completing the pathway. | on their own experiences of care. |
| 5 | **Barclay, S (2011)**<br><br>End of life conversations with heart failure patients: a systematic literature review and narrative synthesis. | The aim of this paper was to systematically review the literature on end of life conversations between patients diagnosed with heart failure and healthcare professionals when considering the prevalence and timing of those conversations, preference's and blockers to these conversations. | 698 abstracts were independently reviewed.<br><br>106 papers were then read in full.<br><br>23 papers met the study inclusion criteria. | Systematic literature review and narrative synthesis | Conversations were found to focus mainly on disease management. There were a number of patients who were not aware of the terminality of their condition. Clinicians avoided having end of life conversations in fear of destroying patients hope. | Prognostic uncertainty and the high risk of sudden death led to the avoidance of end of life conversations. | The review searched three data bases, CINAHL, Medline and PsycINFO. A more comprehensive search using other databases like BNI, Cochrane, grey literature may have yielded a larger sample to include in the review. |
| 6 | **Barnes, S, Gott, M, Payne, S, Parker, C, Seamark, D** | To identify factors available to GP's that are predictive of mortality within | 542 patients ≥ 60 years with heart failure were recruited to the | Quantitative design: quality of life and services use | Women had a 58% lower risk of death, Patients self-reporting NYHA | Identifying factors likely to influence death is useful in primary care, as | Participation rates were relatively low particularly amongst the |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | **Gariballa, S, Small, N (2008)**<br><br>Predicting mortality among a general practice-based sample of older people with heart failure. | a general based population of heart failure patients and to report sensitivity and specificity of prognostic information. | study from 16 UK GP practices. | questionnaires were sent out to patients every 3 months for 24 months or until death. | 111 or1V had an 81% higher risk of death. Patients aged 85 years and over had a fivefold risk of death compared with those aged ≤65years. Patients with comorbidity of cancer had a 78% higher risk of death. | this can initiate discussion about end of life care. | elderly, women and those in the highest NYHA group. Low mortality rates may have been due to participant bias as very few patients with severe symptoms or NYHA 1V |
| 7 | **Beckelman, D, B, Havranek, E, P, Becker, D, M, Kutner, J, S, Peterson, P, N, Wittstein, I, S, Gottlier, S, H, Yamashita, T, E, Fairclough, D, L, Dy, S, M (2007)**<br><br>Symptoms, Depression and Quality of Life in Patients with Heart Failure | To describe the prevalence of and distress from symptom burden of HF patients in an outpatient department. To test the hypothesis that greater depression is associated with a greater number of symptoms. To test the hypothesis that a greater number of symptoms affected quality of life. | Participants were recruited from OPD and met the following criteria<br><br>1) had a cardiology diagnosis of HF 2) had a cardiologist assigned NYHA 11,111, 1V 3) were aged 60 years or older.<br><br>Exclusion included 1) patients with dementia 2) unable to understand the study protocol 3) listed for heart transplant. | Quantitative Questionnaires | More than half the patients in the study reported symptoms of breathlessness, lack of energy, pain, feeling drowsy, or a dry mouth. In adjusted analysis more, severe depression was associated with a greater number of symptoms. | Depression in HF is associated with an increase in symptom burden. This in turn is associated with a decline in the quality of life. | The study was undertaken in a OPD setting and so the findings could only be generalised to this area. Further studies would need to investigate symptom burden across other healthcare settings to gather a broader perspective on the issues. |

| | | | Of 111 patients 60 patients were recruited | | | | |
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| | | | Symptoms were measured using 'Memorial Symptom Assessment Scale-Short Form Depression was measured using Geriatric Depression Scale. | | | | |
| 8 | **Brännström, M, Forssell, A, Pettersson, B (2011)**<br><br>Physicians' experiences of palliative care for heart failure patients | The aim of the study was to describe physicians' experiences of palliative care for heart failure patients. | 15 Physicians in a medical care of the elderly clinic were recruited. | Qualitative design using thematic analysis | The unpredictable disease trajectory made it difficult for the physicians to decide when to transition patients to palliative care. The physicians acknowledged that there needed to be a better follow up service for the patients. | The physicians agreed that there needed to be better cooperation with the palliative care services and that there needed to be clarity on who was principally responsible for the patient. | The study was undertaken in only one care of the elderly clinic in one hospital so limiting the generalisability of the findings. |
| 9 | **Burton, D, Blundell, N, Jones, M, Fraser, A, Elwyn, G (2009).**<br><br>Shared decision-making in | The researchers aim was to study patients with heart disease and to see if shared decision making took place. A further aim was to study | Consecutive sample of 85 patients were recruited to this study (52 men median age 65.5 years and 33 women median age 64 years). | Quantitative design using pre- and post-procedure questionnaires (PICS questionnaire and COMRADE | 40% of the patients wanted to be involved in the decision-making process. Preferences were fund unrelated to demographic | Patients were found to be more confident in decisions in which they perceived more involvement or which were the | The findings were only representative of one group of patients namely patients with heart disease undergoing angiography. Information on the |

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| | cardiology: Do patients want it and do doctors provide it? | factors that predict patients' choices or influence cardiologists' behaviours. | | satisfaction Scale) The OPTION instrument was used to assess the doctors' involvement in the decision-making process. | involvement. Cardiologists involved patients more in decisions concerning severe disease (p=0.0056). Involvement varied between the cardiologists (p=0.001). | product of a longer consultation. | physicians perceptions of decision making was not collected. This data may have been useful when comparing with the perceptions of the patients. |
| 10 | **Chan, R, Webster, J (2010)** End of life care pathways for improving outcomes in caring for the dying (Review). The Cochrane Library, Cochrane Database of Systematic Reviews | To assess the effects of end of life care pathways compared with usual care (no pathway) or with care guided by another end of life care pathway across healthcare settings. | A total of 920 papers were reviewed | Systematic Review | No studies met the criteria for inclusion | It was difficult for the authors to come to any conclusions because there were no studies which met the inclusion criteria | The authors recognised that due to the lack of available evidence recommendations for practice could not be made. |
| 11 | **Chan, R, J, Webster, J (2013)** End of life care pathways for improving outcomes in caring for the dying (Review). The Cochrane Library, Cochrane Database | To assess the effects of end of life care pathways compared with usual care (no pathway) or with care guided by another end of life care pathway across healthcare settings. | A total of 2042 titles and abstracts were reviewed | Systematic Review | No studies met the eligibility criteria | The review did not identify any new RCT, Quasi experimental studies, controlled before or after studies. Without up to date evidence it was difficult for the authors to concluded if the negative | The authors recognised that end of life is a difficult topic to research, However, more RCT studies need to be undertaken which stratify across different departments /s like acute medical care, |

| | | | | | | consequences associated with the LCP were down to poor practice, emotional consequences or poor implementation of the pathway. | emergency care, primary care. |
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| 12 | **Chan, R, J, Webster, Bowers, A (2016)** End of life care pathways for improving outcomes in caring for the dying (Review)**.** Cochrane Library, Cochrane Database of Systematic Reviews | To assess the effects of end of life care pathways compared with usual care (no pathway) or with care guided by another end of life care pathway across healthcare settings. | The authors screened 3028 titles. | Systematic Review | Only one study met the eligibility criteria. An Italian cluster RCT (Costantini et al 2014). Information on 232 cancer patients who were dying was provided by their carers. Only 34 % of patients were found to be cared for in accordance with end of life care pathway. There was very low-quality evidence to support a difference in overall control of breathlessness which favoured the LCP compared with those patients not on a pathway. | There was limited evidence to suggest that the end of life care pathway improved the physical, psychological and clinical outcomes of patients. | The one study included was judged by the authors to be of low quality due to its potential bias: not being able to prevent participants knowing which group they were in. |

| 13 | **Cheang, M, H, Rose, G, Cheung, C, C, Thomas, M (2016)** Current challenges in palliative care provision for heart failure in the UK: a survey on the perspectives of palliative care professionals. | The study aims to explore from a palliative care perspective the perceived underutilisation of palliative care services when managing the care of HF patients across the UK. | 499 Respondents Consultants accounted for 42% respondents, 28% clinical nurse specialists, 6% other PC nurses, 24% non-consultant doctors. The majority of respondents 59% were hospice based, 46% hospital and 21% community. | A prospective survey of palliative care professionals in the UK across 19 regions | The study found that 97% of PC services offered services to HF patients. The levels of interdisciplinary collaboration (58%) and education (36%) were low. There were frequent reports that end of life issues were not addressed by cardiologists prior to the referral to PC. | There were low heart failure referrals despite the willingness of the PC teams to provide end of life care for HF patients. | The study sample did not accurately reflect the PC services in the community. A second limitation was the calculation of the responder rate and the fact that the sample may not have accurately reflected the actual number of PC services. |
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| 14 | **Clarke, A, Ross, H (2005).** Influences on nurses' communications with older people at the end of life: perceptions and experiences of nurses working in palliative care and general medicine. | Exploratory study reporting on nurses 'perceptions and experiences regarding listening and talking to older patients at the end of life. | A purposive sample of 24 nurses were recruited from two medical wards and the palliative care unit. Interviews were conducted in four focus groups; 2 on the medical unit and 2 on the palliative care unit. | Qualitative study using Focus Groups. | Factors which influenced nurses communication with older people at the end of life were; nurses perceptions and experiences of listening and talking to older people, learning from other members of the MDT, environmental and organisational constraints such as time, privacy and | The general nurses wanted to communicate with the older people at the end of life but felt they needed more support. The palliative care nurses appeared empowered to communicate with the older patients at the end of life. The authors concluded that there needs to be supportive structures, | The findings are representative of only one healthcare professional group and therefore it would be difficult to generalise these findings to other tertiary hospitals. |

| | | | | | the culture of care and perceived difference in culture and values of nurses, doctors and the patients. | attitudes, knowledge and skills that should be replicated in all settings. | |
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| 15 | **Constantini, M, Pellegrini, De Leo, S, Beccaro, M, Rossi, C, Flego, G, Romoli, V, Giannotti, M, Morone,P, Ivaldi, G,P, Cavallo, L, Fusco, F, Higginson, I,J (2014)**<br><br>The Liverpool Care Pathway for cancer patients dying in hospital medical wards: A before -after cluster phase 11 trial of outcomes reported by family members**.** | Preliminary assessment of the effectiveness of the LCP on the quality of end of life care provided to adult cancer patients during their last week of life in hospital. | 79 family members were interviewed-46 before and 33 after the implementation of the LCP | Uncontrolled before and after cluster trial | After the implementation of the LCP there was a significant improvement in the mean scores of four Toolkit scales, respect, kindness, dignity and family and emotional support. No significant improvement in symptom control. | Further studies need to be undertaken to investigate the no improvement to symptom control. Possible area for future innovation and development. | The design of the study allows for selection bias. The findings suggest there are some characteristics mainly gender and time in hospital and ward were slightly different. The study was only implemented in one hospital. Further studies would be required in different settings/centres in order to compare the findings. |
| 16 | **Costello, J (2001)** Nursing older dying patients: findings from an ethnographic study of death and dying | The am of the s study was to explore the experiences of dying patients and nurses working in three elderly care | The sample consisted of 74 patients, 29 nurses and 8 physicians.<br><br>The principle data collection were | An ethnographic research design | The findings suggest that there was a lack of 'emotional engagement' with the dying patient. There was a lack of | The researcher concluded that the terminal care of patients was hampered by a reluctance of the nurses and doctors | The study only focussed on three ward areas therefore it would be difficult to generalise findings to other |

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| | in elderly care wards | wards focussing on the management of care for the dying patient. | participant observation and semi structured interviews. | | effective communication about the terminal diagnosis. The individual care needs of the dying patient were aimed at meeting the physical needs. Nurses reported meeting the psychosocial needs including spirituality and emotional care but there was little evidence of this in clinical practice. | to be more open about death and dying.

A biomedical model and the hospital culture were found to shape the experiences of the older dying patient. | populations in the hospital requiring terminal care. |
| 17 | **Currie, V, L, Harvey, G (2000)**

The use of care pathways as tools to support the implementation of evidence based practice. | The aim of this study was to begin to address some of the questions asked around the use of care pathways. For example, Why are pathways so popular? How are they being used in Practice? | Target population were a range of professional staff working in 16 Trusts randomly selected across England, Wales and Scotland (n=76 staff interviewed) | Survey returns on clinical pathways were stratified by country for Scotland, Wales, Northern Ireland and England. | Pathways were found to tackle some of the clinical variation in practice. The pathway was found to improve assessment and treatment regimes. At more strategic level pathways were found to promote organisational development by providing a structure. | The findings of the survey suggested that strategic support and clinical leadership is required for the successful implementation of a care pathway. Education is particularly important when it comes to variance recording. | The professional staff selected to participate were self-selected. The loss of sites resulted in no representation from Ireland and Wales. |

| 18 | Delgado, E, M, Callahan, A, Paganelli, G, Parks, S, M (2009)  Multidisciplinary Family Meetings in the ICU Facilitate End of Life Decision Making | The aim of this study was to assess the feasibility of establishing a multi-disciplinary family meeting (MDFM) program and the impact of such a program on the end of life decision making in the ICU. | During the study period MDFM were planned for patients who had been ventilated for more than 5 days. Twenty-nine were recruited into this study. | Feasibility Study | Thirty-five MDFM were held on twenty- four patients. A meting could not be arranged for four. All meetings addressed the patients' diagnosis, prognosis and goals of care. Fifteen patients had life support withdrawn and died a mean of 4.8±4.2 days after the first family meeting. | Proactive MDFM improve communication and understanding between the patient, family and healthcare professionals and facilitate end of life decision making. | This feasibility study took place in one ICU in a University Hospital therefore it would be difficult to generalise the findings to other hospitals and ICU. The sample recruited to this study were patients with a terminal diagnosis. Further studies would be required to see if MDFM was successful in other groups of ICU patients. |
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| 19 | Dunwoody, P, T, Haarbauer, E, Mahan, R, P, Marino, C, Tang, C, C (2000)  Cognitive adaptation and its consequences: A test of cognitive continuum theory. | The aim of this study was to test some of the principle aspects of cognitive continuum theory and to understand how individuals tailor their own cognitive strategies to different environments. | Participants for this study were 108 college students | Participants were asked to perform tasks at both the surface (task representation) and depth (task structure). Scores for each participant were collected and computed. Participants were also required to make a series of | The surface manipulation influenced cognitive mode in the predicted direction with an iconic information display inducing a more intuitive mode than numeric information display. The depth manipulation influenced | Task achievement was a function of the extent to which participants demonstrated an analytical cognitive mode index, and not a function of correspondence, as predicted. The authors concluded that this difference was like to be due | The authors recognised that this study used tasks which required purely quantitative manipulation. Further research needs to address the relative contributions of both quantitative and qualitative task differences on |

| | | | | threat assessment judgements about aircraft based on a number of cues. This limited environmental predictability was thought to be characteristic of naturalistic contexts. | cognitive mode in a pattern not predicted by CCT. The findings indicate this difference was due to a combination of task complexity and participant satisficing. | to the quantitative nature of the task manipulation. | cognitive mode and the role of motivation in these differences. |
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| 20 | **Ellershaw, J, Gambles, M, McGlinchey, T (2008)** <br><br> Benchmarking: a useful tool for informing and improving care of the dying**.** | The objective of this study was to evaluate the utility of participating in a benchmarking exercise to evaluate the care delivered to patients in the dying phase using the LCP. | A total of 75 participants attending two workshops were asked to complete a questionnaire about their experiences (n=40, phase 1, n-35, phase 2). | Questionnaire Evaluation | Sixty-two participants completed the questionnaire (83% response rate). Respondents found the benchmarking exercise useful and found the opportunity to discuss with fellow colleagues in the workshops really useful. Participants from the hospital sector identified changes in practice as a result of participating in the benchmarking exercise. | Using comparative data readily available from audit of the LCP and attendance at workshops was found by participants to be a valuable way to explore the care delivered to the dying patient. | The authors acknowledge that they only had a 85% response rate which was not representative of all those participants attending the workshops. |

| 21 | **Gagnon, J, Duggleby, W (2013)** The provision of end of life care by medical-surgical nurses working in acute care: A literature review | The aim of the literature review was to explore and gain a in depth understanding of the registered nurses' experiences of providing end of life care in a acute care environment. | The review was undertaken using the following electronic databases CINAHL, MEDLINE, and PsyInfo | Comprehensive Literature Review 16 studies met the inclusion criteria | The findings from the 16 reviewed studies suggest that nurses felt a strong commitment to helping the terminally ill patient. Nurses reported feeling deeply rewarded and privileged in sharing the EOL experience with patients and families. | Further research needs to be undertaken to explore ways to improve communication among nurses and medical colleges. A critical examination of nurses' ideology and assumptions and how it influences end of life care for patients needs further exploration. | This was a narrative review therefore the analysis relied on the interpretation of the reviewers. The authors claimed to have cross checked each other's interpretations. There was little reference to cross cultural variation considering the studies reviewed came from across the globe. |
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| 22 | **Gambles, M, Stirzaker, S, Jack, B, A, Ellershaw, J, E (2006)** The Liverpool Care Pathway in hospices: an exploratory study of doctor and nurse perceptions. | The aim was to explore hospice staffs' experiences, feelings and beliefs when managing end of life care for patients on the LCP. | Purposive sample of eight nurses and three doctors working in a 30-bed hospice in the North West. | Qualitative study exploring hospice doctors and nurses' perceptions of the impact of the LCP using semi-structured interviews. | The nurses and doctors interviewed believed that the LCP had a valuable place in the hospice setting. The LCP was seen to improve documentation, promote continuity of care and enhance communication. | Despite some initial scepticism the LCP was welcomed by the hospice doctors and nurses. The LCP was seen to compliment the already skilled palliative care practitioners. It was acknowledged that education was essential in promoting quality care. | The sample for this study was recruited from one hospice and was relatively small. Therefore, this could impact on transferability of the findings. Only more senior grades were recruited. Further studies would need to include a wide range from junior to more senior. |

| 23 | **Gibbs, L, M, E, Khatri, A, K, Gibbs, J, S, R (2006)** Survey of specialist palliative care and heart failure: September 2004 | To describe English specialist palliative care services provision for patient diagnosed with heart failure and to identify particular interest or expertise in this area. | A total of 452 letters and questionnaires were posted. In total 233 questionnaires were returned. 164 services did not reply. Overall response rate was 59%. | Postal Survey of all lead consultants of English palliative care services. | Out of the 233 services whom replied, 222 services thought palliative care had a role to play in HF. A total of 197 services accepted HF patients. The most common reason for not accepting HF patients was the lack of beds or lack of staff training. | One in ten of the palliative care services in this audit did not accept HF patients. A better understanding on how palliative care services could improve heart failure care needs to be further explored. | The survey did not reveal if the patient was receiving palliative care services from the cardiologist or any other service. There was no evidence to suggest which was the referred model of working. |
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| 24 | **Goodlin, S, Quill, T,E, Arnold, R,M (2008)** Communication and Decision Making About Prognosis in Heart Failure Care | This discursive paper applies the knowledge of participatory decision making and communication about prognosis from other health care settings to heart failure patients. | | Paper explores the communication strategy ask, tell, ask and discusses how this can be applied to heart failure patients. | | | The paper concludes that physicians should discuss prognosis and this should be led by the patients need or care planning. Exploring patients emotions and reflecting on patient responses was found to reduce patient anxieties. |
| 25 | **Gott, M, Ingleton, C, Bennett, M, I, Gardiner, C (2011).** | To explore how transitions to palliative care approach are | 58 health care professionals involved in secondary or primary care. Used focus interviews and | Qualitative study design. Used focus interviews and | Healthcare professionals identified that the transition of HF patients to | Significant barriers still exist which prevent patients diagnosed with end stage heart | Practice was reported by the healthcare professionals in this study but was |

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| | Transitions to Palliative Care in acute hospitals in England: qualitative study | perceived in acute care hospitals. | | individual interviews to gather data. | palliative care did not happen as suggested in UK policy.<br><br>Patients were discharged back to primary care with false hope of a cure.<br><br>Existence of professional hierarchies limited the input of junior doctors and nurses into decisions on care. | failure transitioning to palliative care. | not directly observed by the researchers.<br><br>The group dynamics in the focus groups may have inhibited more junior staff from sharing their experiences. |
| 26 | **Haga, K, Murray, S, Reid, J, Ness, A, O'Donnell, M, Yellowlees, D, Denvir, M, A (2012)**<br><br>Identifying community based chronic heart failure patients in the last year of life: a comparison of the Gold Standards Framework Prognostic | To assess the clinical utility of the Gold Standards Framework and the Seattle Heart Failure Model to identify patients with chronic heart failure in the last year of life | 138 patients were identified with chronic heart failure (NYHA class 111 and1V) | An observational cohort study<br><br>Outcome measures: 12-month mortality and sensitivity and specificity of GSF and SHF | 138 patients with CHF with class NYHA 111 and 1V were identified from a population of 368 patients. 119 (86%) met the GSF criteria for end of life care. The SHF model identified 6 (4.3%) with a predicted life expectancy of a year or less. The sensitivity and specificity of the | Neither the GSF nor the SHF accurately predicted which patients were in the last year of life. | Relatively small sample size and only represents a single health authority in Scotland. The sample was mainly white despite the location being ethnically diverse. |

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| 27 | **Hanratty, B, Mair, D, H, F, Ward, C, Capwell, A, L, Corcoran, G (2002)**<br><br>Doctors' perceptions of palliative care for heart failure: focus group study. | To identify doctors' perceptions of the need for palliative care for heart failure and the barriers to change. | Seven speciality groups of doctors were recruited. GP (n=5) GP teaching and academic (n=5) Cardiologists (n=5) Geriatricians (n=6) General medicine doctors (n=4) Palliative care doctors (n=4) | Qualitative study with Focus Groups | There were three main barriers identified to transitioning the patient to palliative care and these were: The organisation of healthcare, the unpredictable course of heart failure and the doctors understanding of roles. | The clarity of professional roles requires further exploration and redesigning a service that meets the requirement of HF patients. | The researchers acknowledge that they only recruited one health care professional group and that the intention for future studies would be to include other HCP groups. |
| 28 | **Hockley, J, Dewar, B, Watson, J (2005)**<br><br>Promoting end of life care in nursing homes using an 'integrated care pathway for last days of life'. | The aim of this study was to promote quality end of life care in nursing homes using an integrated care pathway in the last days of life. | Eight nursing home managers agreed to take part in this study in one health authority. | Action Research methodology | The researchers found that a pattern emerged around the care given to residents in the last days of their lives; namely that dying was becoming more central to the every day wok in the nursing home instead of being on the periphery. Five main themes emerged; a greater | The researchers concluded that the ICP used in this study encouraged a greater openness around death and dying. It enabled the nurses to take responsibility and ownership of the dying process. The use of the ICP was found to encourage teamwork and value the role of | The study sample was small in comparison to the number of potential nursing homes that could have been recruited. Only one health authority was contacted. |

| | | | | | openness around death and dying, recognising dying and taking responsibility, better teamwork, critically using palliative care knowledge to influence practice and more meaningful communication. | the healthcare assistants. | |
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| 29 | **Houben, C, H, M, Spruit, M, A, Groenen, M, T, J, Wouters, E, F, M, Janssen, D, L, A (2014)**<br><br>Efficacy of Advance Planning: A Systematic Review and Meta-Analysis | To systematically review the efficacy of advance care planning | Fifty-five studies were identified. | Systematic Review and Meta-Analysis. Selection of Randomised Control Trials that describe original data on the efficacy of the ACP in adult populations. Primary outcome measures were the completion of advanced directives and occurrence of end of life discussions. Secondary outcome measures were | Interventions focussing on advanced directives as well as interventions that also included communications about end of life care increased the completion of advanced directives and the occurrence of end of life discussions. Interventions which included communication about ACP improved concordance with preferences for | ACP interventions increase the completion of advanced directives and occurrences of discussions about ACP | 55.4% of the trials included were considered 'low quality trials'. Other limitations were a lack of intention to treat and concealed allocation. Meta-analysis was not possible for a number of outcomes like quality of communication, preferences for end of life care because of variability in definition. |

| | | | | | concordance with preference for care and delivered care | care and delivered care. | |
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| 30 | **Jack, B, A, Gambles, M, Murphy, D, Ellershaw, J, E (2003)**<br><br>Nurses' perceptions of the Liverpool Care Pathway for the dying patient in the acute hospital setting. | The aim of the study is to explore generalists' nurses' perceptions of the LCP | A purposive sample was selected of nurses who worked on wards across the hospital setting and whom were given added responsibility to be a 'network' nurse for the implementation of the LCP. These nurses generally had an interest in palliative care (n=15). | Qualitative study using focus groups to gather the data. Used a hybrid data analysis tool to code the data for themes. | A number of themes emerged relating to the impact of the LCP; symptom control, routine care, care of the relatives, barriers to using the LCP, documentation, impact of the LCP on the nurses. | Overall, the nurses interviewed viewed the LCP as having a positive impact on patients end of life care. The nurses perceived the reduction of documentation associated with the introduction of the LCP. A perceived barrier to the use of the LCP was resistance from some of the medical staff. | The sample size was small and only included the views of the nurses and did not include the views of the medical staff, patients or carers. |
| 31 | **Jack, B, A, Gambles, M, Murphy, M, Hutchinson, T, Ellershaw, J, E (2004)**<br><br>Enhancing hospital nurses' knowledge of palliative care: a network nurse programme. | The aim of this study was to evaluate the implementation of the 'network nurse' a programme designed to enhance the knowledge and skill of ward nurses delivering palliative care to | 41 network nurses were sent a questionnaire, 33 nurses responded (80% response rate) | A survey design using a questionnaire. | The prime motivators for joining the network programme  to be personal interest (61%, n=20) and increasing knowledge (34%, n=12). Of the respondents 97% (n=32) felt that their palliative care knowledge had | Overall, the impact of the 'network nurse' had been evaluated positively. The increase in knowledge round end of life care became apparent when the nurses had to discuss palliation with MDT colleagues. | The questionnaire was aimed at only seeking opinion from the 'network' nurses. Future studies may consider surveying other members of the MDT to get their perspective on the LCP. Gathering opinion form the patient |

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| | patients on hospital wards. | | | | increased. The nurses identified the top three benefits of attending the network; gaining knowledge (79%, n=26), support and networking were also highly ranked. Only 39% of respondent highlighted the impact on nursing care. | The role is designated to one nurse and it is not clear how the education and information is cascaded to the rest of the ward team. | and their carers may provide a unique insight into their experience which may inform practice changes in the future. |
| 32 | **Johnson, M, Nunn, A, Hawkes, T, Stockdale, S, Daley, A (2012)**<br><br>Planning for end of life care in heart failure: experience of two integrated cardiology-palliative care teams | To prospectively assess the care received by patients with advanced heart failure known to both the cardiology and palliative care teams on two different sites in the North of England. | 126 patient data sheets were completed from January to December 2009 | Prospective data collection using a pre-designed data collection sheet | The surprise question was applicable in 70% patients; 89% of whom died within 12 months. Overall, 33% patients died in hospital. Planning for end of life care was evident for 64% patients. | Heart Failure Nurse specialists were central in discussing patients concerns and co-ordinating end of life care. | The business of the HF service may have led to data being missed by the HFNS. A larger sample from other locations may have given a broader picture on the care received by HF patients at the end of life. |
| 33 | **Kwan, J, Sandercock, P, A, G (2004)**<br><br>In hospital care pathways for | To assess the effects of care pathways compared with standard medical care amongst | Three randomised trials (340 patients) and 12 non-randomised studies (4081 patients) were included. | Systematic Review | The review fund no difference between care pathway and control groups in terms of death and discharge destination. | Use of stroke care pathways may be associated with positive and negative outcomes. There is insufficient | The authors recommend that further research into the benefits of a stroke care pathway is required. Current |

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| | stroke (Review). Cochrane Library. | patient with acute stroke. | | | Patients managed on a pathway were found to do better on discharge and less likely to suffer a urinary tract infection. | evidence to suggest the routine implementation of care pathways | non-randomised may only present weak evidence into the effectiveness of the pathways. |
| 34 | **Lown, B, A, Hanson, J, L, Clark, W, D (2009).**<br><br>Mutual influence in shared decision making: a collaborative study of patients and physicians. | The aim was to explore how patients and physicians describe attitudes and behaviours that facilitate shared decision making. | 85 patients and physicians participated in the four research work groups, 50 women (58%) and 35 men (42%). Their ages ranged from 34-79. There were 41 physicians, 20 women (49%) and 21 men (51%). 75% of physician's worked in medical school affiliated practices. There were 44 patients, 29 women (68%) and 15 men (32%). Patients had a variety of conditions including heart failure, hypertension, diabetes and rheumatoid arthritis. | Qualitative research design | The analysis of the data identified six paired patients/ physicians' categories. These were as follows; discuss information and options, seek information, support and advice, share control, negotiate a decision and patients act on their own behalf and physicians act on behalf of the patient. Participants described a dynamic process in which the patients and physcians influence each other throughout shared decision making. | The study demonstrates the mutual influence's both the patient and the physician has on each other and the decision-making process. | The bringing together of patients and physicians to discuss the process of decision making may have resulted in one or the other group member being hesitant in speaking openly. Only primary care physcians participated in this study and only patients diagnosed with chronic health conditions. |

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| 35 | **Maryland, C, Williams, E, M, I, Adlington-Hall, J, Cox, T, F, J, E Ellershaw (2013)**<br><br>Does the 'Liverpool Care Pathway' facilitate an improvement in quality of care for dying cancer patients? | The aim of the study was to investigate whether the introduction of the LCP to the hospital setting had in fact improved quality of care for cancer patients. | 778 next of kin whose relative had an expected cancer death in either the hospice or acute tertiary hospital were sent a postal questionnaire post bereavement. The questionnaire, ECHO-D, was sent out to the relative with an information pack.<br><br>Data was analysed using SPSS v 9.2 | Postal self-completion questionnaire | Of the 778 eligible participants, 52 were excluded (next of kin had died n=3, or moved house n=49). Of the 726 participants only 255 agreed to participate. Overall, the hospice setting reported the best quality of care and hospital patients whose care was not supported by the LCP reported the worse care. Care supported by the LCP and the palliative care team were associated with good family support. | The evidence suggests that patients admitted to hospital who were commenced on the LCP experienced better quality of care and better symptom control. In both settings there needed to be more open discussion about the withdrawal of fluids. There needed to be more openness about dying in the hospital setting with the patient and their families. | The experiences of care were only sought from the relatives and not the dying patient. Therefore, the patient may have perceived the care differently. The sample was only patients with a diagnosis of cancer and did not include any patients with a long-term condition. We are not given any background, for example the ethnicity of the respondents, therefore it is not clear if this is a heterogeneous sample. Further survey would need to include other ethnic group in order to compare their experiences of care |
| 36 | **Matlock, D, D, Nowels, C, T, Bekelman, D, B (2010)** | The goal of this study was to describe patients' perceptions | Purposive sample of 22 patients with symptomatic heart failure were | Qualitative Study. | The 22 patients were predominantly male (73%) with a | Patients with HF use passive and active decisions styles in their | The authors acknowledged that the sample may not be |

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| | Patient Perspectives on Decision Making in Heart Failure. | surrounding difficult decisions along with factors that influenced these decisions. | recruited from cardiology and geriatric clinics. | | mean age of 69 and a median ejection fraction of 33%. Two distinct types of decision makers emerged which were labelled active (55%) and passive (45%). Active decision makers identified interventions such as implantable cardioverter defibrillators, medications and transplants to be difficult decisions. Passive decision makers generally did not identify a difficult decision and described factors like trusting in God trust in the physician | approach to medical decision making. | representative of the full range of views surrounding HF decision making. |
| 37 | **Middlewood, S, Gardner, G, Gardner, A (2001)**<br><br>Dying in Hospital: Medical Failure or Natural Outcomes | The aim of the study was to describe patterns of medical and nursing practice in the care of patients dying of oncological and haematological | 100 consecutive patient medical records were reviewed. Survey tool adapted from Fins et al (1999) | Retrospective research design to study medical records of a sample of patients who died as in-patients. | The authors found that 60 patients were receiving active treatment up until the time of death. Of the 100 patients in the sample, 88 were documented DNR | A high proportion of patients in this study had what Fins et al 1999 termed three outcome measures for end of life care, DNR orders, recognition of | The authors acknowledged that a retrospective audit of medical notes is reliant on accurate data being written by the clinicians. Discussion may |

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| | malignancies in the acute care setting. | | | prior to death. Forty-six patients were documented DNR 2 days or less prior to death. Only 10 patients were considered dying and were DNR and considered for palliative care on the same day. | dying and palliative care goals. However, the evidence from this study that these were not considered until very near to death. | have taken place which may not have necessarily been recorded in the medical notes. |
| 38 | **Mills, M, Davies, H, T, O, Macrae, W, A (1994)**<br><br>Care of dying patients in hospital**.** | To study the dying process in hospital | 50 dying patients (29 female and 21 males with a mean age of 66 years) | Qualitative Non -participant observer (record observations on 13 wards (6 surgical, 6 medical and 1 specialist unit). | Basic interventions to maintain patients comfort were found not to be provided; like oral hygiene. Patients were not given any fluids or diet orally. There was minimal contact between the patient and the nurse and doctor. | The delivery of care to the dying patients was observed to be poor. Lessons to be learned from the hospice model of care. | The study was undertaken in only one hospital therefore it would be difficult to transfer these findings to similar settings. Need to consider observer bias; one person recording their observations and therefore we are reliant on their interpretation of events. |
| 39 | **Murray, S, A, Boyd, K. Kendall, M, Worth, A, Benton, T, F, Clausen, H (2002).** | To compare the illness trajectories, needs and service use of patients diagnosed with cancer and those with cardiac failure. | Purposive sample 20 patients with un-operable lung cancer and 20 patients with advanced cardiac failure. | Qualitative interviews every three months for up to one year with patients, their carers and healthcare professionals. | 219 qualitative interviews were undertaken. The patients diagnosed with cardiac failure had a poorer understanding of their illness | Care for people with advanced progressive illness is currently prioritised by their diagnosis rather than need. End of life care should be | It is isn't clear what methodology was used to underpin this study. The participants were only recruited from one OPD |

| | | | | | trajectory, they received less information and generally had a poorer understanding of their condition and were less involved in their decision making. | designed to meet the specific needs of the cardiac failure patients. | department. Further studies would benefit from recruiting from other acute departments in the hospital to improve transferability of the findings. |
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| 40 | **Offerdy, M (1998)**<br><br>The application of decision making concepts by nurse practitioners in general practice. | The aim of this study was to fold. To examine the decision-making processes of GP's, nurse practitioners, patients and receptionists in relation to the types of patient/cases who require consultation with either the GP or nurse practitioner. Second, to identify the categories of conditions treated by the nurse practitioner and the GP as part of a decision-making strategy regarding | The population of this study were nurse practitioners who had completed the RCN Nurse Practitioner course. A snowball sample of 20 nurse practitioners were recruited from the south east of England. | Hypothetico-deductive method<br><br>Semi structured interviews<br><br>All interviews taped and lasted approx. 40-65 mins<br><br>Observations were recorded of the nurse consultations | Data was analysed using content analysis.<br><br>Observations and analysis indicated that when the nurses were confronted with uncertain or complex problems 'information processing' approach was applied.<br>It was observed that 45% of the negotiations between the nurse and patient resulted in a compromise between chosen treatment and option. A number of nurses | The study demonstrated that the four main concepts of decision making could be applied to nurse practitioners working in a GP surgery: hypothetico-deductive, decision analysis, pattern recognition and intuition. | A disadvantage of using the snowball technique to sample is you are not sure how representative it is of the population. The size of the sample was relatively small and so it would be difficult to transfer these findings to other settings. |

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| | | the allocation of patients. | | | commented on using the OSCE approach to assessing those patients considered to be more complex. | | |
| 41 | O'Leary, N, Murphy, N,F, O'Loughlin, C, Tiernan, E, McDonald, K (2009)<br><br>A comparative study of the palliative care needs of heart failure and cancer patients. | The study aims were to demonstrate if the palliative care needs of advanced HF patients receiving MDT care were being met when compared with cancer patients deemed to have a specialist palliative care need. | A sample of 50 heart failure patients and 50 cancer patients were recruited to this study. | Cross sectional comparative cohort study. Open ended questions were used to explore information and communication needs.<br><br>Nottingham Extended Activity Daily Living Scale was used to assess functional status.<br><br>Edmonton Symptom Assessment Scale to assess symptom burden.<br><br>Hospital Anxiety Depression Scale to assess emotional well-being. | The findings indicated that both cohorts were indistinguishable in terms of symptom burden, emotional wellbeing, and quality of life scores. HF patients valued having close supervision, medication monitoring, ease of access to services and telephone support. Only a small subset of patients had unmet palliative care needs. | The study was able to identify the core components of a HF service most valued by the patients. The study identified a transition point where the focus of care should concentrate in order to manage effectively the transition to palliative care. | An assumption was made that cancer patients referred to homecare had specialist PC needs. No attempt was made to evaluate this.<br><br>Patients were not matched but the sample populations were described as comprehensively as possible in terms of demographics, co-morbidities, functional status and so forth. |

| 42 | Parry, R, Seymour, J, Whittaker, B, Bird, L, Cox, K (2013).<br><br>Rapid Evidence Review: Pathways Focussed on the Dying Phase in End of Life Care and their Key Components. | The report focus is to review published peer reviewed research about end of life care pathways; with a particular focus on those pathways which are used in hospitals. | 80 peer reviewed papers reviewed | Rapid Evidence Review | There is very little evidence specific to interpersonal communication in the last few days /hours of life. The potential benefits and adverse effects of end of life pathways for the dying have not yet been robustly compared with alternative forms. Increasing participation in decision making increases satisfaction but does not necessarily reduce anxiety. | A number of recommendations were made following the review. One recommendation was the need for further research into decision making and communication in relation to end of life care and a comparison of practice with professional guidance. Further studies needed in relation to end of life care for cultural and ethnic groups. | The sample of papers reviewed whilst systematic was relatively small. Undertaken by one University. |
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| 43 | Rice, E, M, Rady, M,Y, Hamrick, A, Verheijde, J, L, Pendergast, D,K (2008).<br>Determinants of moral distress in medical and surgical nurses at an adult acute tertiary care hospital. | To determine the prevalence and contributing factors of moral distress in medical and surgical nurses | The survey was completed by 260 nurses. Of the 260 nurses 250 were female respondents. | A prospective cross-sectional survey using the Moral Distress Scale tool was administered to medical and surgical nurses in a tertiary hospital. | The intensity of moral distress was uniformly high in situations related to physician practice, nursing practice, institutional factors, futile care, deception and euthanasia. Encounter frequencies for | Moral distress is common among nurses in acute medical care and surgical units and can be elicited from different types of situations encountered in the work environment. | The study was only performed on one site and the nurses demographics and education may have been different to other hospitals therefore it would be difficult to generalise these |

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| 44 | **Rodgers, A, Karlsen, S, Addlington-Hall, J (2000)**<br><br>'All the services were excellent. It is when the human element comes in that things go wrong': dissatisfaction with hospital care in the last year of life. | The studies aim was to investigate the sources of dissatisfaction with hospital care in the last year of life. A further aim was to assess the potential of palliative care to improve patient satisfaction. | 229 participants who responded to the VOICES questionnaire. | A post bereavement survey comparing interview and postal questionnaires to evaluate care of the dying. | Questionnaires were analysed using content analysis in which the data was organised into themes and categories. Of the 229 participants, 138 made a comment about hospital care. At least one negative comment was made by 82 participants (59%). Of these 44 (55%) rated the care given by doctors excellent and 50 (63%) rated the care given by nurses as excellent. Qualitative analysis suggests the dissatisfaction arose from feeling dehumanized, devalued and disempowered. | The findings highlighted the need to respect patients' individuality, autonomy and dignity. The findings suggest that the principles of palliative care needed to be adopted across all clinical areas managing the care of the terminally ill patient. | The views of the patients were given by proxy and therefore may not be considered reliable. Views of participants whose first language is English is under represented in this study and therefore may be considered culturally biased. |

| 45 | Rodriguez, K, L, Appelt, C, J, Switzer, G, E, Sonel, A, F, Arnold, R, M (2008). Veterans' decision-making preferences and perceived involvement in care for chronic heart failure. | The aim of this study was to test patients preferred role and perceived level of involvement in decision making and the factors that influenced these choices. | Sample of 90 patients being treated for heart failure. Of the 90 patients most were elderly (mean age, 70.1 years; range 42-88 years), male (94.4%), white (85.6%), married (56.7%) and retired (67.7%). Most had a NYHA class ll disease (55.6%) | A telephone survey. Patients preferred role in treatment decisions was assessed using the Control Preferences Scale. Perceptions about involvement in decision making during the clinic visit was measured using a subscale of the perceived Involvement in Care Scale. | Forty-three patients (47.8%) were found to prefer a passive role in the decision-making process, nineteen patients (21.1%) preferred an active role, twenty-eight (31.1%) patients preferred a collaborative role. Generalised linear regression analysis indicated that when patients perceived decision-making involvement was regressed on age and patients' role preferences, age was no longer significantly associated with involvement (β= -.196; p=0.061), but that control preferences continued to exhibit an independent effect on perceived involvement in medical decision | The findings suggest that heart failure patients preferred to take a more passive role in their decision making and that this maybe a stronger independent predictor of patients perceived involvement in decision making than patients' age. | The study was limited to 90 veterans most of whom were elderly. The generalisability of the findings to other populations would therefore be limited. It was difficult for the researchers to elucidate the relationship between age and the study variables without using a longitudinal study design. |

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| 46 | **Rutledge, T, Reis, V, A, Linke, S, E, Greenberg, B, H, Mills, P, J (2006).**<br><br>Depression in Heart Failure. A Meta-Analytic Review of Prevalence, Intervention Effects, and Associations with Clinical Outcomes. | The aim of the meta-analysis was to answer 3 questions.<br>  1) What is the prevalence of depression among patients with HF? 2) What is the relationship between depression and clinical outcomes? 3) What is the evidence for treatment effectiveness in reducing depression in HF? | Using Medline and PsycINFO databases the search identified 36 papers which met the inclusion criteria. | Meta-Analysis Review of Literature. | Clinically significant depression was present in 21.5% of HF patients and varied by the use of questionnaires v diagnostic interview. There was an increase in hospital visits and visits to the ED by those patients with depression. | There was apparent relationship between depression and outcomes in those patients diagnosed with HF. There was insufficient data to undertake meta-analysis re health care costs. The authors recommended that future studies need to be undertaken in the psychosocial effects of HF. | The authors acknowledge that one limitation could have been keywords missed in their search strategy. |
| 47 | **Seal, M (2007)**<br><br>Patient Advocacy and Advance Care Planning. | To explain the role of patient advocacy in the Advance Care Planning process. | Nurses working on the palliative care, respiratory ward, renal and Colo-rectal wards. Control wards included haematology, cardiology, neurology/geriatric | Likert Scale Survey administered pre- and six months post intervention to pilot and control groups. | Statistically significant results in the post intervention showed nurses experienced greater encouragement in making sure that patients made informed choices | Findings suggest that patient advocacy supported by a good palliative care environment can positively affect the ACP process. | The non-equivalent group is a limitation as the characteristics for an explanatory group should be typical of the population under investigation. Professional |

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| | | | n= 139 in both the intervention and control groups. | | about their end of life care (84%) Nurses believed the ACP provided them with a means to uphold patient's wishes (73%). There was overall an improvement in job satisfaction (67%) compared to those nurses in the control group. | | advice sought from the hospital epidemiologist on ways to reduce the s study bias. |
| 48 | **Selman, L, Harding, R, Beynon, T, Hodson, F, Coady, E, Hazeldine, C, Gibbs, L, Higginson, I, J (2007)** Modelling services to meet the palliative care needs of chronic heart failure patients and their families: current practice in the UK | To describe current palliative care provision for chronic heart failure. | Twenty telephone interviews conducted with staff across 17 services comprising of three main types: hospital based (n=7), community based (n=6), and hospice based (n=4). | Semi structured qualitative telephone survey of key professionals involved in CHF palliative care in the UK | The consensus amongst the HCP was there needed to be improved working between palliative care and Cardiology. Stakeholders needed to be involved from the beginning in service development. | Information regarding existing services challenges, recommendations and referral systems is essential when designing a new service. | A possible limitation of this study is that it did not include all emerging services involved in the care of heart failure patients. |
| **49** | **Sook-Hyo, O, Hyeoun-Ae, P, (2004).** | The purpose of the study was to develop and test a decision tree | Phase 1: 29 cancers patients from 2 Korean general hospitals | The study used methodological triangulation. | The first model was influenced by the perceived seriousness of the | The models were useful in assisting nurses understand the treatment | The study sample was recruited in two hospitals and so it would be |

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| | Decision Tree Model of the Treatment-Seeking Behaviours Among Korean Cancer Patients. | model of the treatment seeking behaviours among Korean cancer patients | participated in semi-structured interviews.<br>Phase 2: 165 cancer patients were sent a questionnaire and then subsequently were interviewed. | Two models were developed; a decision - making model for when to visit the doctor after detecting symptoms and a second model about treatment type following diagnosis. | symptoms, prior experiences of visiting a doctor and social group influences.<br><br>The second model was influenced by curability, social group influences on alternative therapies and confidence in using alternative therapies. | seeking behaviours in cancer patients. | difficult to generalise the findings to other hospitals or community settings. |
| 50 | **Stoppelenburg-Brinkman, A, Rietjens, J, A, C, Heide, van der, A (2014)**<br><br>The effects of advance care planning on end of life care: A Systematic Review | To present an overview of studies on the effect of advance care planning and to gain insight into the different types of ACP. | Search yielded 3571 papers of which 113 were relevant.<br>95% of the studies were observational | Systematic Review | ACP was often found to decrease life sustaining treatment, increase use of hospice and palliative care and prevent hospitalisation | Evidence to suggest that ACP can positively impact on the quality of end of life care. | The terminology used to search for the literature may not have captured all papers.<br>The review did not include studies where ACP was component of a larger intervention. |
| 51 | **Thacker, K, S (2008).**<br>Nurses' Advocacy Behaviours in End of Life Nursing Care | The aim of this study was to describe acute nurses' perceptions of advocacy behaviours in end | A total of 317 (n=317) participated in this study. Age ranges from 20 to 73 years (mean 37.6, standard deviation (SD) =12.1). Nearly | A Comparative Descriptive Design. | 68% of the participants reported their frequency of working with dying patients as 'daily' or 'often'. | The report concluded that nurses despite caring for dying patients spent little time in engaging in | |

| | | of life practice in an acute setting. | half (47.1%) reported a Diploma in Nursing. Only 1/5 (21.2%) held a Batchelor in Science degree. The participants primary areas of clinical practice were medical –surgical (47.5%), and critical care units (23.9%). The majority of participants were staff nurses (89%) and working full time (76.9%). | | Only 41% of the participants had attended end of life education in the previous three years.<br><br>One way analysis of variance (ANOVA) revealed significant differences among the three groups in years of experience ($F$=421.9; $df$=1; p=0.001) and age ($F$=327.1; $df$=1; p=0.001). A majority of both the experienced (88.4%) and novice (88.5%)) nurses reported that the concept of advocacy had been part of their formal or continuing education. | end of life education.<br><br>End of life education and advocacy education positively influenced the perceived advocacy behaviours when caring for end of life patients.<br><br>Novice nurses reported that a lack of communication and lack of time/support served as barriers to their practice of advocacy. | |
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| 52 | Tanner, C, A, Padrick, K, P, Westfall, U, E, Putzier, D, J (1987). | To investigate how junior student nurses, senior students nurses and qualified nurses apply | A convenience sample was recruited to this study. Junior student nurses (n=15), | Quantitative study Participants were asked to complete three simulation | With increased levels of knowledge and experience there was a trend towards more | The study provides insights into how different groups of nurses use information to make decisions | There is very little information about the content used in each of the eleven simulation case studies used. This |

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| | Diagnostic Reasoning Strategies of Nurses and Nursing Students. | diagnostic reasoning to different clinical scenario's | Senior student nurse (n=13) and qualified nurse (n=15) All participants met the studies inclusion and exclusion criteria. | exercises. Each simulation contained a verbal handover, a short-videotaped scene and a complete set of medical notes. Nurses were then interviewed post simulation and their responses recorded. The answers were then scored against a number of diagnostic hypothesis. | systematic data acquisition and accuracy in diagnosis. | and form a diagnostic hypothesis. A similar model to physicians was observed being used by the nurses. The authors concluded this would require further observational study. | information would have been useful in comparing the results between each group. The authors acknowledge further studies are required to understand cue recognition and activating a hypothesis between groups. |
| 53 | **Thompson, G, McClement, S, Daeninck, P (2005)** Nurses perception of quality end of life care on an acute medical ward. | The aim of this study was to explore nurses' perceptions on what they believed to be quality end of life care. | 10 nurses working on acute medical units in two tertiary affiliated hospitals. | Qualitative-Grounded Theory. Data was collected by interviews and participant observation. | The theme which emerged to explain how nurses provided quality end of life care was 'creating a haven for safe passage'. This theme for the nurses represented a continuum of behaviours and strategies which included sub-processes 'facilitating and maintaining a lane | The study highlighted the complexity of delivering quality end of life care to patients and their families and the context in which this takes place. | The participants in this study were all female. The views of the male nurses were not captured who may have had held a slightly different view on quality end of life care than their female counterparts. |

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| | | | | | change', 'getting what's needed', 'being there' and 'manipulating the care environment'. | | |
| 54 | **Veerbeek, L, van Zuylen, L, Swart, S, J, Ellershaw J, (2006)** Audit of the Liverpool Care Pathway for the dying patient in a Dutch cancer hospital | The aim of the audit was to assess if care goals had been achieved for cancer patients admitted to a palliative care unit. All patients were on the LCP. | Audit 80 patients' medical notes. In Rotterdam 40 case notes were audited Liverpool 40 case notes were audited. | Anonymous retrospective review of medical notes of deceased patients aged 18yrs-or older. This review took place between Oct 2001 and Jan 2003. The results were then compared with the Marie Curie Hospice Liverpool between April 2002 and July 2003. | The mean age of death was 61 years. The LCP had been used for more than 48 hours for 42% of the patients and 27% of patients in Rotterdam. 80% of the care goals were achieved for patients both in Liverpool and Rotterdam. Symptom control was achieved in 88% of all cases. The number of episodes for which documentation was missing was less than 5%. | The findings from the audit comparing both UK and the Dutch hospices was comparable. Both acknowledged the need for ongoing education for healthcare professionals on the LCP to maintain its function in enabling staff to deliver quality care. | The audit provided some useful data in comparing two very different hospice sites in the UK and Netherlands. Further studies may need to consider measuring clinical outcomes or explore user and carer experiences o improve the transferability and generalisability of the findings. |
| 55 | **Veerbeek, L, van Zuylen, Swart, S, J, deVogel-Voogt, van der Rijt, C, C, D, van der Heide, A (2008)** | The study aim was to investigate the use of the LCP in a hospital setting, nursing home setting and care home setting. The authors wanted to | A relative was asked to fill out a questionnaire post bereavement. Nurse who had given care to the patient was asked to | Pre- and post-intervention design. | In the intervention period the documentation of care was significantly more comprehensive than compared with the baseline. | The LCP contributed to the quality of documentation and symptom control in the dying patient. | A randomised control trial wasn't undertaken due to practical and ethical considerations. The authors had to rely on their |

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| | The effect of the Liverpool Care Pathway for the dying: a multi-centre study. | assess the degree to which care was documented during the d ting phase, the symptom burden and communication. | complete questionnaire. The nurse was also asked to collect demographic data from the patients notes like gender, age and diagnosis. EORTC QLQ-C30 questionnaire was felt the most appropriate to use along with the VOICES questionnaire.<br><br>In the baseline period 219 nurses and 130 relatives filled in a questionnaire for 220 deceased patients. In the intervention period 253 nurses and 139 relatives filed in a questionnaire for 255 deceased patients.<br><br>The LCP was used for 197 patients | | The average total of symptom burden was found to be lower in the intervention group. | | proxies to collect the data on symptom burden which may have added a degree of variability to the findings. |
| 56 | **Vleminck, De, A, Pardon, K,** | To identify barriers from the | Five focus groups of GP'S (n=36) | Exploratory study using the | In cancer patients the GP lack of | The findings from the study | The GP's recruited to the focus groups |

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| | **Beernaert, K, Deschepper, R, Houttekier, D, Audenhove, Van, C, Deliens, L, Stichele, R, V (2014)**  Barriers to Advance Care Planning in Cancer, Heart Failure and Dementia Patients: A Focus Group Study on General Practitioners' Views and Experiences. | GP perspective to initiating ACP and to gain insight into the disease trajectories of cancer, heart failure and dementia. | | qualitative method of focus groups. | knowledge about treatment options and the lack of collaboration with the specialist was seen as a barrier. Barriers that occurred more frequently with the heart failure and dementia patients was the GP lack of familiarity with the terminal phase. The patients lack of awareness regarding the terminal phase of the disease was also seen as a barrier. | contribute to a better understanding of what factors hinder the GP to initiate the ACP. | were mainly male (n=27), the female GP was under represented female (n=9). Along with GP'S under the age of 39 years. The study only sought the perspective of the GP and not the patient, families or other healthcare professional. |
| 57 | **Wilson, J, Kirshbaum, M (2011)** Effects of patient death on nursing staff: a literature review | The aim of the literature review was to explore how the death of patients in a hospital setting impacted on the nursing staff. | 17 studies met the inclusion criteria for review | A review of the literature was undertaken using the electronic databases CINAHL, MEDLINE, PsyInfo Limited to the English Language and Peer Reviewed articles. | Themes which arose from the literature review were the emotional impact, the culture of the healthcare setting, staffs' previous life experience and support available for health care professional staff. | The death of a patient was found to have an impact on the nursing staff. There needs to be a greater awareness of 'grief theory' and support from other HCP in order that staff can develop strategies to cope with death. | The review was limited in its breath and depth of studies across the acute medical setting. There were very few studies which looked at the impact of dying on nurses in other departments like the ED or MAU departments. This would have |

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| | | | | | | provided a true comparison across the hospital setting. |
| **58** | **Wong, F, K, Y, Man Ng, A, Y, Lee, P, H, Lam, P, T, Ching Ng, J, S, Yim Ng, N, H, Sham, M, M, K (2016)**<br><br>Effects of a transitional palliative care model on patients with end-stage heart failure: a randomised controlled trial. | To examine the effects of home based transitional palliative care for patients with end stage heart failure (ESHF) after hospital discharge. | Participants recruited from three hospitals in Hong Kong.<br><br>Participants needed to for fill the following criteria:<br><br>1)Had to meet two of the ESHF Prognostic Indicator Guidance<br>2) CHF New York Heart Association stage 3/stage 4<br><br>3) three hospital admission in a year<br><br>4) existence of physical and psychological symptoms<br><br>A total of 389 participants were screened with 305 excluded. The remaining 84 | Randomised Control Trial<br><br>The interventions consisted of weekly home visits /telephone calls in the first 4 weeks then monthly follow up provided a nurse case manager. The primary outcome measures were any readmission and count of readmissions within 4 and 12 weeks after discharge. | The intervention group (n=43) had a significantly lower readmission rate than the control group (n=41) at 12 weeks (intervention 33.6% vs control 61.0%, $\chi_2$=6.8, p= 0.009) The mean number of readmissions for the intervention and control groups, was respectively, 0.42 (0.10) and 1.10 (0.16) and the difference was significant (p=0.001). There was no significant difference in readmissions between groups at four weeks. | The study provided evidence to support the effectiveness of post discharge transitional palliative care programme in reducing symptoms and improving symptoms. | The loss of follow up was high in this study. The rate was 24.4% and 14% respectively, for the control and intervention groups, the main reason being death and deterioration.<br><br>The NYHA class in the control group was high compared with the intervention group. |

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| | | | | | participants were randomised. | |
| 59 | **Xu, J, Abshire, M, H, Ra Han, (2016)**<br><br>Decision making among persons living with heart failure. | The aim of this study was to critically evaluate the quantitative literature on decision making among people with heart failure and to identify any research gaps. | Twelve quantitative studies were included in the systematic review of the literature. Five studies were surveys, one was a chart review, two were interventions, two were secondary analyses of data and two used multiple methods. Eleven studies recruited exclusively HF patients and one study recruited 64% HF patients. | A Systematic Review of the literature using CINAHL, PubMed, Psych Info databases | Two thirds of the articles focussed on decisions related to end of life care (resuscitation decisions and advance care planning). The other one third focussed on decisions about care seeking, participants involvement in treatment decisions during their last clinic visit and self-care behaviours. | The review found that the term decision is often ill defined or not defined in the HF literature. Limitations in the methodological rigor of the studies reviewed meant it was difficult to generalise findings. | Only articles published in the English language were included in this review. The inclusion for this review was a sample equal to or greater than 50 % HF patients. The researchers acknowledged that studies may have been excluded if the researchers did not specify the type of participants recruited. |

## Appendix 12 Screening Tool

Print out and attach to each article (tick yes/ no as appropriate for each criteria)

| Title and Abstract relevance screening tool | | |
|---|---|---|
| **Criteria** | **Yes** | **No** |
| Does the study have a clearly addressed research question? | | |
| Doe the study use a valid method to address the research question? | | |
| Are the valid results of this study important? | | |
| Are the results valid and applicable to my studies population? | | |

| Author (s)/Year | | | |
|---|---|---|---|
| **Title** | | | |
| **Inclusion Criteria** | | **Yes** | **No** |
| Exploration of healthcare professionals' decision making when managing the care of adult patients diagnosed with NYHA stage 3 and stage 4 heart failure | | | |
| Exploration of end of life care and palliation in patients diagnosed with NHYA stage 3 and stage 4 heart failure | | | |
| Exploration of relationships between the healthcare professional and the patient when considering end of life decision making | | | |
| Exploration of healthcare professionals and patients' experiences in an acute medical setting | | | |
| Studies undertaken between the years 1997 and 2017 | | | |
| **Exclusion Criteria** | | | |
| Studies not written in the English Language | | | |
| Studies which do not relate to the subject of heart failure, end of life care or palliative care | | | |
| Studies which may involve children under the age of 18 years | | | |
| Studies which explore healthcare professional decision making in patients in a coronary care unit. | | | |
| Exploration of healthcare professionals' decision making when considering end of life care for patients with device therapies like LVAD, ICD. | | | |

| | **Yes** | **No** | **Reason** |
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| Decision to include | | | |
| Decision to exclude | | | |
| Undecided | | | |
| Background Information | | | |

**Notes:**

**Appendix 13 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist**

Developed from:
Tong A, Sainsbury P, Craig J (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care,* 19(6), 349 – 357

| No. Item | Guide questions/description | Reported on Page |
|---|---|---|
| **Domain 1: Research team and reflexivity** | | |
| *Personal Characteristics* | | |
| 1. Inter viewer/facilitator | Which author/s conducted the interview or focus group? | Page 9 |
| 2. Credentials | What were the researcher's credentials? e.g. PhD, MD | Page 10 |
| 3. Occupation | What was their occupation at the time of the study? | Page 9 |
| 4. Gender | Was the researcher male or female? | Page 9 |
| 5. Experience and training | What experience or training did the researcher have? | Page 9 |
| *Relationship with participants* | | |
| 6. Relationship established | Was a relationship established prior to study commencement? | Page 89/97 |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | Page 96 |
| 7. Interviewer characteristics | What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | Page 9/10 |

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| Domain 2: study design | | |
|---|---|---|
| *Theoretical framework* | | |
| 9. Methodological orientation and Theory | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | Page 88 |
| *Participant selection* | | |
| 10. Sampling | How were participants selected? e.g. purposive, convenience, consecutive, snowball | Page 94/95 |
| 11. Method of approach | How were participants approached? e.g. face-to-face, telephone, mail, email | Page 106 |
| 12. Sample size | How many participants were in the study? | Page 90 |
| 13. Non-participation | How many people refused to participate or dropped out? Reasons? | Page 103 |
| *Setting* | | |
| 14. Setting of data collection | Where was the data collected? e.g. home, clinic, workplace | Page 89 |
| 15. Presence of non-participants | Was anyone else present besides the participants and researchers? | Page 95 |
| 16. Description of sample | What are the important characteristics of the sample? e.g. demographic data, date | Page 95 |
| *Data collection* | | |
| 17. Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | Page 107 |
| 18. Repeat interviews | Were repeat inter views carried out? If yes, how many? | N/A |
| 19. Audio/visual recording | Did the research use audio or visual recording to collect the data? | Page 106 |
| 20. Field notes | Were field notes made during and/or after the interview or focus group? | Page 111 |
| 21. Duration | What was the duration of the inter views or focus group? | Page 111 |
| 22. Data saturation | Was data saturation discussed? | Page 132/133 |
| 23. Transcripts returned | Were transcripts returned to participants for comment and/or correction? | Page 202 |

| Domain 3: analysis and findings | | |
|---|---|---|
| *Data analysis* | | |
| 24. Number of data coders | How many data coders coded the data? | Page 113 |
| 25. Description of the coding tree | Did authors provide a description of the coding tree? | Page 122-133 |
| 26. Derivation of themes | Were themes identified in advance or derived from the data? | Page 122-133 |
| 27. Software | What software, if applicable, was used to manage the data? | Page 117 |
| 28. Participant checking | Did participants provide feedback on the findings? | Page 202 |
| *Reporting* | | |
| 29. Quotations presented | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | Chapter4, 5, 6, 7 |
| 30. Data and findings consistent | Was there consistency between the data presented and the findings? | Yes, there was. Chapter 5, 6 |
| 31. Clarity of major themes | Were major themes clearly presented in the findings? | Yes. they were. From page 137 to 167 |
| 32. Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | Yes, Chapter 7 |

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