Heart failure patients' and care givers' experiences and expectations of end-of-life conversations and palliative care provision, and community heart failure nurses' perspectives on implementation into clinical practice.

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Abstract

Heart failure is a long-term condition, and is often terminal. The researcher's clinical experience has highlighted a reluctance from clinicians to have discussions about dying with these patients. To obtain heart failure patients' and carer givers' experiences and expectations of end-of-life conversations and palliative care provision. It further aimed to explore from the perspective of community heart failure nurses how these preferences can be implemented into clinical practice to improve patient care.

This co-produced study used qualitative interviews and focus groups from a nationally sourced sample. The study recruited 19 cases consisting of 8 heart failure patients, 2 carer givers and 9 community heart failure nurses all of whom had taken part in end-of-life conversations relating specifically to heart failure.

Patients and carer givers described a need to be informed regarding their disease and prognosis. A lack of such information impacted on their abilities to rationalised the illness, or prepare for the deterioration in their condition. Those participants that were provided with ongoing conversations described the formation of a patient-healthcare professional relationship, which gave them confidence to take control of their illness and care.
These themes were presented to community heart failure nurses, to establish how these findings can be implemented into clinical practice to improve patients experiences of heart failure communication. They identified barriers preventing end-of-life conversations, including active avoidance, lack of role definition, and apprehension to initiate these discussions. They supported the need for a working partnership with their patients and carers to provide reassurance and confidence in providing this care. There is a pressing need to formulate specific end-of-life and palliative care guidance and policy specific to the unstable

heart failure disease trajectory to reduce the variation in practice and confidence to talk about terminal illness.

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Chapter 1. Introduction

We all have two things in common, we are born and we die. Birth is something that is celebrated within society, and the latter is something rarely discussed. Heart failure is a long term condition, and often terminal. The researcher's experience of working as a heart failure nurse demonstrated that clinicians are reluctant to have discussions about death and dying with these patients.

This chapter will introduce the condition of heart failure, discuss the terminology used in describing palliative care, explore current end-of-life policy, and will provide an insight into the motivation of the researcher in undertaking this research project.

1.1 Heart Failure

It is estimated that over 1 million people in the United Kingdom have a diagnosis of heart failure, with approximately 200,000 newly diagnosed every year (British Heart Foundation, 2024). A population study by Conrad *et al.*, (2018) based on 2002-2014 data showed that heart failure had a higher prevalence than the four most common cancers combined (lung, prostate, breast and bowel).

Heart failure is the end stage condition of most diseases associated with the heart (Davis., Davies., and Lip., 2006). It is a long term condition that has a progressive nature (Connolly *et al.*, 2014), and is associated with a high risk of sudden or premature death (Kane *et al.*, 2018). Despite this prevalence, there are no general definitions of 'heart failure' (Petersen, Rayner and Wolstenholme, 2002; Davis., Davies, and Lip, 2006). In part, this is because it is primarily based on clinical diagnosis with characteristics that are not necessarily specific to the organ involved (Davis, Davies, and Lip, 2006). For example, diagnostic classification of

heart failure can be associated with a reduced pumping action of the heart muscle, or the appearance of a normal pumping action but impairment in the heart's ability to stretch and fill with blood. Both types of heart failure have similar symptoms and ultimately a terminal prognosis (Davis, Davies, and Lip, 2006). Additionally, the ageing population exacerbates the complexities associated with diagnosis and symptom management of this disease as it is often associated with several co-morbidities (Ecarnot *et al.*, 2018).

Whilst evidence-based medical therapies improve prognosis of advancing heart failure (for those with a reduced pumping action) and to some degree quality of life, for some patients their final months (or years) of life can be distressing due to poorly controlled symptoms (Daley, Matthews and Williams, 2006). These symptoms (such as fatigue, pain, breathlessness and anxiety) are commonly associated with those of cancer, and due to this there is a recognition that palliative care practices within oncology should meet many clinical needs of those patients suffering with advanced heart failure (Beattie, Higginson and McDonagh, 2020a).

The disease trajectory of heart failure can also be unpredictable (Beattie, 2014), with episodes of deterioration that often require admission to hospital for intravenous diuretic therapy (Beattie, Higginson and McDonagh, 2020b). After effective medical therapy patients can appear well and stable for a variable period of time, it is this uncertainty and worsening symptoms that is a unique characteristic to heart failure in comparison to other terminal illnesses (Hupcey, Penrod and Fenstermacher, 2009). Despite the high prevalence of heart failure and that it is a terminal condition, palliative care for this group of patients is far less well developed than for other conditions such as cancer. This research therefore aims to

identify the preferences and palliative care needs specific to this patient group, to inform guidance, policy and clinician's practice to improve this aspect of care.

1.2 The terminology used

There are many different terms used to describe the care given in the latter stages of a patient's life. These can include 'palliative care', 'supportive care', 'comfort care', and 'end-of-life care' (Weil *et al.*, 2015). These terms are renowned for being used inter-changeably and as a result healthcare professionals struggle to define their meaning (Gott *et al.*, 2012).

The most commonly used term palliative care is defined by the World Health Organization, (2023) as an approach that offers physical, spiritual and psychological care to improve quality of life. This holistic method of care is frequently associated with the terminal stage of illness (Weil *et al.*, 2015), however in practice it is a philosophy of care that is recommended to start from diagnosis through to the patient's death (Riley and Beattie, 2017). When palliative care is discussed by clinicians it is frequently used to refer to specialist palliative care (Gott *et al.*, 2012), which is administered by healthcare professionals who practice in the specialised area of palliative medicine (Gibbs, Khatri and Gibbs, 2006). Due to palliative care being seen by healthcare professionals as a system of care organisation, rather than a philosophy of care (Hupcey, Penrod and Fenstermacher, 2009), clinicians rarely recognise it with any importance (Weil *et al.*, 2015) resulting in a delay of its introduction (Hupcey, Penrod and Fenstermacher, 2009). Palliative care is frequently provided using a multidisciplinary team approach to ensure the patient receives holistic care (Riley and Beattie, 2017). It is suggested that all clinicians who provide direct patient care should provide supportive interventions to assess and relieve symptoms (Hupcey, Penrod and Fenstermacher, 2009). Those healthcare professionals that offer this aspect of care and are non-palliative specialists are described as

providing ‘general palliative care’ (Gott *et al.*, 2012). The term ‘end-of-life’ is associated with patients who are expected to dying within 6 months to a year (Department of Health, 2008). In offering end-of-life discussions to terminally ill patients allows them to consider, discuss and record their preferences on treatment and care (Wilson *et al.*, 2024).

The work by Hui *et al.*, (2012) undertook a literature review exploring the common phrases used to describe this aspect of care during a patient’s terminal illness. They concluded that ‘palliative care’ and ‘end-of-life care’ were the most frequently cited terms. This replicates the language used in clinical practice by the researcher and as such the phrases used within this thesis are: ‘palliative care’ that will refer to care given in assessing and elevate symptoms rather than therapies that prolong life, and ‘end-of-life conversations’ are discussions that are used to plan and assess the social and clinical needs of patients to manage their symptoms. The terminology relating to this aspect of care within national guidance and policy are comparable to those used by the researcher.

1.3 End-of-life policy and guidance for heart failure

The government acknowledges that current provision for end-of-life and palliative care requires expansion due to the growing requirement of the ageing population who have complex health needs, this includes addressing the current health inequalities and variations in service provision (UK Parliament, 2022). End-of-life policy for heart failure are often tokenistic. For example, the document entitled ‘Ambitions for palliative and end of life care: A national framework for local action 2021-2026’ (National Palliative and End of Life Care Partnership, 2021), aimed to bring together national organisations who are devoted to developing end-of-life care within the UK. The framework is a collaborative approach that

set out six aims and if achieved were believed to improve palliative and end-of-life care. For example co-ordinated, individualised care, prepared clinicians, and accessible care provision. However, this report does not mention heart failure, and has no representation of any heart failure or cardiology partners. Similarly, governmental policy continue to offer vague advice, the Health and Care Act 2022 (NHS England, 2022a) guidance on implementing palliative care suggests that integrated care boards should provide palliative care services as they deem appropriate as part of the healthcare service, with no mention of specific disease requirements. Whilst further guidance for healthcare commissioners is provided within the 'Palliative and end of life care statutory guidance for integrated care boards' (NHS England, 2022b), again there is no mention of heart failure care other than palliative care should be offered to those individuals with non-cancer diseases. This lack of guidance from the government is not however replicated in cardiology guidance.

Even though there is a lack of national governmental policy relating to end-of-life guidance for heart failure which would provide consistency and regularity to care provision, the cardiology societies and charitable organisations have do offer clear recommendations about end-of-life conversations and when palliative care is clinically indicated. The European Society of Cardiology (Ponikowski *et al.*, 2016) and the British Heart Foundation, (2022) both advocate the use of palliative care to control symptoms and support heart failure patients. Clinical indications for this care are deteriorating and unstable symptoms whilst taking optimal prognostic therapies (National Institute for Health and Care Excellence, 2018); multiple hospital admissions due to heart failure symptoms (McDonagh *et al.*, 2021); reduction of disease modifying therapies due to adverse effects and the exhaustion of curative, supportive therapies (Hill *et al.*, 2020; Sobanski *et al.*, 2020). Strong evidence supports the introduction palliative care early within the disease trajectory to ensure a

continual assessment of needs and identification in the patient's change in symptoms (Yancy *et al.*, 2013; Ponikowski *et al.*, 2016; National Institute for Health and Care Excellence, 2018; World Health Organization, 2023). To meet the patient's needs it is suggested within the cardiology guidance that palliative care is delivered by heart failure clinicians who have the expert skills to provide ongoing assessments and who have close links to specialist palliative services should symptoms dictate their need (Yancy *et al.*, 2013; Ponikowski *et al.*, 2016; British Heart Foundation, 2022). These guidance provide a framework to incorporate end-of-life conversations and palliative care into heart failure care, however they do not use evidence from palliative research with heart failure patients and care giver as participants. Whilst the recommendations are based on what care should look like there is no evidence to substantiate how this would be administered.

1.4 The researcher's motivation for this research

The researcher has previously worked as a community heart failure nurse, working within a nurse led service, who's ethos was that a large part of their clinical role involved providing palliative care to their patients. This aspect of care was seen as equally important as the introduction and titration of the drug therapies that prolonged life.

During years of clinical experiences, the researcher learned the importance of end-of-life preparation and the challenges associated with initiating these discussions. However, the occasions when patients and their care givers had not had opportunity to plan for their deterioration were a motivation for the researcher to ensure others had the chance to be prepared. The researcher observed that for those who had been provided with the time and support to plan their death, who had confidence in their clinician and who were fully

informed of the network of services available to them their experiences, even though it was emotive, tended to die peacefully and calmly.

The researcher believes administering end-of-life conversations and palliative care provision was a positive experience. It was not an easy aspect of care, and yet with planning and open dialogue the researcher felt they had made a huge difference to vulnerable patients. There were episodes where fellow clinicians failed to acknowledge the deterioration of their patient and recognising that the administration of general palliative care was needed. The researcher drew frustration from this practice. There was a clinical need to improve this aspect of care, to ensure all patients received similar experiences. It was these encounters that have driven this research.

1.5 Aims and objectives of this research

The wider literature is inadequate in providing evidence to inform practice on this topic, and as such there are documented barriers as to why these conversations do not happen. The proposed research is to offer an insight into heart failure patients and care giver's preferences and then provide evidence on how this can be implemented into national policy would provide structure to this care and reduce the current variation in practice. It is these disparities in current practice that have influenced the researcher to undertake this research.

The aim of the study was to gain an insight into heart failure patients and their care givers experiences relating to these discussions, and their palliative care provision. The findings were then presented to community heart failure nurses to establish how the identified preferences could be implemented into clinical practice.

The study objectives were to improve palliative care provision for heart failure patients and their care givers through better end-of-life conversation and by providing guidance that can be implemented into clinical practice to enhance patient's experiences.

The research questions devised to address this gap in evidence are:

What are heart failure patients' and carer givers' experiences and expectations of end-of-life conversations and palliative care provision? And how can this be implemented in clinical practice?

Sub research questions

- What are heart failure patient's experiences and unmet needs of end-of-life conversations and palliative care provision?
- What are heart failure patients carer giver's experiences and unmet needs of end-of-life conversations and palliative care provision?
- How can heart failure professionals address heart failure patients and carer giver's expressed care needs and how can these be implemented to improve clinical practice?

1.6 Chapter summary

This chapter has discussed the prevalence and impact heart failure as a condition affects individuals, whilst highlighting how palliative care is required as the disease progresses. The multiple terminology used in describing this care adds to the challenges associated with its understanding, therefore the researcher has rationalised the terms used within this thesis to aid understanding.

It has been demonstrated that end-of-life conversations and palliative care policy are vague in informing and guiding clinician's practice, which inhibit the provision of this care. The researcher's motivation has also been discussed to offer a rationale for undertaking this research, based on their clinical practice experiences.

1.7 Organisation of this thesis

Chapter outlines

The **literature review chapter** discusses the wider literature available on the topic of end-of-life conversations and palliative care. A systematic approach to the review of the literature looks specifically at this topic relating to heart failure patients, care givers and the healthcare professionals involved in caring for these patients. This will demonstrate the evidence and identify any gaps in current knowledge.

The **methods chapter** describes how the research was conducted and the approach taken in collecting and analysing the data gathered. This is done in relation to the theoretical and methodological underpinnings, and descriptions will be offered in how this has guided the course of the research.

The **analysis chapter** demonstrates the methods and analysis of the data collected from both arms of the study. Comparable methods were used from both arms to present the findings from patients, care givers and community heart failure nurses.

The **discussion chapter** provides proposals for future practice, whilst discussing the strengths and weaknesses of this research. Recommendations for future research will be suggested and the researcher will reflect on the research process.

Finally, the **conclusion chapter** presents recommendations for a change in current heart failure practice to improve end-of-life conversations and palliative care provision.

Chapter 2. Literature review

2.1 Introduction

This chapter will begin with a scoping review of the available literature to provide an insight into the emerging evidence (Munn, Peters, *et al.*, 2018), providing a discussion about the taboo nature of death within society, what is meant by experiencing a 'good death', and the emergence of specialised end-of-life care. The hospice movement has evolved over the years, and whilst it has been predominantly influenced by cancer there is a call for palliative care to be offered to all terminal illnesses. Examining the end-of-life needs and care provision of cancer patients will enable a comparison to those with heart failure. Having explored these aspects of care, a systematic approach of the literature review will focus specifically on end-of-life conversations and palliative care among patients with heart failure. This type of review is recognised for not the strategic methods advocated by the Cochrane collaboration however, it does use a systematic procedure of identifying, critiquing and analysing the literature relating to this topic of interest (Aveyard, H., 2019). The clinical experiences of the researcher demonstrated a lack of end-of-life conversations, this perspective was compared to the literature and experiences of others to offer a comparative view.

2.2 A need for end-of-life conversation

Death is unavoidable, and ultimately will affect us all emotionally (Petts, 2018; Pearce, 2020), and yet it is perceived as a taboo topic within societal culture (Nelson and Peterson, 1975) leading to a reluctance in addressing patient's inevitable demise (Pearce, 2020). This opinion has been researched previously in an attempt to try and establish why healthcare professionals rarely acknowledge a patient's deterioration (Barclay *et al.*, 2011). This belief has been associated with medical advancements and the evolvement of hospitals from institutions that provided care for the dying, to establishments that are dedicated to

caring, healing and restoring good health (Kübler-Ross, 1986). Developments in healthcare are now viewed as life prolonging rather than supportive, and end-of-life care is perceived as futile (Barra, 2021). This ingrained opinion by healthcare professionals has influenced how death continues to be seen as a medical failure (Balaban, 2000). The dominance of this is also reflected in the education of our future clinicians. It is reported that there is sub-optimal education within undergraduate physician training, resulting in them being unprepared or unexposed to the concept of dying and therefore they do not have the competencies to address this experience within clinical practice (O'Dowd, 2015).

The opinion that palliative care is an afterthought in comparison to curative therapies has been a view for some time and as a result funding has not be sufficient to offer end-of-life care to patients (Murray and Amblàs, 2021). The World Health Assembly, (2014) addressed the lack of funding for this form of care by generating a report requesting member states to develop, increase and delivery palliative care to all. The work by Peeler, Afolabi and Harding, (2024) reported a decade later that only 14% of patients internationally who would gain from palliative care input, have received it. This deep-seated view of irrelevance associated with palliative care by healthcare professionals and those who control care commissioning impose a negative bias on the importance of death and palliative care provision.

The attitude of clinicians however, is not necessarily reflective of those of the general public. Exploration of people's attitudes regarding an unwillingness to have death and dying conversations, was analysed by Nelson *et al.*, (2021). They surveyed a sample of 8077 participants from all areas within the United Kingdom. This sample was a general population sample. They found that approximately half (51%) of the total sample believed that as a

society death and dying was not discussed enough; 84% of participants felt there was nothing to inhibit them from having discussions relating to death and dying, and only 14% had formally expressed future preferences and their healthcare wishes relating to their own death. Further research on this topic has been explored by Wilson *et al.*, (2024), who found that the idea of death being seen as a taboo topic was not reflective in their findings. Their participants did acknowledge a contrast in discussing death and dying, and then relating this to their own demise. They described end-of-life conversations as a practical planning exercise rather than focusing on their spiritual and emotional needs, Wilson *et al.*, (2024) concluded that the clinician's motivation for these discussions were not the same as those of patients.

End-of-life care policy has encouraged healthcare professionals to have open discussions with patients for some time now (Department of Health, 2008), the lack of conversations continued to be experienced by the researcher within clinical practice when caring for patients with this incurable illness.

There is a recognised need for clinicians to having end-of-life conversations with their patients (Larson and Tobin, 2000), with evidence suggesting that healthcare professionals second guess what they think patients want from their care providers rather than listening to them. There is a necessity to reshape views of professionals regarding end-of-life conversations and palliative care to allow it to be a priority and viewed positively rather than overlooking this clinical need (Balaban, 2000). Guidance and campaigns have reiterated the importance of these discussions to promote public awareness, provide individualised care, and ultimately ensure each person experiences a 'good death' for those with a life-limiting condition (Gott *et al.*, 2011; Whellan *et al.*, 2014; Wilson *et al.*, 2022; NHS England, 2023).

The idea of a ‘good death’ is a fundamental concept of the modern hospice movement. However, this notion has changed its meaning over the years and is disputed that this ideology can exist (Hart, Sainsbury and Short, 1998). For clinicians a ‘good death’ is associated with the administration of treatments; pain relief to ensure comfort, sedation to provide emotional wellbeing and ease, whereas for patients the evidence suggests the priorities are the physical symptoms of pain, as well as the psychological aspects, religious and spiritual wellbeing (Meier *et al.*, 2016). Whatever the interpretation of a ‘good death’ is, it is agreed within the wider literature that it revolves around individualised care (Marie Curie, 2015). The philosophy of a ’good death’ is felt to support the idea of a dignified, peaceful death (Hart, Sainsbury and Short, 1998). To enable this to occur end-of-life conversations must happen to address the patient’s preferences, ensuring healthcare services are accessible to meet the needs to the patient (Wilson *et al.*, 2022). This concept of available support enables patients to feel protected, safe and understand their changing clinical needs (Marie Curie, 2015), allowing patients to make informed decisions at the end of their life.

2.3 End-of-life and palliative care policy

The lack of end-of-life discussions, and patient’s inabilities to make care decisions ultimately affects the provision of palliative care. The Department of Health and Social Care advocated that funding and policy driven palliative care is inclusive for everyone who are nearing the end of their life (Department of Health, 2008), and national policy has continued to address the incorporation of palliative care delivery into day to day medical care. However, evidence demonstrates an unwarranted variation in the provision of this care for cancer and non-cancer patients (Davidson *et al.*, 2013). This variation was explored by Gadoud *et al.*, (2014), when comparisons were made between patients with heart failure and cancer that had been entered onto a palliative care register, indicating that these patients were

receiving care from palliative services. In a sample that was deemed representative of the general population, of those entered onto a palliative care register, 7% were diagnosed with heart failure and 48% with cancer. Given the evidence about prevalence of heart disease at a population level, this discrepancy is marked. Gadoud *et al.*, (2014) concluded this disproportionate difference illustrated inequalities of accessing palliative care between cancer and heart failure patients, and the findings were a reflection that even though there are clear policy guidance on palliative care provision this philosophy of care is still interpreted as mainly being available to cancer patients.

Cardiology and end-of-life guidance provide clear definitions and recommendations about end-of-life conversations and when palliative care is clinically indicated. The European Society of Cardiology (Ponikowski *et al.*, 2016) and British Heart Foundation, (2022) both advocate the use of palliative care to control symptoms and support heart failure patients. Identified signs and symptoms of deterioration include; unstable symptoms whilst taking optimal disease modifying therapies (The National Institute of Health Research, 2018; Sobanski *et al.*, 2020); multiple hospital admissions due to heart failure (Hill *et al.*, 2020; Sobanski *et al.*, 2020; McDonagh *et al.*, 2021); reduction of disease modifying therapies due to adverse effects and the exhaustion of curative, supportive therapies (Hill *et al.*, 2020; Sobanski *et al.*, 2020). Strong evidence supports the introduction of palliative care early within the disease trajectory to ensure a continual assessment of needs and identification in the patient's change in symptoms (Yancy *et al.*, 2013; Ponikowski *et al.*, 2016; The National Institute of Health Research, 2018; World Health Organization, 2020).

The NHS Health and Care Act 2022 (NHS England, 2022a) introduced reforms to ensure that the newly established Integrated Care Boards (ICBs) commission palliative care as part of the

integrated care offered to their patients. The aim of these reforms were to ensure a more coherent national approach to healthcare provision (Gadoud *et al.*, 2014), whilst addressing the care needs of the local population. A potential criticism of this act is that the recommendations are vague, with local ICBs left to 'consider' appropriate palliative care services that need to be commissioned (NHS England, 2023). It is unclear if this approach will actually provide nationalised care, anecdotally the researcher is aware there are currently wide variation within their own locality, with some geographical areas offering prominent specialist palliative care services, whilst other local regions seemingly omit a specific palliative service provision, with the incorporation of specialised end-of-life care into general clinical services.

In another attempt to highlight the importance of addressing end-of-life needs, governmental policy provides guidance on how end-of-life and palliative care should be integrated into care provision (NHS England, 2023). It attempts to emphasise the importance of patients being involved collaboratively with healthcare professionals when planning their end-of-life care. For this to happen, evidence suggest there needs to be equality within the relationship (Chipidza, Wallwork and Stern, 2015) to ensure patients are prepared to make informed decisions about end-of-life care (Caldwell, Arthur and Demers, 2007).

2.4 Patient and clinician relationships.

Historically doctors have made care decisions for their patients (Mühlbacher and Juhnke, 2013), and in an institution such as the NHS there is a long history of embedded hierarchy (Fernandopulle, 2021). Healthcare professionals were, and still are on occasion viewed as 'higher beings' due to their ability to use medical knowledge in formulating care plans, whilst foreseeing potential consequences and accommodating them within treatment

plans (Haynes, 2002). Their medical knowledge is often viewed as superior by patients and as a result patients tend to be happy to be guided by them and take a passive role when making decisions regarding their care planning (Goranson *et al.*, 2020).

Changes within the NHS saw the introduction of the Department of Health's, (2010) document *Equality and excellence: liberating the NHS*, which offered guidance on how shared decision making between clinician and patient should become the norm. In an attempt to move away from the dictatorial practice of clinicians making care decisions, governmental guidance declared a need for an alternative way of practice to ensure patient's needs, desires and preferences were to be central in shared decision making on their care (Coulter and Collins, 2011). Defining shared decision making as being a collaborative working between the patient and their clinician to ensure the benefits and potential negative effects are shared (Montori *et al.*, 2023).

The researcher's experiences within clinical practice showed that patients rarely take the lead in planning their care, with many still of the mindset that they will take a passive role in the decisions regarding their care. The attempts to involve patients by offering information to enable them to make informed choices, is on occasion not embraced by patients. The challenges of involving patients has been acknowledged in the work by Coulter and Collins, (2011) who comment that patients can be of the opinion that it is not their role or they have no wish to participate in making care decisions as their doctor or clinician 'knows best'.

It is reported medical guidance has strived to incorporate patient engagement into policy for some time (Foot *et al.*, 2014), and yet this is not necessarily reflected in the UK professional standards for nursing and medicine education. The work undertaken by Moore *et al.*, (2021) looked at how the UK standards incorporate patient centred care into the learning of their

nursing and medical students. They reported that the model of care taught in medicine remains predominantly paternalistic, appearing to bias towards doctors 'do to' rather than 'equal sharing' with their patients. The standards and education for nursing however, has incorporated patient centred care throughout their model of care, indicating that nursing as a profession has embraced the patient-nurse relationship as an equal stance. These findings are relevant in the success of involving patients in their care decisions, and demonstrate a need for an increased priority to be made for it to be successfully implemented into clinical practice, and move away from historical practice.

The purpose of actively involving patients in decision making is to ensure they have a stronger voice in informed decisions regarding their own care (Foot *et al.*, 2014), have an increased knowledge about their illness, and a more accurate expectation of treatments and disease progression (World Health Organization, 2016). To implement this into clinical practice it is recognised that the first phase is to promote conversations that encourage patients and their healthcare professional to work in partnership in devising a plan of care (Montori *et al.*, 2023).

2.5 Hospital versus hospice.

Healthcare provision within the UK is the responsibility of the NHS, working collaboratively with social care, and charitable organisations. The history of palliative care stems back prior to the creation of the NHS with care given from hospice organisations (interchangeably referred to today as the voluntary or charitable sector), end-of-life care is currently provided by both institutions (Mathew *et al.*, 2003). The hospice movement pioneered by Dame Cicely Saunders viewed palliative and end-of-life care as a philosophy of care rather than that associated with the bricks and mortar of the hospice building (Saunders,

1996). These values have motivated care progression and through the innovation of research and medical advancements has led to the recognition of palliative care as a medical speciality (Doyle, 2005). The funding of the charitable sector comes from public, private and charity sources allowing it to be diverse, and dominant in how it delivers its services (Mathew *et al.*, 2003). This dominance has become recognised within the NHS, and as such has filtered palliative care provision into national governmental health policy (Milligan and Potts, 2009).

The modern hospice movement originally focused on caring for those with cancer (Hockley, 2005), which it continues to be strongly affiliated with (Traue and Ross, 2005). Dame Saunders herself acknowledged the need for hospice care to be extended to those with non-cancer disease, who were terminally ill (Saunders, 1996), and yet it was some years later before this recognition appeared in governmental policy. The end-of-life strategy in 2008, provided the guidance that chronic terminal illness needed to be integrated into palliative care provision (Department of Health, 2008). However, today there has been little change, and palliative care provision is still mainly utilised by those with a cancer diagnosis (Gadoud *et al.*, 2014; Orlovic *et al.*, 2022). Heart failure patients in comparison to those with cancer rarely experience hospice care, referrals to this service are found to be significantly lower than those with cancer (Liu, O'Riordan, and Pantilat, 2020). The wider literature suggests heart failure patients do not access hospice care due to the acute episodes of deterioration requiring hospital admission (Orlovic *et al.*, 2022), and the unstable disease trajectory inhibiting healthcare professional's ability to identify the appropriate time of referring heart failure patients to palliative services (De Vleminck *et al.*, 2014).

2.6 Nurses role in providing palliative care

Caring for patients who require palliative care is viewed as highly emotional and at times challenging (Dijxhoorn *et al.*, 2023), with the task frequently allocated to nurses due to their acknowledgement of the importance of this care (Ecarnot *et al.*, 2018). To address the emotional aspect of administering palliative care, it is recommended that healthcare professionals need to be able to undertake emotional labour (Kinman and Leggetter, 2016). The traditional opinion of emotional labour is seen as 'women's work' (Gray, 2009a), and as the conventional view of a nurse is portrayed as female, who are naturally empathic due to them taking on a mother role (Gray, 2009b) there is an expectation that nurses will provide the emotional support to patients (Gray, 2009a).

Emotional labour is rarely a recognised part of patient care, and whilst nurses have the abilities to provide sentimental support (Gray, 2009a), as discussed by Hochschild, (1983) physicians tend to suppress their emotions behind a façade of competence (Gray, 2009a). The characteristics of palliative care can be emotional for all individuals involved, patients, care givers and clinicians (Stevens, Brenner and Stevens, 2019). Nurses are seen as having emotional resilience whilst addressing the psychological support of their patients (Delgado *et al.*, 2017), whilst adapting their own emotions to ensure the quality of care they provide is not effected (Sorensen and Iedema, 2009). This reiterates the view that nurses are ideally placed to offer palliative care.

2.7 End-of-life care and heart failure

The progressive nature of heart failure produces difficulties in symptom management. These difficulties have implications for palliative care in general, and are exacerbated with heart failure patients due to the unpredictable disease trajectory and

complex ongoing medical needs (Maciver and Ross, 2018). Whilst evidence-based medical therapies improve prognosis of advancing heart failure and to some degree quality of life, for some patients their final months (or years) of life can be distressing due to poorly controlled symptoms (Daley, Matthews and Williams, 2006). Many of these symptoms (such as fatigue, pain, breathlessness and anxiety) are commonly associated with those of cancer, and due to this, there is a recognition that palliative care practices within oncology would meet many of the needs of those patients suffering with advanced heart failure (Beattie, Higginson and McDonagh, 2020b). Despite these similarities and recognition that heart failure is a terminal disease (Johnson, 2018) the government's policy into to non-cancer terminal conditions have tokenistic references within guidance for palliative care provision (e.g. see Department of Health, 2008; National Institute for Health and Care Excellence, 2019), with no strong source of advice on how this should be implemented.

2.8 End-of-life conversations and palliative care for cancer patients

Palliative services initially focused on providing care for cancer patients (Dixon *et al.*, 2015). The delivery of this end-of-life care has been found to improve quality of life for both patients and their carer givers by offering physical, psychosocial and spiritual support (World Health Organization, 2023).

There is guidance available from both governmental and charitable sources relating to end-of-life care provision (Department of Health, 2008; National Institute for Health and Care Excellence, 2019; Marie Curie, 2020; National palliative and end of life care prartnership, 2021; Hospice UK, 2023). However cancer is the main focus of terminal illness, with non-cancer diseases having often no more than a tokenistic mention (e.g see Department of Health, 2008).

The guidelines do provide some clear and concise advice regarding end-of-life conversations. Healthcare professionals responsible for providing advanced cancer end-of-life care are expected to offer open discussions for their patients to express their care requirements (Department of Health, 2008). Good communication is essential for ongoing assessment of care needs (Marie Curie, 2020), whilst they acknowledge these conversations can be difficult they are an essential aspect of patient care (National Institute for Health and Care Excellence, 2019).

Having conversations with cancer patients comes with associated barriers. McCaughan *et al.*, (2018) conducted qualitative interviews with haematologists and oncologists to gain an insight into their experiences of referring patients to specialist palliative care services. They found that the clinicians were reluctant to instigate end-of-life conversations, as they did not want to appear to be 'giving up' on their patients. This feeling of defeat was also reflected in the research by Horlait *et al.*, (2016). They reported that clinicians believed discussing end-of-life care was viewed as personal failure. The perception of palliative care is seen as negative by both professionals and patients, and is associated with a loss of hope (Gouldthorpe *et al.*, 2023).

Relationships between patients and their clinician contributed to the hesitancy in undertaking end-of-life conversations. For example, if the clinician had not built a close bond with the patient, or they had not developed a working relationship this often resulted in an unwillingness to initiate discussions (Horlait *et al.*, 2016).

Evidence suggests that patients benefit favourably from early initiation of palliative care, with improved quality of life, and health related economic benefits (Gouldthorpe *et al.*,

2023). Guidance and policy both recommend early, ongoing communication with patients to assess their health and support needs (British Heart Foundation, 2022; Wee and Linker, 2023).

2.9 A literature review of end-of-life conversations and palliative care provision for heart failure patients using a systematic approach.

2.9.1 Search framework

A search framework has been used to assist in clarifying the principal concepts of the research question for this review. In keeping with the development of qualitative research questions the framework PICo (Population, Phenomena of Interest and Context), has been used (Lockwood, Munn and Porritt, 2015). The **P** (population) for this research question refers to healthcare professionals, palliative care patients and their care givers, **I** (phenomena of interest) is their experiences of taking part in end-of-life conversations and palliative care provision, and the **Co** (context) is the association with heart failure. It is acknowledged that alternative frameworks exist, for example PICO (Population, Intervention, Comparison, and Outcome), SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type), that are appropriate for quantitative research questions (Rehman, 2021), however it is recommended that the PICo tool be used when the research question is focusing on participant's experiences, and there is no comparative group (Munn, Stern, *et al.*, 2018). The PICo framework is displayed in Appendix A. The research question for this literature review is:

What are the experiences of healthcare professionals, patients and carers partaking in heart failure end-of-life conversations and palliative care provision?

2.9.2 The process of a systematic approach to a literature review

This section of the literature review chapter discusses how the systematic approach to the literature review was undertaken to explore what had already been published, avoid repetitions of research, whist summarising findings to identify new areas of focus that have not been previously addressed (Ferrari, 2015). The researcher has considered the process when undertaking this systematic approach, due to risk of selection bias (Furley and Goldschmied, 2021). Therefore this review followed the guidance recommended by Booth, (2006) to provide a structured approach, in an attempt to reduce the researcher's influence on the research reviewed, selection bias of the presented literature, and provide rigor and replicability to the literature search.

2.9.3 Databases

The use of electronic databases have provided an extensive search of the available literature (Green, Johnson and Adams, 2006). Databases used were CINAHL, Open Dissertations and eBook collection (sourced through EBSCOhost), alongside a MEDLINE search. CINAHL and Open Dissertations provided a resource to search through published and grey literature, for example; nursing dissertations, educational software and conference texts (Green, Johnson and Adams, 2006), which were used in an attempt to reduce publication bias. An eBook collection search allowed the exploration to reach out over the full text of eBooks (EBSCOhost, 2025).

Table 1 overleaf demonstrates the STARLITE mnemonic in relation to the search strategy used within this thesis.

S: Sampling strategy	Comprehensive: attempts to identify all relevant studies on the topic.
T: Type of studies	Full reporting - qualitative and quantitative research methods will be sought. (In searching for participants 'experiences' it is expected a large number of the literature will use qualitative methods, however quantitative methods may have been used in the form of surveys or numerical data. Therefore these studies cannot be excluded).
A: Approaches	Citation, subject, and internet searches will be used.
R: Range of years (start date–end date)	There will be no restrictions placed on the search dates. The date the literature search was carried out was: June 2025.
L: Limits	The limitations placed during the search were human participants, and English language.
I: Inclusion and exclusions	Inclusion – all methodologies, that demonstrated experiences of taking part in end-of-life conversations and receiving or providing palliative care for heart failure. Exclusion – any research that did not identify heart failure patients, care givers or healthcare professionals experiences of taking part in end-of-life conversations and palliative care provision. Animal studies were excluded along with non-English language research. Due to the need to gain an insight into previous experiences translation may lose the context of the dialogue.
T: Terms used	**S1:** experienc* OR view* OR perception* OR attitude* OR feel* **S2:** congestive heart failure OR chf OR heart failure OR chronic heart failure OR cardiac failure **S3:** end of life care OR palliative care OR terminal care OR death OR dying or support* care **S4:** discuss* OR convers* OR decision* **S5:** patients or clients or client or patient or individual or service user or carer* or care giver* or advocate* **S6:** healthcare providers or healthcare professionals or clinicians or nurses or doctors **S7:** S1 AND S2 AND S3 AND S4 AND S5 AND S6
E: Electronic sources	MEDLINE ultimate, CINAHL ultimate, eBook collection (EBSCOhost) and OpenDissertations.

Table 1. STARLITE mnemonic

The results of each search from the terms used is demonstrated in Appendix B, titled 'The literature search results'. The date of which the search was undertaken was June 2025.

2.9.4 Inclusion and exclusion criteria.

An initial review of the literature prior to undertaking the more systematic approach of the literature review provided little guidance relating specifically to end-of-life conversations in the context of heart failure, and palliative care provision. The inclusion criteria for a more extensive systematic approach was expanded to include literature that incorporated heart failure with other 'terminal' illnesses and their experiences of end-of-life conversations and palliative care provision. Additional inclusion criteria included human participants; participants who's age range was limited to 18 year olds and over, due to the trajectory and prognosis complexities of under 18 year olds participants (Cousino *et al.*, 2023), and the literature was limited to those published in the English language. To provide an extensive search of end-of-life and palliative care, there was no restriction placed on the publication dates of previous research, this was to broaden the literature available (Atkinson and Cipriani, 2018). All research methodologies of relevant literature were included to offer an insight into how previous research in this field had been undertaken, and reduce bias of literature being selected that could then influence the findings of the review (Baumeister and Leary, 1997).

The exclusion criteria omitted any literature that did not contain heart failure experiences of end-of-life conversations or palliative care provision, as it is these specific experiences that are relevant to the field of enquiry (Ferrari, 2015).

2.9.5 Search Terms.

To provide a relevant collection of literature, appropriate search terms were identified. A feature of the MEDLINE database is MeSH (Medical Subject Headings), which was used to provide a thesaurus of 'labels' that denote biomedical themes (Baumann, 2016). This

assisted in identifying keywords which were appropriate to the topic being searched. Table 1 outlines the search terms used in the literature search alongside the alternative relevant keywords.

Cancer was not used as a specific search term. Although the palliative care needs in symptom management are similar for both cancer and heart failure (Beattie, Higginson and McDonagh, 2020b), the differences in disease trajectory and progression influence the undertaking of end-of-life conversations. Some cancer patients have a more linear, predictable decline compared to those with heart failure (Murray, 2002) allowing time to anticipate when to undertake end-of-life conversations and provide palliative care. Whereas heart failure and non-cancer illnesses such as chronic obstructive pulmonary disease (COPD) follow a different course of sudden episodes of decline and then considerable improvements in their symptoms, making the task of initiating end-of-life conversations increasingly variable (Murtagh, Preston and Higginson, 2004). Due to these variations in progression, inclusion of cancer literature would not be representative of heart failure participant's experiences. Literature that included heart failure experiences in comparison to those with cancer and non-cancer participants or had a mixed sample were included within this systematic approach review.

The use of Boolean operators were used when searching the literature. The Boolean term 'OR' was initially used to identify relevant search words. It is recognised that this can produce a high level of results so to refine the search, the term 'AND' was used (EBSCOhost, 2025). Another feature used in the electronic search was the use of truncation. This prevented each connotation of the word needing to be listed as it provided terms to be found

with an equivalent word stem (Salvador-Oliván, Marco-Cuenca and Arquero-Avilés, 2019). The search terms used are listed in Table 1.

2.9.6 Search strategy

There are possible limitations when searching electronic databases, resulting in them not always incorporating all avenues of the literature . In order to counter this, an alternative Google scholar search, and the snowballing method have also been used (to gain further literature from the references), to provide an alternative sources of literature . This has expanded the search strategy further, with a combined total of 26 records suitable for inclusion into the literature review. Appendix C demonstrates the Prisma flow diagram.

The literature included in this systematic approach (as listed in Figure 1) were critically appraised to evaluate the reliability and validity of the research (Haile, 2022).
Of the 26 records identified as being relevant to heart failure end-of-life conversations and palliative care; 17 were qualitative studies, 5 were quantitative studies, 3 were literature reviews and 1 a mixed methods study. It is acknowledged that systematic literature reviews are rarely included in a literature reviews (Aveyard, 2019). The researcher included the 3 literature review articles due to their direct relevance to the research topic and the possibility of adding knowledge to the subject matter. Their inclusion provided a comprehensive search that did not compromise the replicability.

To provide a cohesive approach when appraising the data across the different research methods used, it is recommended that a framework be selected that is applicable to the evidence being reviewed (Haile, 2022). The researcher has used a widely employed, succinct tool to critically appraise the different methods of research. The Critical Appraisal Skills

Programme (CASP) is believed to offer a 'stable' platform (Noyes *et al.*, 2019) that covers a variety of methodologies allowing direct comparisons (Aveyard, 2019). Alternative tools do exist, for example the Joanna Briggs Institute method however, the widely accessible CASP tool offered a programme that promoted replicability to the individualised research methods (Aveyard, 2019). Examples of the critically appraised research can be found in Appendix D. All of the literature listed in this review (Figure 1) were critiqued using the CASP tool applicable to their methodological research design, the examples included in Appendix D have had the relevant tool used to appraisal the literature in question and demonstrate a structured approach of how the researcher has undertaken the critical appraisal of each paper. Although there were different research methods appraised within the literature review including quantitative and mixed methods research, the themes drawn from the data analysed were from a qualitative perspective as this was relevant to the focus of this research.

2.9.7 Strengths and limitations of the systematic approach literature review

The systematic approach to this review has been undertaken using the STARLITE mnemonic which offers (Booth, 2006), a systematic and transparent methodology providing a replicable review process (Aveyard, 2019). Attempts to gain an insight into topic being studied have provided a limited number of results which have failed to provide a specific insight into the experiences and preferences specific to heart failure patients when taking part in end-of-life conversations and receiving palliative care. In an effort to provide an understanding of these experiences, the researcher has critically appraised a breadth of the literature which is multinational and includes a variation of research methods. The use of a critical appraisal tool programme (CASP) has provided a platform for the different research methodologies displaying the appraised results in a comparable way using the appropriate checklists (Buccheri and Sharifi, 2017). This has allowed the researcher to appraise the

themes and display them in a qualitative format. The CASP tools do not have an assigned scoring system when assessing the quality of the literature reviewed. However, it is recommended that if the person critiquing the research are unable to answer 'yes' to the initial 2-3 questions then the evidence presented may be of poor quality. The use of such categories as high, moderate and low assessment of quality or risk of bias are felt as acceptable (CASP, 2025a). The literature reviewed in this research were scored as high or moderate in relation to their quality however, their topic matter did not specifically always address end-of-life conversations and the palliative care provision associated with heart failure. This lack of research focus has also demonstrated the lack of evidence available on this specific topic, especially when using a participatory approach. Therefore identifying a gap in current research.

Author	Method	Participants	Setting (location)	Main findings	Themes identified / key points identified
Ziehm et al 2016	Qualitative, semi structured interviews	Heart failure 23 Healthcare professionals	Germany	Discusses the barriers associated with palliative care and heart failure. (education)	• There is a need for palliative care • Cardiologist seen as 'curative'. • Knowledge deficit of what palliative care is. • Poor co-operation between clinicians. • Unpredictable disease trajectory. • Palliative care is cancer related.
young et al 2017	Quantitative, face to face questionnaires	Heart failure 400 patients	US	End-of-life conversations – recollections of chats	• Lack of end of life preference discussions. • Discussions provided preparation for patients.
Strachan 2009	Quantitative, cross sectional survey.	Heart failure 106 patients hospitalised with heart failure	Canada	How care can be improved when hospitalised	• Lack of end of life discussions. • Patients expressed need for ongoing conversations.
Stocker 2017	Qualitative, interviews	Heart failure 13 Patients 10 carers 14 healthcare professionals	UK	Views on whether heart failure should be viewed as terminal	• Healthcare professionals did not see heart failure as 'terminal'. • Healthcare professionals role confusion in giving palliative care. • Timing – early discussions, confusion over disease trajectory. • Patients panicked as term 'heart failure'. • Patients did not understand prognosis, and shocked at 'end of life'.
Siouta 2016	Qualitative, interviews	Heart failure, COPD 22 healthcare professionals	Belgium	Need for palliative care and an increase in recognition	• Conversations to be ongoing. • Palliative care has negativity associated with it.
Singh 2020	Qualitative, thematic analysis	Heart failure 15 healthcare professionals	UK	Educational needs, understandings of palliative care	• Unstable disease trajectory influences conversations. • Patient views on palliative care influence referrals to services.

					• Referral to palliative care occurred too late. • There are educational needs.
Murray et al 2002	Qualitative	Heart failure versus cancer 20 heart failure patients, 20 cancer patients	UK	Less care and info for heart failure patients compared with cancer	• Heart failure patients unaware of the information they needed. • Poor information given resulted in unable to make decisions.
Rogers et al 2017	Quantitative, Random controlled trial	Heart failure 150 patients	US	Compared cardiac care, & cardiac care and palliative care. Patients improved experiences	• Quality of life is improved by having palliative care.
O'Leary et al 2009	Mixed methods	Heart failure versus cancer 50 cancer patients, 50 heart failure patients	Ireland	Compared access to palliative care for cancer and heart failure patients. Mainly discussing symptoms and wellbeing.	• Heart failure patients were unaware of the disease trajectory. • Cancer patients were unaware of their prognosis.
Molzahn et al 2020	Qualitative	Heart failure 12 patients, 8 carers	Canada	Wanted conversations, and information. Mainly discusses living with the condition.	• Early conversations to be prepared and make decisions.
Lewis and Stephenson 2005	Literature review	Heart failure	UK	Barriers associated with palliative care in heart failure.	• Healthcare professionals lack of confidence prevented them starting conversations.
Im et al 2019	Qualitative, interviews	Heart failure 12 patients, 7 carers	Canada	Awareness of heart failure, discusses understanding of HF. Discusses experiences of uncertainty and end-of-life communication in	• Patients understanding of their illness. • Their sample had not had end of life discussions, except one couple. • Unstable disease trajectory prevented conversations. • Healthcare professionals decided if the patient was ready to chat.

				context of understanding illness.	
Hanratty et al 2002	Qualitative, focus groups	Heart failure 34 Healthcare professionals	UK	Obtained doctor's views on p/c provision. Not their role.	• Unstable disease trajectory a barrier to discuss end of life. • Role confusion prevented conversations. • Concern how patients will perceive them negatively.
Glogowska et al 2016	Qualitative, interviews	Heart failure 24 Healthcare professionals	UK	Recognised difficulties in discussions, when to discuss end-of-life and other barriers	• Concerns of negative interpretation of palliative care. • Doctors feel nurses should take the lead in conversations. • Unstable disease trajectory seen as barrier.
Ecarnot et al 2018	Qualitative, interviews	Heart failure 16 Healthcare professionals	France	Discuss communication difficulties and barriers	• Healthcare professionals reluctant to discuss end of life. • Lack of knowledge and confidence seen as a barrier. • Conversations not seen as important.
Dunlay et al 2015	Quantitative, survey	Heart failure 95 Healthcare professionals	US	Discuss barriers associated with end-of-life conversations	• Healthcare professionals reluctant to discuss end of life. • Conversations do need to occur.
Caldwell et al 2007	Qualitative, interviews	Heart failure 20 patients	Canada	Patient's preferences of Healthcare professionals to initiate end-of-life conversations	• Highlighted conversations happen too late in the disease. • Unstable disease trajectory seen as barrier. • Open and honest conversations are preferable. • Patients and Healthcare professional's relationships are important for honest conversations.
Boyd et al 2004	Qualitative, interviews and focus groups	Heart failure	UK	Barriers associated with end-of-life care provision	• Some patients preferred to leave the decisions to the Healthcare professionals. • Dying considered as age related not illness related.

		20 patients, carers and Healthcare professionals			
Remawi et al 2023	Qualitative, interviews	Heart failure 7 patients, 5 carers	UK	Palliative care preferences	• Open conversations referred. • End of life conversations necessary part of care. • Importance of open conversations with Healthcare professionals. • Lack of confidence is a barrier to undertake conversations.
Barclay 2011	Literature review	Heart failure	UK	Barriers associated with end-of-life conversations	• Patients desire more information. • Conversations are to be honest, early and sensitive. • Gentle introduction to the topic. • Timing of conversations – early, concerns expressed of giving info too soon. • Clinical time pressure, reluctance to discuss end of life.
Higginbotham et al 2021	Qualitative, interviews	Heart failure 16 patients, 31 Healthcare professionals	UK	Discusses barriers associated with end-of-life conversations	• Nurses use 'gut feeling' when to discuss end of life. • There is a need to be honest. • Concern of losing hope. • Lack of confidence to initiate conversations.
Hjelmfors et al 2014	Quantitative, Surveys	Heart failure 111 Healthcare professionals	Sweden	Barriers associated with palliative provisions	• 27% not confident to discuss end of life. • Unstable disease trajectory is a barrier to conversations. • Inadequate time used to not discuss end of life.
Momen and Barclay 2011	Literature review	Heart failure	UK	End-of-life conversations and barriers	• Patients value honest communication. • There is uncertainty in what patient's wishes are.
Selman et al 2007	Qualitative, interviews	Heart failure 20 patients, 11 carers, 12.	US	Barriers associated with palliative care provision	• Lack of awareness for patients to decide on future care. • End of life conversations were a source of anxiety for patients.

		Healthcare professionals			• Unpredictable disease trajectory a barrier to discussions. • Cardiologist concentrate on curing patients.
Barrett and Connaire 2016	Qualitative, questionnaires	Heart failure 77 Healthcare professionals	UK	Healthcare professional's experiences and knowledge of end-of-life conversations	• Negativity associated with the term palliative care. • End of life conversations cannot occur whilst having active medical management.
Browne et al 2014	Qualitative	Heart failure Patients, carers & Healthcare professionals	UK	Address disjointed end of life care.	• Lack of information given to patients. • No Healthcare professionals group identified themselves as ones to undertake conversations. • Reluctance to undertake end of life conversations. • Assumption from Healthcare professionals that patients do not want to have conversation.

Figure 1. Literature included in the systematic literature review

2.9.8 Identification of themes

The results of the relevant literature have been read, and thematic analysis has been applied to classify identified themes . Figure 1 also shows each research paper and the themes relevant to their study findings. It is these themes that are pertinent in gaining an understanding into the dynamics that influenced decision making and experiences when participating in end-of-life conversations and palliative care provision for heart failure patients. Due to the different perspectives of both healthcare providers and receivers of this care, it has been decided to separate the analysis of data into these individual fields. This will highlight gaps in knowledge that could improve clinical practice.

The appraisal of literature provided 4 themes, all of which were aimed at providing an insight from healthcare professionals and heart failure patients and care givers, to establish what influences the process of initiating end-of-life conversations. The themes were separated into 2 sections, firstly the experiences of healthcare professionals:

- the experiences of those clinicians responsible for providing care to this group of patients.
- what were the barriers preventing clinicians having these discussions.

The second section was the experiences of heart failure patients and care givers:

- the emotional and physical impact when not given the opportunity of taking part in end-of-life conversations.
- The preferences on these discussions to help patients and care givers be prepared for their death.

2.10 Themes from healthcare professional's perspective:

2.10.1 Delegation or avoidance

It is recognised that due to the terminal nature of heart failure, end-of-life conversations are considered a necessary part of patient care (Singh *et al.*, 2020; Remawi, Gadoud and Preston, 2023), and yet the initiation of such conversations are still lacking in clinical practice (Caldwell, Arthur and Demers, 2007). Whilst society's opinion of death as a taboo subject partly account for this lack of dialogue (Glogowska *et al.*, 2016), so do the attitudes of physicians (who are ideally placed to instigate these conversations). Research by Ecarnot *et al.*, (2018) and Singh *et al.*, (2020) were aimed at exploring healthcare professionals' views of heart failure care in end-of-life situations. Both studies were comparable in research methods, sample (recruiting physicians and nurses), and their findings. The data reported physician's reluctance to acknowledge the importance of this task, labelling conversations as participating in 'public relations' (Ecarnot *et al.*, 2018). Physicians preferred not to discuss death with heart failure patients, as it was described as an undesirable task, and therefore actively avoided. These attitudes were also reflected in the research by Ziehm *et al.*, (2016), whose findings were based on healthcare professional's views of palliative care in heart failure management. They reported that cardiologists felt the necessity for palliative care was insignificant and 'non-existent'. The physician's focus was on providing curative therapies (Singh *et al.*, 2020). However, even though these studies had comparable findings, it has been noted that they did not come without some limitations. Both Ziehm *et al.*,(2016) and Singh *et al.*, (2020) acknowledged their samples were obtained from clinical areas that had an interest in palliative care, and therefore may have influenced the data collected. Whilst Ecarnot *et al.*, (2018) recognised their sample was acquired from one cardiology department, potentially inhibiting other healthcare professionals who also take part in end-of-life conversations.

Some attempts have been made to provide a justification for these opinions with doctors explaining they have a fear of being misinterpreted, and the negative impact this will have on their public persona (Hanratty, 2002). Physicians not only have a desire to protect themselves from undertaking this task, they also feel a need to protect patients from the negative consequences associated with this disease (Murray, 2002; Barclay *et al.*, 2011; Glogowska *et al.*, 2016) and the terminology used (Siouta *et al.*, 2018). This was echoed in the work by Dunlay, *et al.*, (2015). They reported that 52% of clinicians interviewed expressed one or more reason for hesitating in discussing end-of-life care with their patients. Of this sample 11% were reluctant due to the impact on their own emotions, whilst 21% expressed concerns for the effect on the patient's mental health.

It is possible that these concerns relate to the terminology associated with palliative care. The label of palliative care is viewed within healthcare settings as having negative connotations for patients, with palliative regarded as a 'bad word' (Siouta *et al.*, 2018). This association influences the attitudes of clinicians in initiating conversations about death and dying (Barrett and Connaire, 2016; Siouta *et al.*, 2018). The reluctance to initiate end-of-life conversations within the doctor community, does not however dispute the need for discussions to take place (Dunlay, *et al.*, 2015; Ecarnot *et al.*, 2018). And yet doctors are wanting to look at alternative healthcare professionals to take on this role (Hanratty, 2002; Browne *et al.*, 2014). Work by Browne *et al.*, (2014) found there was no agreement in which particular healthcare professional group should be identified in undertaking this responsibility. They concluded that heart failure nurses were well placed to attend to patient's care needs, due to their frequent contacts and ability to reiterate information given to patients and carers. The findings within this study are to be considered with some caution as the sample for this particular research was recruited from a well-established heart failure nurse service, which

may not be representative of other heart failure services. However, the endorsement of nurses taking the lead in providing end-of-life conversations is a recurring theme within the wider literature (Hanratty, 2002; Glogowska *et al.*, 2016). But there is evidence to suggest that nurses are reluctant to take on this role especially if the patient's physician had not already considered it (Ecarnot *et al.*, 2018). This was reiterated in the research by Singh *et al.*, (2020), who found that heart failure nurses did have the capability and skill to offer palliative care to their patients, however would not do so if the physician omitted to instigate it.

This reluctance from both nurses and doctors to initiate end-of-life conversations does inhibit care provision (Barclay *et al.*, 2011). The literature attempts to address this dilemma by highlighting the importance of an effective patient-healthcare professional relationship (Singh *et al.*, 2020). Those clinicians who have an honest, open relationship with their patients, allowed them to feel at ease in discussing sensitive topics (Remawi, Gadoud and Preston, 2023), and a long term relationship allowed constant assessment of patient's goals and desires (Siouta *et al.*, 2018). Establishing a sound patient-healthcare professional connection provided clinicians with an assurance to use their intuition and have comfort in the sensitive conversations (Singh *et al.*, 2020). This awareness was highlighted in the research by Higginbotham, Jones and Johnson, (2021), who compared experiences of specialist palliative care nurses versus those clinicians working in cardiology who care for heart failure patients. The specialist palliative nurses were accustomed to discussing end-of-life care, and as a result were prepared for patients being sad, or upset as this was an expected normal response. This was not the case with cardiology nurses which relates to the theme below.

2.10.2 A lack of confidence and other barriers

To undertake a sensitive conversation with a patient, healthcare professionals must have confidence in their abilities (Singh *et al.*, 2020). In particular cardiology nurses lack of confidence was a common theme within the literature influencing their abilities to undertake this task (Singh *et al.*, 2020; Remawi, Gadoud and Preston, 2023). This barrier is used as justification for a lack of discussions and information given (Lewis and Stephens, 2005; Stocker *et al.*, 2017; Higginbotham, Jones and Johnson, 2021b). The work by Dunlay, *et al.*, (2015) and Hjelmfors *et al.*, (2014) contradict these findings. Hjelmfors *et al.*, (2014) surveyed heart failure nurses and found that only 27% of respondents were not confident in discussing end-of-life. Whereas Dunlay, *et al.*, (2015) questioned both cardiology and primary care nurses, of which only 30% reported low / very low confidence in one or more of providing end-of-life discussions, palliative care and / or referral to hospice care. Both of studies used survey data collections from experienced nurses, which may have impacted on the confidence recorded. Whilst Hjelmfors *et al.*, (2014) collected data from Sweden and Dunlay, *et al.*, (2015) from America these results may not be reflective of practice and confidence levels within the United Kingdom. Dunlay, *et al.*, (2015) acknowledged that clinicians may also have inflated their level of communication based on expectation rather than actual practice therefore placing questions on the reliability of this data presented.

Another barrier that is frequently mentioned within the literature for not initiating end-of-life conversations are the unstable symptoms of heart failure. The unpredictable disease trajectory results in hesitation for healthcare professionals to commence these discussions (Selman *et al.*, 2007; Hjelmfors *et al.*, 2014; Higginbotham, Jones and Johnson, 2021b). This includes uncertainty of predicting the condition's progression into the terminal phase of the illness (Glogowska *et al.*, 2016). The timing of this change in illness provides healthcare

professionals with concern, as early discussions are perceived as being impactful on the patient's ability to maintain hope (Barclay *et al.*, 2011). However the initiation of conversations too late in the disease trajectory results in opportunities of care provision being missed (Glogowska *et al.*, 2016). However, Momen and Barclay, (2011) concluded that no one can predict the ideal time for these conversations, a finding which was reiterated by Ziehm *et al.*, (2016).

An alternative observation that was associated with timing was the conversations were viewed as time consuming (Barclay *et al.*, 2011,; Hjelmfors *et al.*, 2014; Remawi, Gadoud and Preston, 2023). This resulted in healthcare professionals expressing a reluctance to engage in the discussions as their general workload takes priority over these lengthy tasks (Browne *et al.*, 2014). Physicians accept that a conversation with a deteriorating patient, will result in an increasing claim on their time, and as such the patient would need a lot of psychological support. However, nurses see themselves as being able to provide more time to commit to these discussions (Glogowska *et al.*, 2016).

The barriers discussed are preventing healthcare professionals from instigating end-of-life conversations. This evidence provides an insight into why there is a reluctance to engage in these sensitive discussion (Ecarnot *et al.*, 2018). Clinicians have described a need for someone to initiate these conversations and provide palliative care to heart failure patients (Ziehm *et al.*, 2016a; Singh *et al.*, 2020), with a lack of confidence and willingness to provide opportunities for conversations, there is little evidence this is being done (Hjelmfors *et al.*, 2014).

Within the literature healthcare professionals have expressed opinions regarding patient's care and discussion preferences, which appear contradictory to the perceived barrier of professionals lacking in confidence due to uncertainty and poor knowledge (Barclay *et al.*, 2011). The research by Browne *et al.*, (2014) found that clinicians controlled the information given to patients, citing patients *may* not want to be informed about their prognosis. This view was reflected in the work undertaken by Glogowska *et al.*, (2016) who found that healthcare professionals considered the risks of information giving versus the adverse effects of having these sensitive conversation prior to a patient actively dying.

With no agreement regarding who should provide end-of-life conversations (Ziehm *et al.*, 2016), little confidence to initiate them (Singh *et al.*, 2020), and ill-informed patients unaware of the decisions to be considered (Murray, 2002), it is predictable that end-of-life conversations rarely happen. In an attempt to improve this provision of care and provide evidence to improve clinician's knowledge, a review of the literature from a patient and carer's experience has been undertaken.

2.11 Themes from heart failure patients and care giver's perspectives:

2.11.1 A lack of knowledge

There is a limited evidence relating specifically to heart failure patients and carers experiences of participating in end-of-life discussions. The literature available on this topic is incorporated within research discussing alternative aspects of palliative care. For example, Murray, (2002) researched a comparison study between heart failure and cancer patients that focused on whether the medical services accommodated their care needs. They explored the type of information given to the two groups, however there is limited evidence on the communication preferences specific to end-of-life conversations. Work by Im *et al.*, (2019)

aimed to research heart failure patients and carer's understanding of their condition, and their perceptions of end-of-life conversations. The evidence they presented provided little insight and guidance on undertaking end-of-life conversations. The reason for this was a majority of their sample (with the exception of one couple), had not been involved in these discussions and could therefore could not provide data on their experiences.

The limited information pertinent to end-of-life conversations for heart failure patients and carer givers, does provide some insight into their preferences. The initial theme is they have expressed a need for more information (Murray, 2002). Research by Strachan *et al.*, (2009), who analysed patient's perspectives on the quality of end-of-life care in heart failure, concluded that only 11.3% reported having had a conversation regarding their life expectancy. These findings were reflected in the study undertaken by Stocker *et al.*, (2017), who provided quantitative survey data on the discussions relating to end-of-life care. They found 330 participants (from a total sample of 400), had not previously discussed end-of-life preferences. As a result of these lack of conversations there is a poor understanding that heart failure is a terminal disease (Browne *et al.*, 2014; Stocker *et al.*, 2017). A comparison study by Murray, (2002) explored the experiences of both lung cancer and heart failure patients, in whether services met their end-of-life needs. Patients with cancer reported they had received suitable written information that was understandable, and appropriate, heart failure patients seldom recalled receiving any information, and as a result had a poor understanding of their illness. Attempts were made by Im *et al.*, (2019) to get a deeper understanding of this lack of knowledge. They reported that even though patients understood how to manage their heart failure symptoms, they did not comprehend the severity of the condition despite experiencing advanced heart failure symptoms. Highlighting the fluctuations in patient's symptoms were seen as a potential opportunity for healthcare professionals to initiate end-of-life discussions.

Both patients and carers felt that clinicians would wait until they experienced further deterioration of symptoms before instigating end-of-life conversations. This hypothesis was also addressed by Caldwell, Arthur and Demers, (2007), who found patient's wishes were to have discussions prior to them becoming too symptomatic. The justification for this was to enable patients to have control of their decisions and end-of-life care planning.

2.11.2 Preparation and conversation preferences

Patients have expressed a wish for end-of-life conversations to take place (Barclay *et al.*, 2011) to enable them to be better prepared in decisions relating to care preferences (Molzahn, *et al.*, 2020). In doing so it was felt they were provided with a better understanding of the condition (Young *et al.*, 2017)**,** and the knowledge of possible disease trajectories which may influence their decision making (Caldwell, Arthur and Demers, 2007). To provide this information patients have certain desires to meet their needs, and recommendations regarding how discussions should be conducted.

Honest and open conversations were strongly favoured by patients (Murray, 2002; Caldwell, Arthur and Demers, 2007; Strachan *et al.*, 2009; Momen and Barclay, 2011; Molzahn, *et al.*, 2020; Remawi, Gadoud and Preston, 2023). However, to prevent distress and not lose hope patients did prefer a gentle approach, with a compassionate patient – healthcare professional relationship (Molzahn, *et al.*, 2020). Work by Caldwell, Arthur and Demers, (2007), highlighted the importance of this relationship. They reported that in discussing the deterioration of illness without providing hope concurrently, would have a damaging effect on the patient – healthcare professional relationship which could diminish the impact of the valued skills that patients rely on (Murray, 2002).

The limited evidence that recommended patients need a competent healthcare professional offers a small insight into their preferences when undertaking end-of-life conversations. There is a clear need for increasing information to be shared with patients and in doing so will provide them with the ability to make informed decisions regarding their own care.

2.11.3 Critique of the literature

The literature studied within this systematic approach review has not primarily researched the experiences of those taking part in heart failure end-of-life conversations and palliative care provision, due to the limited literature sourced on this topic. Therefore the literature examined was not inclusive to just heart failure, and included comparable experiences of heart failure versus other 'terminal' illnesses. The literature review included 26 papers, figure 2 demonstrates a breakdown of the literature reviewed.

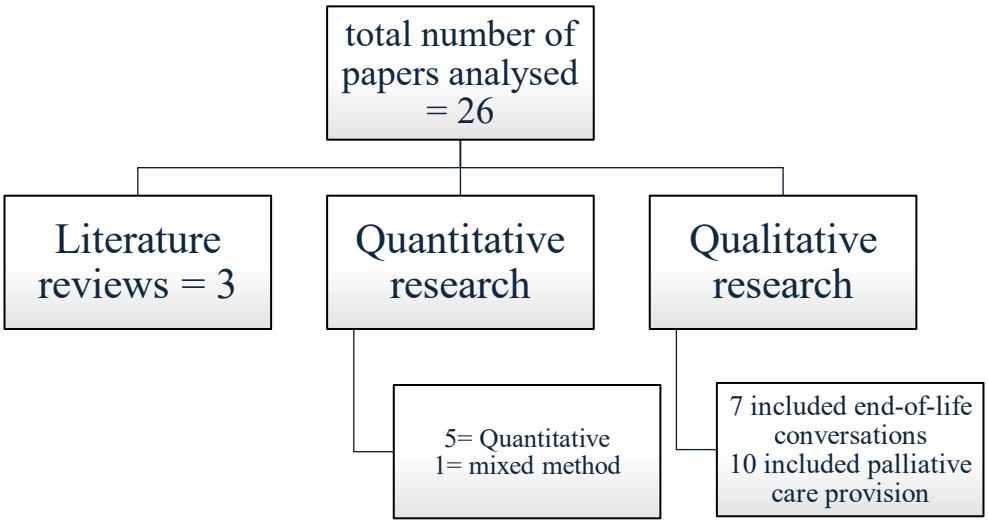

Figure 2. Literature reviewed

Of the 26 papers appraised within this review, 3 were literature reviews (Lewis and Stephens, 2005; Barclay *et al.*, 2011; Momen and Barclay, 2011). The evidence gathered by Barclay *et al.*, (2011) and Momen and Barclay, (2011) examined end-of-life conversations for heart failure patients. A majority of their appraised literature was included as primary source papers within this systematic approach review, therefore not adding any new insight into the topic of interest. The authors included evidence from end-of-life discussions from the perspective of terminal illness rather than those specific to heart failure patients, and some of the heart failure literature that was included was not specifically related to end-of-life conversations and palliative care provision. The researcher felt this generalised end-of-life conversation experiences, which may not be representative and transferrable to heart failure patients and care givers. The final literature review included was that undertaken by Lewis and Stephens, (2005), which gathered data on the barriers of palliative care provision. Their findings were related to service provision and they concluded that there is a lack of guidance and funding which provided an insight into the potential improvement needs of end-of-life care for heart failure patients.

The quantitative evidence included in this literature review was provided by 6 papers; 5 quantitative studies (Strachan *et al.*, 2009; Hjelmfors *et al.*, 2014; Dunlay, *et al.*, 2015; Rogers *et al.*, 2017; Young *et al.*, 2017), and 1 mixed methods (O'Leary *et al.*, 2009). The data provided by Dunlay, *et al.*, (2015) was obtained from healthcare professionals providing an insight into the barriers preventing end-of-life conversations, whilst this research offered descriptions relating to timing of conversations, clinician's approach to the discussions and who was responsible for providing this care there were some limitations of the study to note. The findings concluded that even though healthcare professionals have a varied opinion in initiating end-of-life conversations, a common theme was some clinicians lacked confidence

and expressed a need for further professional development. The limitations for this research were raised by the authors included healthcare professionals who were asked to complete the surveys may have overestimated their conversational practices resulting in bias within the data collected. The sample of the study was also acknowledged as limited due to the single geographical area used for recruitment. It was felt that this impacted on the generalisability of the findings often associated as a strength in quantitative research (Slevitch, 2011). The findings from Dunlay, *et al.*, (2015) despite their noted limitations, were similar to those of Hjelmfors *et al.*, (2014). Both discussed the confidence of healthcare professionals to initiate end-of-life conversations. Dunlay, *et al.*, (2015) had a mixed sample of nurses and doctors who described a lack of confidence in undertaking these discussions, whilst Hjelmfors *et al.*, (2014) had the only study within the review of the literature to have a sample of heart failure nurses. They found that the nurses were confident to initiate the conversations however did not believe they had the competence as this was the role of physicians. This provided an insight into the needs of healthcare professionals who may be responsible for end-of-life conversations. The final quantitative study that obtained data on end-of-life conversations was by Young *et al.*, (2017). The research observed discussions from the perspective of heart failure patients, using face to face questionnaires to obtain data on conversations from patients with acute decompensating heart failure. Their findings concluded that most patients did not recall having a conversation with their physician to articulate their end-of-life preferences. It must be noted however, that patients were acutely unwell and invited to take part in a face to face questionnaire, it is unclear from the study what time period after their hospital admission the patients were interviewed. As expected the limitations of this trial reported potential recall bias due to the patient being ill. The last 2 quantitative studies gathered data on care experiences. The work by Strachan *et al.*, (2009) gathered data from patients on preferences for end-of-life care in the form of satisfaction surveys. This study

provided an insight into the preferences of patients with advanced heart failure. It concluded that to improve this aspect of care there was a desire for adequate care planning post hospital admission, and the need for honest discussions. This added to the recommendations of alternative literature that patients do want to have end-of-life conversations. The weakness to be acknowledged regarding this study was that it was unclear in the reporting who conducted the face to face interviews, limitations were noted to be a potential bias as participants may have been influenced by interactions with the interviewer.

The only randomised control study within this systematic approach review was undertaken by Rogers *et al.*, (2017). The aim of this research was to provide evidence assessing the impact of a palliative care intervention on the quality of life of heart failure patients. This highlighted the importance of palliative care provision and how it benefited patients. The findings recommended a multidisciplinary approach to this care provision, to improve patient's quality of life. Finally, the mixed methods study undertaken by O'Leary *et al.*, (2009) gained an insight into the comparisons of palliative care provision for heart failure and cancer patients. Their findings reiterated those of Rogers *et al.*, (2017) in deducing the importance of palliative care for both cohorts of patients, and each gained positive experiences from receiving this care.

The quantitative research included in this literature review, has provided an understanding of the potential experiences of heart failure patients. They have not been without their limitations, and as a result cannot be viewed as reliable sources for generalisability. The alternative research methods of qualitative studies have also been used to gain an insight into the experiences of end-of-life conversations and palliative care provision.

The qualitative studies included can be divided into 2 categories, those that have gained experiences on end-of-life conversations and those who have sought to obtain an insight into the care needs of end-of-life heart failure patients. The first critique of qualitative research is a study by Molzahn, *et al.*, (2020), they gathered data on the uncertainty associated with dying from heart failure. The evidence concluded patients requested honest conversations to understand their disease however there was a need for information to be given to them in a gentle manner. The methods used in this research involved patient and care giver dyads, and the authors acknowledged there were some limitations due to the challenges of understanding this approach. Further research associated with the topic of communication was by Stocker *et al.*, (2017). Healthcare professionals were interviewed using a grounded theory approach and then observed interacting with patients and care givers, who were then also interviewed. The study aim was to establish participant's views on heart failure being seen as a terminal illness and observed the communication between clinicians and their patients. The findings indicating that heart failure was not seen as a life limiting illness and highlighted the complexities of communicating with these patients. The study provided an insight into how care should be adapted to the individual and the importance of discussions around personalised care. They concluded the Advance Care Pathway (ACP) was highly significant to enable this to happen.

The work by Caldwell, Arthur and Demers, (2007) and Im *et al.*, (2019) continued the theme of communication by documenting the preferences and understanding of information given to heart failure patients. The findings reported by Im *et al.*, (2019) demonstrated patients had an understanding of their medical treatments however, there was less knowledge regarding disease progression. It was concluded that to provide individualised care patients needed to be informed about the deterioration of their illness. The communication preferences gathered

by Caldwell, Arthur and Demers, (2007) found that patients did want to know about their illness, and for their progression to be addressed early on in the disease trajectory. These studies have provided an insight into the communication needs of heart failure patients.

Obtaining experiences from healthcare professionals in undertaking end-of-life discussions Barrett and Connaire, (2016), Glogowska *et al.*, (2016) and Ecarnot *et al.*, (2018) have all interviewed clinicians in an attempt to obtain data on potential barriers, and enablers in having these conversations. The research that provided evidence from a mixed sample of clinicians (Glogowska *et al.*, 2016; Ecarnot *et al.*, 2018) described within their findings that conversations were hard to participate in, the challenges associated with emotional impact on patients, and the lack of affiliation this aspect of care has with clinical guidance. The limitation acknowledged by Glogowska *et al.*, (2016) in their study provided a unique barrier. They felt due to the research interviewers not being experts in palliative care provision, may have inhibited the quality of data collected. The work undertaken by Barrett and Connaire, (2016) provided an alternative stance by having a sample of cardiac nurses. This obtained data from the perspective of clinicians who were used to offering this aspect of care, they found that the nurses who were confident in having end-of-life discussions had a positive attitude towards palliative care provision.

The final group of literature to be critiqued in this review of the literature have researched the experiences of participants who either provide or receive palliative care due to heart failure. Of these, 4 studies recruited solely healthcare professionals and described themes associated with this aspect of care. The work by Hanratty *et al.*, (2006) continued to describe the importance attached to palliative care, participants within this study were specialist physicians who felt the role of palliative care provider was more in line with nursing. Even

though they had some understanding of the principles of palliative care the doctors believed it was not in their remit, providing evidence that there are professional barriers associated with this care provision. The attitude towards this aspect of care was continued in the research by Ziehm *et al.*, (2016), who sought the opinions of healthcare providers regarding palliative care. A lack of information, and understanding by clinicians were identified as barriers preventing palliative care provision, findings that were reiterated by in Siouta *et al.*, (2018) in their work with a mixed study of chronic obstructive pulmonary disease (COPD) and heart failure clinicians. Comparisons were not made between the diseases as it was felt the patient's palliative needs would be similar. In providing comparable data it would have offered an greater insight to the end-of-life requirements for heart failure patients in relation to other non-cancer illnesses. The work by Singh *et al.*, (2020) also looked at the experiences of palliative care, however from the perspective of accessing services. This research presented data that analysed the service provision and provider barriers such as lack of education, whilst it considered the wider picture of care provision for example funds, and service availability, the study did have its limitations. The authors felt the participants may present a sample bias as they self-identified themselves and had particular interest in palliative care. This was believed to reduce the generalisability of the findings.

The qualitative evidence from healthcare professional participants has provided an understanding of the barriers associated with caring for heart failure patients. Personal attitude, lack of information and service provision are all felt to be influential in offering this care.

The experiences of receiving palliative care has been studied by Selman *et al.*, (2007), Boyd *et al.*, (2009) Browne *et al.*, (2014) and Remawi, Gadoud and Preston, (2023). The initial

aims of the research varying from establishing participant's experiences of receiving this care (Remawi, Gadoud and Preston, 2023), providing evidence to make recommendations for care provision (Selman *et al.*, 2007; Boyd *et al.*, 2009), and analysing how care needs to be improved from current experiences (Browne *et al.*, 2014). The recommendations for all 4 studies were that heart failure palliative care was suboptimal and improvements for co-ordinated care was needed to enhance it. These findings were collaborated by the work of Higginbotham, Jones and Johnson, (2021) and Murray, (2002) who concluded that palliative care is currently given on the basis of diagnosis rather than need.

2.11.4 Summary of literature

The research within this literature review has offered an insight into end-of-life conversations and palliative care provision. The limited literature available that focused on heart failure end-of-life discussions from a patient and care giver perspective did provide some evidence on patient and care giver tendencies. A majority of this type of data collection was centred around recall of conversation incidence (Young *et al.*, 2017; Im *et al.*, 2019; Molzahn, *et al.*, 2020; Higginbotham, Jones and Johnson, 2021), rather than conversation preferences (Caldwell, Arthur and Demers, 2007). This type of literature provided confirmation that discussions do need to take place, and yet they rarely happen (Remawi, Gadoud and Preston, 2023). Information regarding end-of-life conversations was mainly gathered as part of a wider aims of the research conducted, which was to understand the barriers associated with palliative care provision (Boyd *et al.*, 2004; Selman *et al.*, 2007; O'Leary *et al.*, 2009; Strachan *et al.*, 2009; Hjelmfors *et al.*, 2014). This demonstrates the lack of literature specifically associated with patient and care giver's experiences of taking part in end-of-life discussions.

A majority of the literature reviewed was from the perspective of healthcare professionals who were felt to be responsible in offering palliative care to heart failure patients (Hanratty, 2002; Hjelmfors *et al.*, 2014; Dunlay, *et al.*, 2015; Barrett and Connaire, 2016; Glogowska *et al.*, 2016; Ziehm *et al.*, 2016; Ecarnot *et al.*, 2018; Singh *et al.*, 2020), or from a mixed sample of patients, caregivers and clinicians (Boyd *et al.*, 2004; Selman *et al.*, 2007; Browne *et al.*, 2014; Stocker *et al.*, 2017; Higginbotham, Jones and Johnson, 2021b). The samples of healthcare professionals involved in these studies were varied by including both physicians and clinicians, mainly from acute clinical areas of practice. There was only one study that obtained experiences from heart failure nurses (Hjelmfors *et al.*, 2014), who have been identified as ideally placed to offer palliative care to heart failure patients (O'Hanlon and Harding, 2011). The focus of these studies was to gain an insight into the experiences of end-of-life conversations and palliative care provision from the receiver and provider perspectives. There was a lack of research gathered directly from heart failure patients and care givers, which could have then been presented to healthcare professionals with the aim of establishing how these preferences may be implemented into clinical practice to improve direct patient care.

The literature review has also demonstrated a lack of research engaged in the use of a participatory approach. Palliative research is known to be associated with several challenges, for example the sensitivity of the topic, accessing participants receiving palliative care, and the ethical issues of addressing end-of-life experiences (Addington-Hall, 2002). The use of participatory research is felt to address some of the considerations when undertaking this type of research (Riffin *et al.*, 2016) however there was a lack of evidence utilising these methods.

This appraisal of the literature relating to end-of-life conversations and palliative care has identified the limited data specific to heart failure patient's experiences. Recommendations on caring for this group of patients are made based on the wider literature of palliative care for all terminal illnesses. The lack of research on this topic does omit to offer an insight as to why end-of-life conversations are rare within clinical practice, and why healthcare professionals fail to acknowledge the deterioration of patients with this illness resulting in them having unmet palliative care needs.

Chapter 3. Methods

3.1 Introduction

This chapter will describe the process of how the research was conducted. It will start by discussing the aims of the study, then outline the theoretical and methodological underpinnings. The chapter then provides a detailed description of the study design including data collection and analysis, followed by an exploration of the ethical considerations and quality assurance. The chapter ends with a piece on the potential tensions between clinical and research perspectives given that this research was in an area in which the researcher had clinical experience.

3.2 Study aims and objectives

The purpose of the research stemmed from the researcher's experiences of working as a community heart failure nurse specialist. The researcher witnessed a reluctance from fellow clinicians to acknowledge heart failure patient's deteriorating symptoms and an unwillingness to have end-of-life conversations with them.

The aim of the study was to gain an insight into heart failure patients and their care givers experiences relating to these discussions, and their palliative care provision. The findings were then presented to community heart failure nurses to establish how the identified preferences could be implemented into clinical practice.

The study objectives were to improve end-of-life conversations, and palliative care provision for heart failure patients and their care givers. Therefore providing guidance that can be implemented into clinical practice to enhance patient's experiences.

3.3 Theoretical underpinnings

The researcher can influence research throughout each stage of the process, starting with the initial decisions regarding topic choice, and the focus of interest taken (Colbourne and Sque, 2004). This awareness was something considered by the researcher due to their nursing background and heart failure clinical experience. Nursing education is based primarily on science, whilst the researcher's nursing experience adds experimental knowledge. The translation of evidence into practice provides safe and optimal care (Curtis *et al.*, 2017). However, to gain insight into the research question of what were heart failure patients and care giver's experiences and preferences of end-of-life conversations and palliative care provision required an alternative source of information. To gain an insight needed to answer the research question the researcher will need to draw on the experimental knowledge of patients and care givers.

The commitment towards a participatory research approach was used as the doctorate was linked to an inclusive involvement stream, and was viewed by the researcher as an approach to reduce the researcher's bias. The patient involvement leans towards a relativist ontological stance that the world is built upon individual's opinions and experiences (Ryan, 2018). Different individuals will have diverse experiences and perspectives and therefore, construct different realities.

The epistemological views of how knowledge can be generated, broadened and shared (Bradshaw, 2000), influence the foundations of which research is created (Grix, 2019). The researcher's nursing experiences of information gathered by social interaction and knowledge is based on an experimental paradigm generally leans towards a social constructionist position (Creswell, 2013). This thesis draws upon this theory, grounded in the belief that

knowledge is ‘constructed’ by people, due to interactions between them and their social environment (Ritchie *et al.*, 2014).

Social constructionism focuses on how meanings are made from experiences, and through social interaction (Kham, 2013), assuming that participants being studied are able to express the meaning of a situation through the process of discussion and interactions (Crotty, 1998). The proposition of this approach is that social interaction happens within a social cultural context (Ritchie *et al.*, 2014). In keeping with this premise, a community based participatory research approach has been used in the development of the research design. A socially constructed epistemological position is grounded in participatory research due to many views and ways of understanding provided by the participants in the coproduction of the research (Warwick-Booth, Bagnall and Coan, 2021). An additional reason for using community based participatory research was to enable the researcher to prioritise the voice of the heart failure patient and care giver. Due to limited research on this topic, this approach allowed theories to emerge rather than using previously applied concepts (Ritchie, J. *et al.*, 2014). The aim of this research was to provide evidence that would inform clinical practice therefore, the focus was placed on the research methods and implementation of findings rather than its theoretical orientation.

3.4 Methodological underpinnings

3.4.1 Inclusive involvement

An Inclusive involvement approach was used as it is important to place the experiences of patients and care givers at the centre of an implementation plan to improve end-of-life conversations. This approach is defined as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. This calls for an active

partnership between the researcher with patients, care givers and members of the public which can help to develop patient focused questions, assist with recruitment to the study, and aid dissemination of the research findings to a broader community (The National Institute of Health Research, 2021). This research worked collaboratively with patient educators from a national heart failure charity who had experienced end-of-life conversations and palliative care provision.

To date there is little evidence on inclusive involvement research in palliative care (Johnson *et al.*, 2021). The work by Chambers *et al.*, (2019) concluded that due to the sensitivity and frailty of patients receiving palliative care, there is an opinion by researchers that patients and their carer givers do not want to be involved. However, these findings are contradictory to those opinions of patients and care givers receiving end-of-life and palliative care (Bloomer *et al.*, 2018). This research has used an inclusive involvement method in collaboratively working with a national heart failure charity throughout the research process.

3.4.2 Community based participatory research

Defining participatory research within current literature has resulted in considerable discussion, due to the variability of participation within research of service users and community members (Warwick-Booth, Bagnall and Coan, 2021). There are a number of participatory research methods that are thought to produce evidence that is relevant and meaningful to patient's health care experiences (Andress *et al.*, 2020). Co-production in research is believed to provide an environment where researchers and the public work together with equal power and responsibility (Warwick-Booth, Bagnall and Coan, 2021). As previously mentioned the researcher's position leans towards that of social constructionism, a

view that meaning is constructed through human interaction. Co-production research provides this communication therefore, CBPR complements this theory (Schubotz, 2020). Considering the sensitive topic of this research a co-produced approach such as participatory action research (PAR) is not thought to be appropriate due to the complexities of the patients nearing the end of their lives. PAR designs involve action through repeated reflection, planning and evaluation of processes. These methods are integrated through the collection and analysis of data (Warwick-Booth, Bagnall and Coan, 2021). Due to the vulnerability of the participants in this study and the sensitivity of the topic the researcher felt this approach was not appropriate.

The use of a community based participatory approach provides a coherent research process, that is relevant to the community members involved in its development. Community based participatory research (CBPR), is defined as an 'action-focused' approach that is used to address variations in health care delivery and will allow an increased understanding of complex health inequalities (Schubotz, 2020). This was achieved by community members from a national heart failure charity and the researcher working collaboratively to generate new insights into locally relevant issues, with the purpose to change current practice (Warwick-Booth, Bagnall and Coan, 2021). As CBPR provides a process of involving those experiencing variations in healthcare (Foster *et al.*, 2012), it is a recognised research approach that will address disparities in palliative care (Rosa, Elk and Tucker, 2022), and will produce research findings that can be translated into clinical practice (Springer and Skolarus, 2019). As with all participatory methods challenges are associated with using CBPR. Engagement with community groups involves potential differing opinions, to overcome these Freeman *et al.*, (2006) recommend open and honest two-way conversations in articulating viewpoints as it is unrealistic to expect perfect agreement.

To address these challenges the researcher began by identifying a 'community of concern'. The community who are within this group are described as individuals from a particular geographical region or with a communal identity (Riffin *et al.*, 2016). The community of concern relevant to this research are patients, care givers, and community heart failure nurses who have taken part in end-of-life conversations due to heart failure.

The work undertaken by Park, (2020) acknowledged there are challenges associated with participatory methods when engaging with vulnerable groups, and as a result there are gaps in palliative care research. Heart failure patients are described as vulnerable due to instability of symptoms and their high risk of poor health outcomes (Satici *et al.*, 2022). Addressing these potential barriers during the CBPR development process will enable service users with chronic illness to have a voice in this specific research (Riffin *et al.*, 2016). The researcher should therefore identify and engage with the community group allowing them and patients to work together in creating research aims and objectives (Warwick-Booth, Bagnall and Coan, 2021).

In this study, the researcher obtained consent from a national heart failure charity to work with them collaboratively on this research project. A group of six patient educators (from the charity) agreed to meet with the researcher via an online conferencing platform. The initial meeting allowed discussions about the research topic, whether it was appropriate to address this area of care and whether the educators felt this was an important topic to research. Conversations were had regarding the use of qualitative research methods and whether the research question was appropriate to gain an insight into experiences of end-of-life conversations for heart failure patients. During the period between the first and second

meeting the researcher documented a draft research schedule. The schedule was devised from the conversations had between researcher and patient educators during their first meeting. The topics of conversations around the specific area of end-of-life discussions were noted by the researcher during that meeting and as such developed a basis for the interview schedule. Once drafted this was sent via email to the patient educators for their review. The second meeting allowed discussions to take place regarding the wording of the interview questions. These conversations concentrated on the specific wording used to ensure it was in layman's terms and was understandable to the general public. The time prior to the third meeting allowed the researcher to make the recommended alterations to the interview schedule and re-send this to the patient educators for their review. The final meeting prior to data collection provided opportunities to make any final changes to the interview schedule and allow both parties to agree the draft questions were now suitable as the final version. During this process the group of patient educators remained unchanged. Over all the three separate meetings permitted discussions regarding the appropriateness of the topic, potential research methods to be used, and the wording of documents and the interview schedule to ensure they were written in a sensitive, layperson language (Butler, Copnell and Hall, 2019). This process enabled the sensitive topic of interest to be researched from a patient perspective. It was agreed collaboratively that the predetermined qualitative methods would be appropriate to answer the devised proposed research question.

3.4.3 Qualitative research methods

In keeping with the forementioned theoretical underpinnings of this research, qualitative methods have been used to answer the research question of patients and care giver's experiences of taking part in end-of-life conversations and receiving palliative care.

Historically the use of quantitative research has been seen as providing empirical healthcare evidence (Fox, Martin and Green, 2007). Due to its statistical methods data is viewed as being more scientific and superior (Pyo *et al.*, 2023). In measuring causal relationships within events that are value free, these methods were viewed as generalisable to the population (Slevitch, 2011). However, qualitative research is now considered to provide reliable, replicable evidence as it allows in-depth understanding of participants opinions and motivations (NHS England, 2017), allowing examination of the topic from the perspective and narratives of the participants to provide a 'lived experience' perspective (Creswell, 2013; Ritchie *et al.*, 2014). This is particularly relevant to research studies where the topic is of a sensitive nature, and has a tendency to generate emotive reactions (Ritchie *et al.*, 2014). These considerations are pertinent to the exploration of complex topics such as end-of-life care (Koenig, Back and Crawley, 2003; Van Der Steen, Bloomer and Martins Pereira, 2022). There are alternative methodologies that can be considered when obtaining participant's 'lived experience' within research. For example an Interpretative Phenomenological Approach (IPA) would provide findings based on how the participant makes sense of their own experiences, this would focus on the individual's personal events and not those that can be applied to the wider population (Ritchie, J. *et al.*, 2014). Alternatively Grounded theory is a method where the researcher confronts the data without any preconceived ideas of the research topic (Smith and Firth, 2011). Both of these approaches were unsuitable for this research aim. The researcher in this study had their own preconceived ideas of the research topic due to previous clinical experiences. As the research aim was to implement findings into clinical practice IPA would not provide data that would go beyond an individual's experiences and offer a more generalised pattern for the wider audience. The researcher felt in using a CBPR approach this would address the study aims (Holkup *et al.*, 2009).

3.5 Study design

The proposed study design is demonstrated in figure 3. This depicts the initial plan of the research process, prior to undertaking the study.

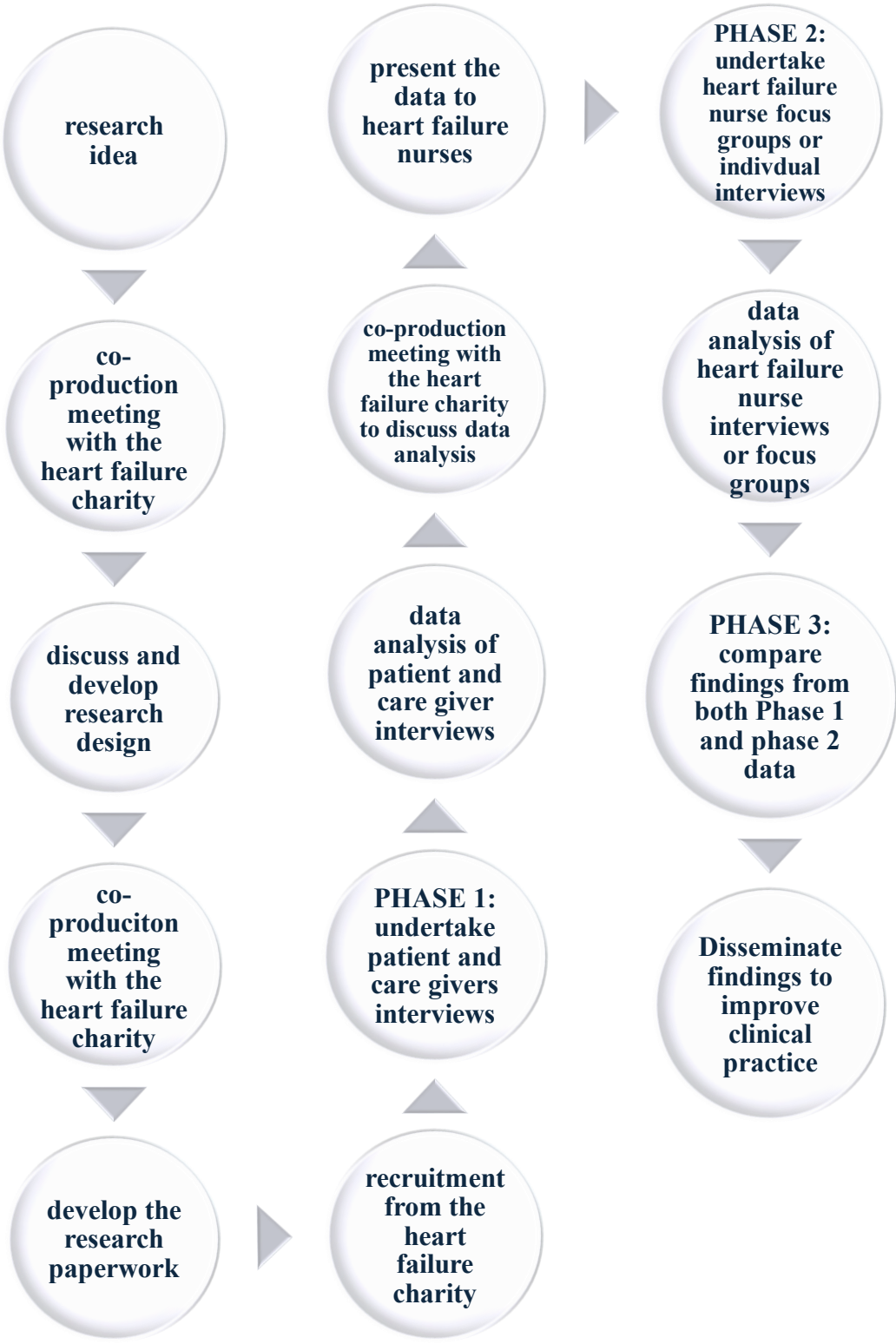

Figure 3 – Proposed research co-production process

The proposed process of the research plan was as follows:

- the initial research idea steamed from the researcher's clinical experience. They witnessed disparities in end-of-life care for heart failure patients however, where unable to rationalise why these occurred.
- The national heart failure charity was to be approached by the researcher to seek their insight and support in undertaking this research. The initial online meeting with the patient educators (who are heart failure patients themselves, and have taken on a role within the charity to support and educate fellow patients in living with heart failure), was to discuss the topic of interest, and to collaboratively agree the methods used.
- the second meeting with the heart failure patient educators was to discuss the words used to describe this sensitive topic and devise the interview questions and schedule.
- potential participants were to be engaged with via the heart failure charity, once the initial contact had been made the researcher would gain the consent to participate.
- The interviews were to be undertaken by the researcher due to their previous experiences of discussing this sensitive topic with heart failure patients.
- Data analysis was to be done by the researcher due to the sensitive topic being discussed, and to maintain participant confidentiality.
- The next contact with the heart failure charity was to present the findings from patient and care givers. The reason for this was to ensure the themes and experiences were presented from a patient perspective and to reduce the potential bias of the researcher.
- The research findings were then to be presented to the community heart failure nurses in the form of vignettes in an attempt keep the findings true to the patient and care giver's experiences.

- Individual interviews or focus groups of community heart failure nurses were to be used to gain experiences of taking part in end-of-life conversations and providing palliative care to this group of patients.
- The findings from the heart failure nurses' data were to be analysed and recommendations made on how the findings could be implemented.
- Once the final analysis was done the findings are to be disseminated to the wider audience.

3.6 Population sample

3.6.1 Inclusion and exclusion of patients and care givers – phase one

The eligibility criteria for this research was that patients had a diagnosis of heart failure (either heart failure with a reduced pumping action of the heart muscle, or with a normal pumping action but impaired ability of the muscle to stretch and fill with blood). Both types of heart failure are associated with high mortality (Oktay, Rich and Shah, 2013), and the advancing symptoms are comparable to those of cancer (Beattie, Higginson and McDonagh, 2020c), resulting in patients ultimately requiring end-of-life conversations and palliative care. Both patients and care givers that have experienced of end-of-life conversations and palliative care provision associated specifically to heart failure were included.

All participants were required to be over the age of eighteen years old, due to the complex clinical needs of those with heart failure under this age, and English speaking to ensure they had a clear understanding of previous conversations and experiences. Due to the sensitive nature of this research the researcher had to be able to assess the participant's verbal and non-verbal signs during the interviews to enable them to offer the support that the participant may

have needed. There was concern this assessment may have been inhibited with the use of a translator or restricted due to a translation of dialect.

Exclusion for the research also included those participants with a reduced cognitive impairment or dementia, both of which could impair participant's ability to recall previous conversations or care experiences. Reduced cognitive impairment may signify an advanced stage of the participant's heart failure (Petrucci *et al.*, 2006), indicating that they were too frail to take part. A current diagnosis of cancer was another exclusion, as the participant's end-of-life conversations and palliative care provision would not be specific to their heart failure diagnosis.

3.6.2 Inclusion and exclusion of healthcare professionals – phase two

It is acknowledged that palliative care is best administered alongside patient's continuing heart failure management due to the unstable disease trajectory (Browne *et al.*, 2014; Barrett and Connaire, 2016). Therefore, heart failure nurses who are based within the community are ideally placed to provide general palliative care (O'Hanlon and Harding, 2011) due to their pivotal role as co-ordinators of care and support (Johnson *et al.*, 2011) and continual assessment of patient needs.

The eligibility criteria for this research was nurses who had been or were currently a community heart failure nurse, and had taken part in end-of-life conversations with their patients. Community nurses within this speciality, as opposed to other practicing heart failure nurses are identified as being ideally placed to have end-of-life discussions and provide general palliative care (British Heart Foundation, 2008). There were no defined exclusion criteria for the community heart failure nurse sample.

3.7 Sampling strategies

The process of selecting potential participants who will inform the phenomena being studied needs to be reflective of the study aims and objectives (Ritchie *et al.*, 2014). Strategies used in qualitative research move away from a random, representative sample (Strang, 2000), and concentrate on specific groups that are experts in the topic of interest (Warwick-Booth, Bagnall and Coan, 2021).

The researcher used purposive sampling for both parts of the study, to identify participants that were proficient and knowledgeable in end-of-life discussions (Etikan, 2016), this strategy uses small participant numbers, whilst providing depth of enquiry (Patton, 2002). It is acknowledged that in qualitative research designs there can be several stages with each one forming a foundation for the preceding one, and purposive sampling can be useful in allowing the researcher a resource to gain a non-probability sample (Sharma, 2017). The disadvantage of using this strategy is its subjectivity of unit selection, and as a result it can be difficult to defend the representativeness of the sample (Sharma, 2017). The researcher has addressed these challenges by ensuring there was a clear criteria for selecting potential participants, and in using a variety of resources to recruit participants. The initial patient and care giver sample was to be sourced with the assistance of a national heart failure charity, however due to low recruitment numbers (as discussed below), an alternative resource in the form of a national health service trust was also used.

3.8 Recruitment

3.8.1 Recruitment of sample – phase one

Participants for the first stage of the research were patients and care givers who had taken part in end-of-life conversations due to their heart failure, to obtain data on their

experiences and preferences in this aspect of their care provision. It is well documented within previously conducted palliative care research, that recruitment of end-of-life participants comes with its challenges, such as locating vulnerable participants (Anderson and Hatton, 2000), unstable symptoms inhibiting participation (Jordhøy *et al.*, 1999), and the higher risk of death (Chaiviboontham, 2011) increasing attrition. Van der Ven *et al.*, (2022) attempt to address these difficulties by advising that researchers need to take time, be flexible and inventive to overcome the obstacles of recruitment, especially accommodating the needs of a vulnerable population (Hanson *et al.*, (2014).

Locating vulnerable participants was a challenge experienced by the researcher. It was necessary to use a gatekeeper, who is defined as someone that has control over access to potential participants (Singh and Wassenaar, 2016). Some evidence suggests that gatekeepers may have a negative impact on accessing potential participants, inhibiting people from making their own choices regarding research involvement (Kars *et al.*, 2016), others describe the importance of the gatekeeper's role in recruitment as vital especially when researching sensitive topics (Dempsey *et al.*, 2016). The initial source of recruitment for this study identified a gatekeeper within the charity who agreed to support this research and would provide access to potential participants. However a series of organisational changes took place within the charity, during the research development process and this impacted on the identification and enrolment of participants. The structural changes within the organisation included the introduction of an online study platform. This was felt by the researcher to be empowering to participants by enabling them to be informed of the studies pertinent to their condition (Kars *et al.*, 2016), and allowing them to decide if they want to take part without the feeling of obligation that a gatekeeper may have produced (White and Hardy, 2010). This required the target population to be proactive in terms of finding out about different studies

and putting themselves forward to participate rather than reacting to an invitation from a gatekeeper. As a result, the number who came forward to take part were lower than originally anticipated.

As mentioned, the Community participatory research project initially sought participants from the heart failure charity, to obtain a community sample. However, due to the challenges in recruitment flexibility was key in seeking alternative sources of research participants (van der Ven *et al.*, 2022). A deficiency in participant numbers from the original source, resulted in the researcher engaging with alternative organisations, in an attempt to increase recruitment numbers.

Additional charitable organisations were approached to assist with the promotion of the research, and assistance was sought from a national health care trust to act as a gatekeeper in the recruitment process. Due to the collaborative relationship between the researcher and the recruiting health trust, the heart failure clinicians had an understanding of the importance of this research (Dempsey *et al.*, 2016). As a result the clinician gatekeepers were motivated to seek potential participants.

The resources used in promoting recruitment for patients and care givers were the forementioned heart failure charity's online recruitment platform, a promotional poster inviting participation (appendix E), and social media posts from alternative appropriate charities.

Potential participants from the heart failure charity identified themselves through the online research platform. This instigated a generic email sent to the researcher, enabling them to

ensure the patient met the eligibility criteria prior to receiving any participant personal data. Further communication procedures linked to the online platform allowed the participant to take the lead in decisions regarding them taking part.

Patients and care givers from other charitable sources contacted the researcher via secure email to express their interest. Those from the national health care trust were identified and approached by their community heart failure nurse and provided with a participant information sheet (PIS) (appendix F). A minimum of twenty four hours lapsed before a member of the community heart failure team contacted the patient via phone to see if they wished to participate enabling potential participants time to read the PIS and consider the appropriateness of them taking part. This recruitment practice is reflective of other research involving vulnerable participants (Reid, 2009). If patients confirmed their intention to participate, oral consent was obtained to share their contact details with the researcher. These details were sent to the researcher via secure email, and all future contact of recruitment was made by the researcher.

There is a general agreement that a sample size for a qualitative study usually lies at under 50 participants (Ritchie *et al.*, 2014). The intention for this study was to be guided by previous research within this field (Murray, 2002; Almack *et al.*, 2012; Im *et al.*, 2019; Pini *et al.*, 2021), with recruitment aimed to achieve up to 20 interviews with patients and care givers. However, recruitment was far more challenging than anticipated and despite extending the recruitment period by 12 months, a total of 10 participants (8 patients and 2 care givers) were recruited from the forementioned sources. While falling short of the numbers hoped for, it was not possible to extend the interview period for longer and it was felt that 10 would be sufficient for key issues related to the research topic to emerge. There was a high degree to

repetition of themes within the individual interviews conducted and a variety of demographics and recruitment sources within the sample.

In addition, although the proposed sample size for this part of the research did not meet the intended quota for patients and care givers, Ritchie *et al.*, (2014) discuss how sample size can be influenced by studies that have more than a single sample. The data analysis for the research evaluated experiences for both patients and care givers, and then community heart failure nurses; resulting in a combined sample size of nineteen, which is similar to those of previously conducted research in this field. Table 2 demonstrates the sources of recruitment of patients and care givers, and the participants loss to attrition.

Table 2 - Sources of recruitment

Recruitment source	Total Participants contacted	Recruited	Withdrew	Reason for withdrawal
Charity	6 patients 0 care givers	4 patients	2 patients	Both due to unstable symptoms
Healthcare trust	8 patients 2 care givers	4 patients 1 care giver	4 patients 1 care giver	3 unstable symptoms, 2 changed their mind
Hospice	1 care giver	1 care giver	0	-

3.8.2 Recruitment of sample – phase two

Community heart failure nurses were recruited for this aspect of the research by virtue of their role, as opposed to their affiliation to a particular national health service trust. Invitations for the healthcare professionals were generic emails sent nationwide to community heart failure services informing them of the research, and invitation to participate. A promotional poster (appendix G) was attached to invitation emails, to provide a concise and clear document with the relevant study information. The use of 'personal touch' recruitment strategies such as emails from a personal source, is seen as the most effective form of recruitment for engaging nurses into research studies (Luck, Chok and Wilkes, 2017).

3.9 Data collection procedures

3.9.1 Semi structured interviews and interview schedule – phase one

The purpose of using semi-structured interviews in qualitative data collection is to collect information from participants who have had experiences of the topic being researched (DeJonckheere and Vaughn, 2019). The flexibility of semi-structured interview questions provide the researcher with a format that can be adapted to the participants answers, and questions elaborated into the participant's level of comprehension (Gysels, Shipman and Higginson, 2008). The researcher used this data collection method to provide a one-off interview for end-of-life participants, and their care givers. The open nature of these questions provide the interviewee a medium to articulate their perspective, that is not offered in using structured interview questions (Gysels, Shipman and Higginson, 2008).

It is recommended that an interview schedule is used when interviewing vulnerable participants. It allows the researcher to actively listen to the participant, and adapt their proposed questions to their needs (Dempsey *et al.*, 2016). To ensure the questions were relevant to the participant perspective patient and public involvement (PPI) members were used to co-produce the interview schedule.

The involvement of patient and public members in qualitative research methods can enhance its integrity (Moult *et al.*, 2023). The collaboration between researcher and the PPI members - patient educators from the national heart failure charity were used to ensure the sensitive topic of end-of-life conversations were presented to participants in a sympathetic way. By working in a collaborative manner with patient educators the interview schedule (Appendix H) was developed from the outset to provide wording that was understandable from a patient perspective. The initial questions were devised by the researcher and sent to patient

educators for their input. Any recommendations for change were discussed at subsequent meetings. An example of this was the original question of 'do you remember if they told you that this condition is not curable?'. The patient educators felt heart failure patients may feel they had been 'cured' as drug and device therapies would make them feel better or even normal. Following their suggestions the interview question was reworded as 'do you remember if you were told that this is a life-long condition and was potentially life limiting?'

The interviews were conducted between July 2022 and December 2023. All the patient and care giver interviews were conducted via a video conferencing platform, the reasons being that symptoms of heart failure can be unpredictable, and debilitating (Beattie, Higginson and McDonagh, 2020c). The physical activity of engaging with face to face interactions can have a negative impact on the participant's disease (Jaarsma *et al.*, 2021), therefore to enhance patient safety whilst taking part in the research it was decided a video platform would be preferable. Recruitment was via a national heart failure charity resulted in participants being located countrywide, thus the practicalities of participation were aided by the use of an online conferencing platform. In addition, the application for ethical approval was submitted at a time when face to face contact between researchers and participants was discouraged due to Covid 19, this was particularly relevant to those participants with underlying health conditions that increased their frailty risk.

All interviews were digitally recorded and lasted on average forty nine minutes in length, with a time range of thirty six minutes to one hour. They were all recorded in one sitting, with no participants expressing a need to pause or stop the interview due to distress or exacerbation of their symptoms. The audio recordings and transcripts were stored in a secure, password protected University of Essex computer drive.

3.9.2 Vignettes, semi structured interviews and interview schedule – phase two

The patient and care giver's findings were presented to community heart failure nurses, to establish how they could be implemented into clinical practice. The proposed data collection for this phase of the research was to be focus group based, however due to the variation in working patterns nationally of community heart failure nurses this had to be reviewed. The challenges of data collection were overcome by using one focus group (of three participants) and six individual interviews. They were conducted between February 2024 and March 2024 and lasted on average 56 minutes in length. All forms of data collection were conducted via a video conferencing platform, to accommodate the nurse's work patterns.

To gain an insight in these healthcare professionals' attitudes and opinions regarding the evidence, vignettes were used in the conducted interviews (Hughes and Huby, 2002). Vignettes are defined as short hypothetical descriptions of actual events (Tremblay *et al.*, 2022). They are recognised as being particularly useful when researching sensitive matters (Bain, 2024), such as end-of-life discussions and care (Denk *et al.*, 1997). The researcher used this method to gain an insight into the professional practice of community heart failure nurses whilst they administered this aspect of care. The scenarios described were hypothetical. Bain (2024) expressed concerns that this can result in answers being given in a similar, hypothetical manner. The researcher has addressed this consideration by ensuring the vignettes were closely related to the patient and care giver findings whilst maintaining participant anonymity. This was achieved by offering descriptions of patient experiences that were closely associated with their quotations from the interview transcripts.

Vignettes can be used as a stand-alone methods or in combination with other research methods (Hughes and Huby, 2002). The researcher combined them with semi-structured interview enquiry, allowing the use of open ended questions which contributed to participants providing long, detailed responses (Bain, 2024). Both the vignettes and semi-structured interview questions formed the interview schedule (Appendix I), which ensured the data collection methods were integrated into the research design and the theoretical underpinnings of the study (Bain, 2024). It is recognised that these methods can be used within individual interviews as well as focus groups (Tremblay *et al.*, 2022).

Data collection was recorded digitally and stored securely on the researcher's University of Essex computer drive, which is password protected. Participants were allocated a pseudonym to ensure anonymity was maintained.

3.9.3 Transcription

All interviews were transcribed and anonymised by the researcher. This process involved listening to the audio-recordings, and converting them into text to a suitable level of detail (Braun and Clarke, 2006a). The transcript was then compared back to the original audio (Braun and Clarke, 2022), ensuring accuracy of the text.

Although it is recognised that this process can be time consuming, and delay the analysis of data (Hill *et al.*, 2022), the researcher felt this was not the case. Converting the audio-recordings into text, the researcher was able to immerse themselves into the analysis stage straightaway. This provided opportunity to annotate, and add meaning to the text (Point and Baruch, 2023) inductively as the analysis developed.

3.10 Pilot study

The use of a smaller study to test the research protocol, recruitment strategies and the process of data collection is recognised as a pilot to the full study (Hassan, Schattner and Mazza, 2006). The procedure of piloting is thought to be more relevant to assessing the feasibility of the research process (Jones *et al.*, 2017) than providing data or outcomes on the topic being studied (CASP, 2025b). As there are a number of challenges associated with palliative care research for example, low recruitment rates and high attrition rates and the ethical issues of recruiting end-of-life participants (Chaiviboontham, 2011) the researcher considered the ethical challenges associated with undertaking a pilot. This research experienced slow recruitment, an expected hurdle in the process of palliative research however this allowed time to lapse between the initial 3 interviews, providing opportunity for data to be analysed, the research protocol and appropriateness of the interview schedule to be considered in relation to the data it collected. The researcher felt a sense of ethical commitment in using data obtained from a patient who had been identified as end-of-life, therefore did not feel it appropriate to just use interview data as a source of piloting the research process. Although a formal pilot study was not undertaken the researcher believed the pace of recruitment allowed the feasibility of the research protocol to be assessed.

3.10 Framework data analysis

Community based participatory research (CBPR), impacts on the interpretation of the research results (Schubotz, 2020) as it requires working in partnership with heart failure patients and care givers. To ensure an equal partnership between the researcher and participants during the CBPR process (Schubotz, 2020; Warwick-Booth, Bagnall and Coan, 2021), a Framework approach has been used to offer transparency in the analytical stage.

The interconnecting stages within this method clearly describe the routes that guide the systematic analysis (Smith and Firth, 2011), allowing both the researcher and patient representatives to have a clear view of the exploration of data.

The framework approach was applied to all of the transcripts from both studies; heart failure patients, care givers and then community heart failure nurses. The five stages of data management provided a systematic process of analysing the raw data, into key concepts (Furber, 2010). From these concepts themes were developed which provided evidence in examining participant's experiences.

3.10.1 Familiarisation

The first stage of the analysis was to become familiar with the data (Goldsmith, 2021) in order to allow the researcher to initially ensure the content of data collected was relevant to the research topic (Baldwin and Bick, 2021). Further familiarity obtained an understanding (Furber, 2010) of what participants had said relating to the research question (Goldsmith, 2021), in order to provide an insight into this aspect of care. This was achieved by listening to the audio recordings, reading and re-reading the transcripts and studying the field notes that were made following each interview, (Srivastava and Thomson, 2009; Hackett and Strickland, 2019).

Familiarisation with the material enabled the researcher to become immersed in each transcript prior to dividing the data (Ward *et al.*, 2013). Ritchie and Spencer, (1994) reiterate the importance of this process, as the researcher will have formed 'hunches' on key issues and potential themes during the data collection. Reappraising the data methodically, by reading the transcripts from beginning to end, whilst making notes and adding labels to the

data in the margins of the document allows it to be viewed within the context of the collected material. Thus ensuring that any labels created, are supported and substantiated by the data (Ritchie *et al.*, 2014).

Appendix J shows an extract of an interview transcript (from phase one). Segments that were identified to be of interest and relevant in providing an insight into end-of-life conversations and palliative care provision were highlighted and then along with pertinent sections of field notes, were transferred into a Word document. By incorporating 'in-vivo' codes, key phrases were supported by participants own words (Smith and Firth, 2011). Table 3 presents examples of these findings, and demonstrates the thought process during the analysis of reoccurring experiences and views of the participants (Ritchie and Spencer, 1994).

Table 3 – Examples of coding

Interview transcript	Description (in-vivo codes)	Preliminary thoughts (What is this about?)	Initial categories
I don't know that precise details the um, it was diagnosed because of a lot of quite sudden and rapid fluid build-up.	'I don't know that precise details..'	Not been told or doesn't remember.	Gap in knowledge
And so obviously you know [they] saw the doctor, etc. Um, [they], they then said that they thought it was heart failure. Um because we, because we felt we wanted to know more.	'They *thought* it was heart failure…. we wanted to know more'.	Vague. Patient and carer needed to know more to be informed.	A need for information
I've been very lucky. That's why I've got no regrets. I've been very healthy up til this time, and I fell to pieces since but I can't help that.	'I've been very lucky'. 'That's why I've got no regrets'.	Downplaying severity. Having the illness is better than dying from it.	Rationalising illness

The familiarisation stage continued over a number of days, until the researcher felt they had a richer understanding of the data (Ward *et al.*, 2013), whilst ensuring the labels were

continually referenced to the study aims and objectives (Furber, 2010). On completion initial codes were identified as being closely associated with emerging themes from the interview transcripts. These were then used to construct labels, and in the continuation of the data analysis (Ritchie *et al.*, 2014; Baldwin and Bick, 2021).

3.10.2 Constructing the initial conceptual framework

The raw data were continually referenced during this section of analysis. Repeated review of the material provided additional immersion and interpretation (Hackett and Strickland, 2019), allowing the emergence of new insights from the data (Smith and Firth, 2011). The stage of constructing the initial thematic framework, labels and topics were organised into themes and subthemes (Ritchie *et al.*, 2014). It is felt by undertaking this more specific arrangement of the data it would provider a greater insight and inform the research topic. Ritchie *et al.*, (2014) discuss the importance of this process to ensure the inventory of what may appear important is pertinent to the objectives of the research.

It is recognised that the initial stages of a framework will be largely descriptive and embedded in a set of a *priori* issues (Ritchie and Spencer, 1994). However, Ritchie *et al.*, (2014) believe this to be an important phase, as the analysis will remain grounded in the data. Table 4 displays the initial conceptual framework (as used in phase one). Not all of the initial labels (as displayed in Table 1) were thought to provide enough evidence and contribution to the research question in a significant way, due to either a review of the context of data not being specifically relevant to end-of-life conversations and palliative care provision. Therefore, they were not included in the development of the framework.

Initial Conceptual Framework	
1. Knowledge	**3. Control**
1.1. Degree of knowledge	3.1. Take control
1.2. Sources of information	3.2. Losing control
1.3. Retaining information	3.3. Effects on emotions
1.4. Interpretation of information	3.4. Rationalise diagnosis
1.5. Frequency of conversation	
1.6. Preferences of information given	**4. Communication**
1.7. Withholding information	4.1. Honesty
1.8. Understanding of terms used	4.2. Timely conversations
1.9. Confidence in information given	4.3. Inclusivity
	4.4. Gently
2. Support Network	
2.1. Source of support	
2.2. Frequency of support	
2.3. Meeting supportive needs	
2.4. Abandonment	
2.5. Charitable support	

Table 4 – Initial conceptual framework

3.10.3 Indexing and sorting

The initial framework was then referenced back to the interview transcripts (Furber, 2010), re-immersion of the data enabled labels to be applied to sections of data (Ritchie *et al.*, 2014). This was done by re-reading each sentence, and paragraph to determine what was being said by the participant, and decide which section of the framework it would sit in (Ward *et al.*, 2013). Table 5 demonstrates an example of this, in column A, there are the preliminary themes and subthemes, whilst in column B there are extracts of the transcripts thought to be pertinent to that particular theme. The bold text are highlighted extracts that were considered to be relevant to the specific subtheme. These bold extracts are displayed within the original text, to ensure there was no loss of context of data (Furber, 2010). Baldwin and Bick, (2021) describe this phase as being crucial in allowing the researcher to examine each theme individually, so each subtheme can be explored further. Whilst these early stages are to be completed methodically, analysis is still seen as crude, and ongoing adjustments maybe needed (Ritchie *et al.*, 2014).

Column A – subtheme	Column B – data extracts
1.0 Knowledge 1.1 degree of knowledge	**I don't know that precise details** the um, it was diagnosed because of a lot of quite sudden and rapid fluid build-up.
1.1 degree of knowledge	And so obviously you know she saw the doctor, etc. Um, she, they then said that they thought it was heart failure. Um because we, because we felt **we wanted to know more.**
1.1 degree of knowledge	that was that was good, I mean we, **we knew at that point** that this condition was going to deteriorate over time and that, ultimately, you know, be at least at the very least a significant factor in in her you know when she died.

Table 5– Examples of indexing

3.10.4 Reviewing data extracts

This stage is to reassess the indexed data and consider alternative ways of organising data to establish more refined groups (Baldwin and Bick, 2021). In re-reading the 'piles' of indexed data, data extracts were examined to ascertain whether there were any relevant themes that may have been missed from the initial conceptual framework (Ritchie *et al.*, 2014). Each subtheme was reviewed and Table 6 demonstrates how the framework was amended or merged to develop a conceptual framework. By undertaking this process, the smaller themes that neglected to offer anything new to the research question or omitted to offer enough data to underpin them were discarded to prevent disjointed data (Ritchie *et al.*, 2014).

Initial Conceptual Framework	Conceptual Framework
1. Knowledge	**1. Knowledge**
1.1 Degree of knowledge	1.1 Degree of understanding
1.2 Sources of information	1.2 Experiences of receiving information
1.3 Retaining information	
1.4 Interpretation of information	
1.5 Frequency of conversation	
1.6 Preferences of information given	
1.7 Withholding information	
1.8 Understanding of terms used	
1.9 Confidence in information given	
2. Support Network	**2. Support Network**
2.1 source of support	2.1 Support needs
2.2 Frequency of support	2.2 Experiences of receiving support
2.3 Meeting supportive needs	
2.4 Abandonment	

Table 6 – Example of revised conceptual framework

3.10.5 Data summary and display

The final stage of framework analysis prior to undertaking the interpretative phase is advocated by Ritchie *et al.*, (2014), and involves data being organised into a format that is increasingly manageable (Somerville, Jonuscheit and Strang, 2023). Sections of data that were indexed were arranged in a spreadsheet format, providing a chart of themes (Srivastava and Thomson, 2009). This allowed the researcher to move back and forth throughout the themes, without neglecting the raw data, providing a platform for cross case and within case analyses (Ritchie *et al.*, 2014). Table 7 displays an example of the matrix. The first lefthand column are participant's pseudonyms, allowing each participant their own row within each theme (Somerville, Jonuscheit and Strang, 2023), and individual subthemes have their own column which allows the researcher to see each participant's contribution in each theme (Somerville, Jonuscheit and Strang, 2023). Each subtheme column contain extracts taken from the indexed data, with sections of text from researcher's own thoughts underlined. This

process allowed further immersion of the data, whilst providing an increased understanding on the varied content (Ritchie *et al*, 2014). Once the data had been organised in this way, attempts were made to establish what has happened between each theme or subtheme (Baldwin and Bick, 2021). The review of each experience, and participant views were recorded (Baldwin and Bick, 2021).

Theme: Knowledge

Case	1.1 Degree of understanding	1.2 Experiences of receiving information
Number: 1 Pseudonym: Sue Classified: Care giver	Understandable information, advice was clear regarding progression. 'that was that was good, I mean we, we knew at that point that this condition was going to deteriorate over time'	Individualised information, no inclusive to other family members. They were not given comprehensive information. Missing information. 'my [relative] had a couple of conversations with the district nurse who, who was basically saying you know it's quite likely that your [relative] hasn't got very long, but... they didn't really discuss any options'

Table 7 – Example of the matrix

Following on from the matrix, data was then arranged into detected elements using participant's own words to describe their experiences in correlation to these citations detected elements were listed that describe the data extracts. Table 8 shows an example of this.

Column A Summaries for subtheme 1.1 degree of understanding	Column B Detected Elements
No. 2 'it probably left us a bit up in the air. I didn't realise I was just as bad as I was'.	• Up in the air. • Abandoned, unsure. • Unaware of seriousness of condition.
No. 10 '[they] said it won't cure you. It really won't cure you, you know. And I knew that anyway because of what I'd been told previously'.	• Reiterated information. • Able to recall information given. • Accepted due to awareness.

Table 8 – Example of detected elements

The process provided a list of elements, which were then sorted according to their key dimensions (Baldwin and Bick, 2021), progressing away from the descriptive analysis into the analytical properties with the development of thoughts becoming apparent (Ritchie *et al.*, 2014). For example, as displayed in Table 8, participant 10 described experiences of having end-of-life conversations with their clinicians. The element associated with this 'reiteration' of conversations enhanced the patient's ability to 'recalling information'. The detected elements were then listed, and analysis of these characteristics provided the key dimensions relating to the research topic (Ritchie *et al.*, 2014). Table 9 demonstrates an example of this. Next to each element listed there are numbers bracketed, these refer to each participant identifier to allow identification of where this element is detected (Ritchie *et al.*, 2014). Once the key dimensions were identified, the final themes are extracted. These have summarised any variation whilst ensuring all relevant data is included (Ritchie *et al.*, 2014).

Column A Detective Elements across the data set for 'experiences of receiving support at the end-of-life'.	Column B Key Dimensions
▪ Inclusive support for carers (1) ▪ Family support network (2) ▪ Needed the nurse (3) ▪ Consistent care from heart failure nurse (5)	**Support needs**
▪ No ownership of regular support (4) ▪ Been left, felt abandoned (7)	**Impact of no support**
▪ Desperately frustrating and upsetting (1) ▪ Struggled as alone (4) ▪ Family support impacts emotions (7) ▪ Lull in support caused stress (8)	**Emotional impact**
▪ Reassurance from phone call (3) ▪ Just verbal support (5) ▪ Converse in person or phone (8) ▪ Comfort from accessible support (9)	**Types of support**
▪ Specialist overseeing care (1) ▪ Trusted support (3) ▪ Personalised coping needs (5) ▪ Continual, trusted care (6) ▪ Reassurance from specialist support (7) ▪ Agreed care decisions (10)	**Collaborative partnership**

Table 9 – Example of key dimensions

It is from the identified key dimensions that the subthemes and themes were extracted. Table 10 demonstrates an example of this.

Theme	Subthemes
6. Support delivery	**6.1** The types of support available **6.2** Identified support needs **6.4** The impact of having a collaborative partnership **6.5** The emotional impact of receiving support

Table 10 – Example of subtheme and theme development

The process of framework analysis has been described and examples demonstrated from phase one of the research. Phase two – the data analysis obtained from community heart failure nurses, underwent the same method.

3.11 Participatory research feedback

Initially patient educators from the national heart failure charity were invited to provide feedback on the patient and care giver data analysis. A hiatus in reciprocal communication from the charity resulted in the researcher seeking advice from the patient and public involvement team from the East of England Applied Research Collaboration (ARC) who were part funding this research. The advice sought involved guidance on how the researcher may engage with the charity in a more profitable manner to obtain feedback on the analysis, without breaking down the collaborative relationship between researcher and charity. It was advised that the findings should be presented to the national heart failure charity in the format of easy read, layman, non-medical terms to ensure they understood the interpretation of the data. An example of this is demonstrated in appendix K. There were 4 patients who provided the feedback from the heart failure charity, this gave the researcher reassurance that their analysis was reflective of patient's experiences. The researcher then fed back to the ARC patient and public involvement group, to apprise them of the progress made with obtaining PPI feedback on the patient and care giver data analysis.

3.12 Ethics

Ethical approval was obtained for phase one – recruitment of heart failure patients and their care givers was initially sought through the heart failure charity. Due to the charitable contact agreeing to assist and identifying themselves as a potential gatekeeper from a non NHS source, the ethical approval application was made via the University of Essex. Structural reorganisation within the charity during the researcher's ethics application resulted in a loss of the original gatekeeper. It is thought that in being able to access a vulnerable population a gatekeeper is vital due to the advantages they bring in the form of local influence and motivation of potential participants to take part (Dempsey *et al.*, 2016). This

research was subject to low recruitment numbers, and due to this looked to alternative resources to seek participants. An amendment to the ethical application obtained through the University of Essex was obtained, allowing the promotion of the study through appropriate charitable sources. Potential patients were not actively recruited from in-patient areas within hospice facilities, as it was felt these patients were likely to be either actively dying or experiencing unstable symptoms (Westlake and Smith, 2015). The promotion of this research was restricted to the out-patient waiting areas where patients' conditions were likely to be more stable. Ongoing low recruitment numbers continued and resulted in the researcher seeking alternative sources of potential participants, and when it became necessary to widen the recruitment net to include NHS trusts, a separate ethical approval was obtained from the health research authority through the IRAS system for phase one – recruitment of patients from the supporting healthcare trust (Appendix L). This provided access to potential participants who had been diagnosed with heart failure and identified as requiring palliative care. The use of healthcare professionals as gatekeepers enabled the patient's condition to be assessed prior to approaching them to take part, and those patients who were felt to be unstable or actively dying were omitted until a stage where their condition was improved. In this situation the health of the potential participant was put before the need to be part of the study (Kars *et al.*, 2016).

3.13 Informed consent

For a participant to make an informed decision when consenting to take part in research, they must be provided with adequate information, which includes the risks and benefits of study involvement (Fouka and Mantzorou, 2011). Whilst the consent process is usually described as 'static' (Beaver, Luker and Woods, 1999), the unpredictability of a heart failure patient's symptoms (Browne *et al.*, 2014), and the frequent changes in work

commitments for community heart failure nurses, influenced how consent was obtained within this study. The use of 'process consent' was employed at regular intervals, enabling the researcher to clarify participants willingness of being involved in the research process (Addington-Hall, 2002); for patients - to ensure their disease trajectory was not influencing the patient's cognitive impairment and their physical abilities to undertake the interview (White and Hardy, 2010), and for nurses – to confirm their working practice accommodated the freedom to be interviewed.

3.13.1 Consent process – phase one

All patients and care givers that had expressed an interest in participating were contacted via phone or email to reiterate the purpose of the research, confirm their desire to take part and provide an opportunity for them to express any questions. Once their intensions had been corroborated by the participant, they were sent another copy of the PIS (to ensure they had received a copy) and the consent form (Appendix O). On returning a signed consent form the researcher then contacted the participant again to arrange a convenient date and time for the interview (DeJonckheere and Vaughn, 2019), providing them another opportunity to express any questions they may have. A further contact was made by the researcher on the day of the appointment to ensure the participant felt well enough, and happy to proceed with the interview.

This approach allowed each participant opportunities to decide when they would like to be interviewed (Beaver, Luker and Woods, 1999), and enabled the researcher to assess the patient's clinical state to ensure participation would cause no harm to the interviewee.

3.13.2 Consent process – phase two

The community heart failure nurses, on receiving the invitation to participate identified themselves by contacting the researcher directly via secure NHS.net email. Opportunities were provided for them to ask any questions relating to the study, and to notify the researcher of a convenient date and time they wanted to be interviewed.

Consent forms and another copy of the PIS were emailed to each participant individually, to ensure anonymity. Once the participant had returned the signed consent form, an invite to take part in a video conferencing platform interview was sent, again via secure email.

3.14 Confidentiality and anonymity

Adhering to the codes of ethical approval both for anonymity and confidentiality of participants were addressed. The procedures used were identical for both parts of the study. Participants were provided with a written version of the procedures in the form of a PIS (Fouka and Mantzorou, 2011), and verbal reiteration of the process was given at the beginning of the interview as the researcher followed a documented check list (Appendix P).

Confidentiality was maintained by anonymising all transcripts, by removing all identifiable data. Anonymised transcripts and audio recording were stored on a secure University of Essex computer drive, only accessible to the researcher. Any back-up audio recordings were permanently deleted at the end of the interview, once it was confirmed the video conferencing platform had successfully taped the interview, and it had been saved to the secure computer drive. Each interview and associated paperwork were allocated with a number to ensure all documents were anonymised. To guarantee confidentiality each participant was given a

pseudonym and only extracts of the interview transcripts were available to those outside the research process.

All participants were notified that anonymised interview transcripts were only accessible to the researcher and their supervisors. Whilst anonymised extracts may be used in the data analysis, write up and dissemination of the study findings.

3.15 Risk of harm

As a registered general nurse the researcher has a duty of care to their patients (Nursing and Midwifery Council, 2010). This was an ethos that continued throughout the planning, and implementation of the research process. The completion of a documented risk analysis as part of the ethical approval procedure, prior to data collection (Warwick-Booth, Bagnall and Coan, 2021), enable the researcher to address potential risks to both participants and the researcher themselves.

The risks of research can evolve from the research topic (Ritchie *et al.*, 2014), which is especially pertinent when researching sensitive topics, such as end-of-life discussions. Safety procedures were made clear to each participant prior to the interview. Confidentiality was to be maintained throughout, but should at any time the researcher feel the participant was at risk, this confidential agreement may be broken. In this situation the researcher would discuss these findings with the participant and converse how they should be resolved.

The researcher addressed the potential expectations of the participants due to their dual role of both nurse and researcher. Whilst the researcher would use their professional skills to assess the participant's physical and psychological state before, during and after the interview, their professional capacity was as a researcher. Therefore they would not be able to

offer any medical or counselling advice. Participants were offered a follow-up contact with the researcher within one week post interview, to consider the topic discussed and if required their sources of support available to them within their circle of care. Whilst all participants accepted the additional contact, there were no support needs identified from this contact. In keeping with the findings of Bloomer *et al.*, (2018) participants only described a therapeutic benefit of taking part.

Participants were advised they could withdraw from the research at any time, and during the interview if they became distress or emotional the interview could be paused, rescheduled or discontinued. All interviews were completed at the proposed date and time agreed, with no attrition at this stage of the study.

There was no risk identified for the researcher, due to their experiences of having end-of-life conversations previously with this patient group, and their care givers. The provision of regular meeting with their supervisors allowed the opportunity for any concerns to be discussed.

3.16 Quality measures

To enhance trustworthiness to the data interpretation and findings, credibility checks have been incorporated into the study design, data analysis and interpretation of findings. The assessment criteria for qualitative research, as advocated by Yardley, (2000) has been used, and will be displayed as the four key dimensions: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance.

3.16.1 Sensitivity to context

Sensitivity to context was addressed by using a methodical approach to exploring the literature pertinent to end-of-life conversations and palliative care provision. The decision to focus on research specific to heart failure patients, and care giver's perspectives was deliberate to ensure it represented the particular social context surrounding this group.

The study design was carefully considered when contemplating how this vulnerable group would be interviewed. The use of a community based participatory research methods provided the voice of those who had experienced this disease. This collaborative approach ensured equality and respect between research and the heart failure patient educators providing a legitimate voice to both parties (Bastida *et al.*, 2010).

To remain sensitive to this vulnerable group's circumstances the decision was made to interview them online, ensuring that participation did not impact on their physical and cognitive symptoms. Semi structured, open interview questions were used to allow participants to express their own views, whilst avoiding researcher bias through the use of leading questions.

3.16.2 Commitment and rigour

The aspects of the data collection and analysis process are elaborated on previously within this chapter. A commitment has been demonstrated by the extensive engagement of the data. This included the undertaking of interview transcription, to ensure the researcher was fully immersed in the data (Ritchie *et al.*, 2014).

Respondent validation through the use of community based participatory research provided rigour to the research findings (Mays, 2000), in seeking feedback on the research analysis allowed those with the patient voice to be represented through each stage of the research process (O'Sullivan, Desmond and Buckley, 2023). Critiques of the findings were then fed back to the researcher to confirm the analysis was comparable of a patient perspective, and experiences.

3.16.3 Transparency and coherence

The methodological decisions made throughout the research process have provided transparency and coherence. The use of qualitative methods are described as appropriate for examining the intricacies of patient experiences relating to the provision of their healthcare (Smith and Firth, 2011; Gale *et al.*, 2013), and are associated to the research aims and question. Stages of Framework analysis provide a transparency during the process of analysis (Furber, 2010) by using a systematic approach.

Reflexivity in the research process enables the researcher to consider how they have influenced the collection of data, and its analysis (Mays, 2000). The researcher's professional background prior to embarking on this research, has the potential of imposing bias on all aspects of the process. Therefore a reflective research diary, and notes were recorded after each interview.

The use of CBPR also provided consistency through the research process. By following a structured progression through the study, the researcher and patient representatives worked collaboratively in agreeing on the topic of interest, recruitment, data analysis and dissemination of the research findings (Bastida *et al.*, 2010).

3.16.4 Impact and importance

The experiences of heart failure patients and care giver's taking part in end-of-life conversations is rarely documented within current empirical research. The findings from phase one were presented to community heart failure nurses within phase two, to establish how they can be implemented into clinical practice. The evidence reported in this research has been undertaken with the intention of improving clinical practice for heart failure patients. Disseminating these findings will aim to impact of patient care. It is hoped that sharing the results with the wider health policy audiences will assist in facilitating change in care provision (Wilson *et al.*, 2010). The use of a co-produced study such as CBPR is believed to add importance to the research by improving the relevance, and quality of findings in actively working in collaboration with those who have the lived experiences (Springer and Skolarus, 2019).

3.17 Chapter summary

This chapter has discussed and outlined the methods used for this research. The aims of the study are to gain insight into heart failure patients and care giver's experiences of end-of-life conversations and palliative care provision. These findings were then presented to community heart failure nurses to establish how they can be implemented into clinical practice. The theoretical underpinnings of the research question and the use of participatory research methods have dictated the application of qualitative methods, with data collection gained by semi structured interviews, and focus groups. Framework analysis was used in both phases of the study to provide comparable data set analysis.

The following chapter will address the findings from the perspective of the proposed research question of what are heart failure patients and care giver's experiences and preferences of

end-of-life conversations and palliative care provision, and how can these be implemented into clinical practice.

Chapter 4. Analysis

4.1 Introduction

This chapter presents the findings from both arms of the study. The process of analysis is demonstrated in Figure 4. The initial collection of data within phase 1 involved interviewing heart failure patients and their care givers. This provided experiences of taking part in end-of-life conversations and receiving palliative care. The data was analysed using Framework thematic analysis where themes were derived from the lived experiences of the participants (Braun and Clarke, 2006b).

For phase 2 of the study real life vignettes were obtained from the descriptions patients and care givers provided, and were presented to community heart failure nurses using fictious names to protect the participants identity and maintain confidentiality. These provide a focus for conversation within either focus groups or individual interview with the nurses, allowing the capture of participant's responses to the same stimulus (Hughes and Huby, 2002). An example of a vignette can be found in Appendix H. Qualitative data was collected from the nurse's response to the vignettes, along with the use of semi-structured interview questions to obtain an insight into end-of-life conversations and palliative care provision from a clinician's perspective.

Phase 3 of the research allowed the comparison of themes derived from phase 1 and phase 2 of the research to establish how the findings and preferences could be implemented into patient care to improve clinical practice.

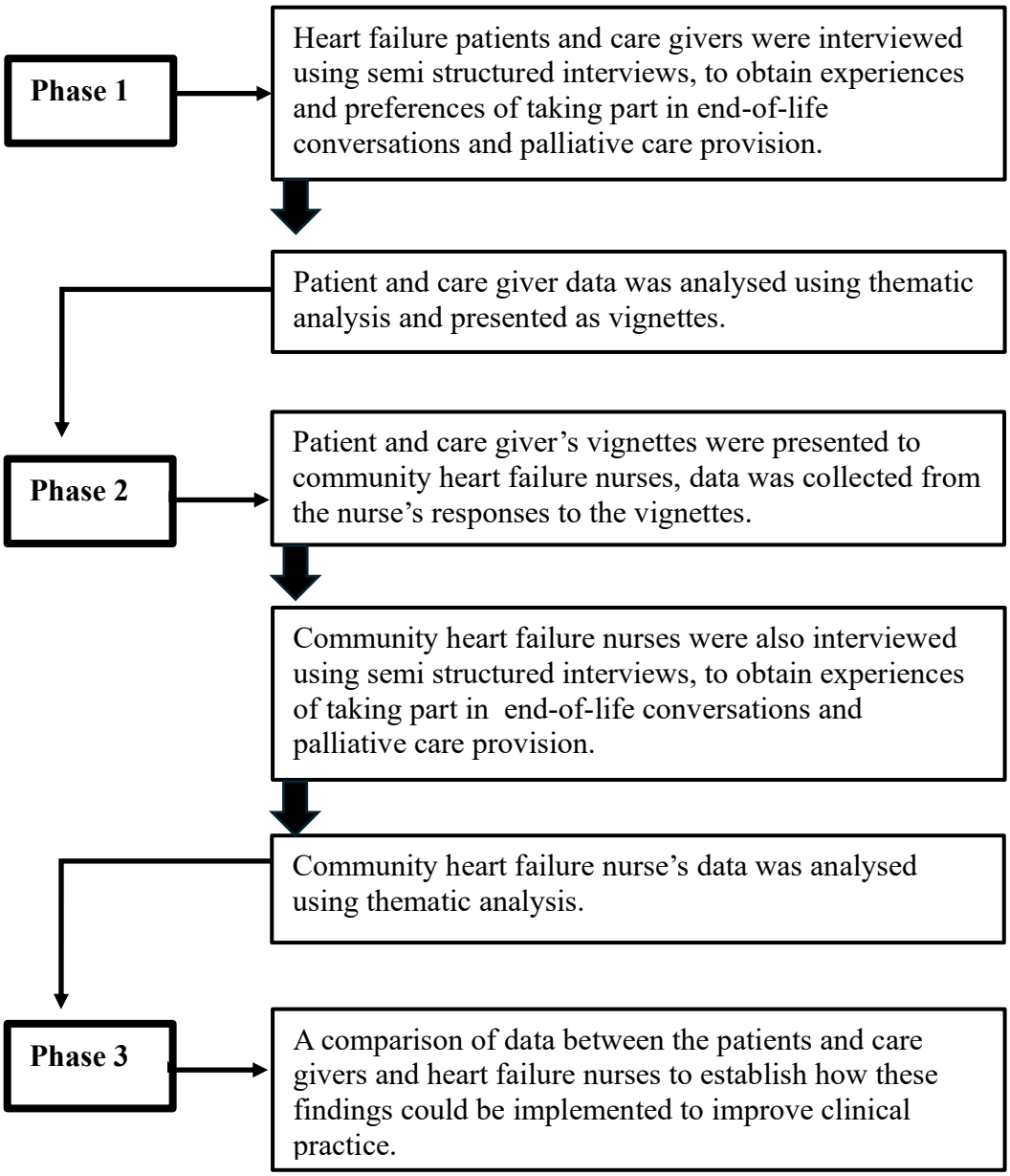

Figure 4 - Phased approach to data analysis

The 2 data sets from patients and care givers within phase 1, and from heart failure nurses within phase 2 provided 2 separate data sets that were both analysed using framework thematic analysis. This delivered comparable data from both phases 1 and 2 which allowed the final phase to provided evidence on recommendations to improve clinical practice.

4.2 Participants

Table 11 shows the demographics for the patient and care giver's sample from phase 1 of the study. It includes the pseudonym given to each participant.

Pseudonym	Age	Gender	Ethnicity	Patient or care giver
Nicola	26	Female	White, British	Patient
Polly	39	Female	White	Patient
Andrew	46	Male	White, British	Patient
Phillip	56	Male	White, British	Patient
Haley	59	Female	White, British	Patient
Sue	70	Female	White, British	Care giver
Stella	76	Female	White, British	Care giver
Paul	78	Male	British national	Patient
Robert	82	Male	White, British	Patient
Thomas	85	Male	Mixed race	Patient

Table 11. Patient and care giver sample

The demographics of the community heart failure nurses from phase 2 of the study are displayed in table 12, below. All nurses identified themselves as specialising in community heart failure.

Pseudonym	Age	Gender	Ethnicity	Geographical area
Jenny	26	Female	White, British	South east England
Shelley	39	Female	White, British	East England
Jessica	44	Female	White, British	East England
Joanna	53	Female	White, British	South east England
Beth	53	Female	White, British	East Midlands
Fiona	56	Female	White, British	Northern England
Laura	57	Female	White, British	North west England
Mary	60	Female	White, British	South east England
Ellen	67	Female	White, British	South east England

Table 12. Community heart failure nurse sample

4.3 Themes and subthemes

The two data sets from phase 1 and phase 2 were analysed separately, to provide themes and subthemes from the perspectives of patients and care givers, as well as community heart failure nurses. Each phase of the study had a slightly different focus. Phase 1 obtained experiences and preferences on end-of-life conversations and palliative care provision from heart failure patients and care givers. In phase 2 the community heart failure nurses were presented with phase 1 findings to gain their experiences of end-of-life conversations, with phase 3 comparing the experiences to provide an insight into how the preferences from patients and care givers could be implemented into clinical practice to improve patient care. As a result some themes and subthemes emerged from both data sets, for example the difficulty of having end-of-life conversations was discussed by both patients and care givers and by heart failure nurses, both phases highlighting that these discussions are classed as difficult however, needed to take place. Alternative themes were only apparent from a single phase of the study. For example patients and care givers were able to describe the psychological impact of inadequate information being given to them, whilst this was not something the nurses had experienced as the delivers of the information rather than the receivers. Results were then compared to offer an insight into the experiences of taking part in heart failure end-of-life conversations and palliative care provision, and how their preferences can be implemented into clinical practice. In comparing the themes from each phase of the study phase 3 demonstrated that certain themes were pertinent to both participant groups of the study, whilst others were only derived from one group (e.g. patient and care givers or community heart failure nurses) .

Table 13 demonstrates an overview of the themes and subthemes from both data sets, and how some have overlapped between the two.

Data set – patients and care givers		Data set – community heart failure nurses	
Themes	**Subthemes**	**Themes**	**Subthemes**
1. Conversation practices	**1a.** it is a difficult conversation **1b.** Conversations should happen; however they do not	**1.** Conversation practices	**1a.** it's a difficult conversation **1b.** Conversations should happen; however they do not
2. Interpreting information	**2a.** Left us up in the air **2b.** I don't remember		
		3. Influences on initiating end-of-life conversations	**3a.** Everybody immediately thinks the worst **3b.** Not enough time **3c.** Gradually build that trust
		4. Influences on palliative care delivery	**4a.** Just as long as someone does it **4b.** prioritisation and variation of end-of-life conversations and palliative care
5. Autonomy	**5a.** Emotional impact **5b.** Rationalising illness	**5.** Autonomy	**5c.** Competence and confidence
6. Support delivery	**6a.** The types of support available **6b.** Identified support needs **6c.** The impact of having a collaborative partnership **6d.** The emotional impact of receiving support	**6.** Support delivery	**6a.** The types of support available **6c.** The impact of having a collaborative partnerships **6d.** The emotional impact of receiving support

Table 13. Themes and subthemes

4.3.1 Theme 1: Conversation practices

This core theme and its 2 subthemes were derived from both phase 1 and phase 2 of study analysis. The experiences of taking part in end-of-life conversations were discussed within both data sets due to all participants having had experiences in undertaking these

discussions. The theme will now be examined to provide a comparison of experiences relating to the influences on initiating these discussions and being involved in them.

Subtheme 1a: It is a difficult conversation

Participants across both data sets have discussed conversation practices which have resulted in negative experiences for them. Patients and care givers described the process of receiving information from their healthcare professionals. They discussed how their lack of understanding of heart failure, and how its association with being a terminal illness made them feel unprepared for the sensitive conversations. For example Stella, who is a care giver (CG) said

... to tell you in that way we had no idea we had no idea (Stella, CG).

The experiences patients and care givers have of delicate discussions, whilst being unaware of the disease and progression resulted in distress. They have described how this could be avoided. By being prepared Robert, a patient (P), felt would have alleviated some anguish caused by the conversation:

It came out too sharp, they probably could have been introduced a little bit easier (Robert, P).

Some participants described how being forewarned of the instability of heart failure and the progression of their illness would have enabled them to cope with its deterioration.
Nurses have recited incidence within practice of reluctance and active avoidance from fellow clinicians to have these discussions. Mary a heart failure nurse (N) has endorsed this idea:

actually I do think sometimes it's deliberate avoidance at the point of diagnosis because it's a, it's a difficult conversation (Mary, N).

Likewise, Joanna also a nurse recounted how she had experienced a similar occurrence when caring for her patients. She described how physicians had referred patients to the heart failure service, without acknowledging their deteriorating symptoms, or considering the terminal aspect of their condition. The clinician's reluctance to address the terminal needs of the patient resulted unrealistic treatment expectations from ill-informed patients and care givers.

not even with GPs. The patients will be deteriorating. Oh, we'll refer to the heart failure nurses. And if that's going to, we're going to change everything and make them a whole lot better. And there's not that conversation there (Joanna, N).

Whilst community heart failure nurses agreed with patients and care givers that conversations are avoided, resulting in ill-preparation for the terminal phase of the disease, some nurses have attempted to rationalise this omission by considering the personality traits of some healthcare professionals. Shelley reflected on the members of her heart failure team, and described how different dispositions can influence their clinical abilities and reluctance in having sensitive conversations with patients:

there are some in the team that are a bit more timid or a bit would feel a bit more unable to deliver the conversation (Shelley, N).

The concept that healthcare professionals avoided end-of-life conversations was a reoccurring theme which has evolved from the heart failure nurse data and perhaps goes some way to explaining the inadequacy of about end-of-life conversations reported by patients and care givers.

Community heart failure nurses have rationalised not initiating end-of-life discussions by describing concerns of being wrong, and the impact this will have on their patients. Concerns that these conversations would negatively affect patients and care givers prevents them from being conducted, even though they acknowledged that having the discussion is an important aspect of end-of-life care. For example, Jenny said

I think there is a balance with it a little bit about you don't want to mention it really, really early because it might also scare them (Jenny, N).

Ellen likewise discussed her experiences of having end-of-life conversations, when thinking about the emotional impact on her patients. She described feeling conflicted, as she felt her patients needed to be informed however she then considered the negative effect it may have on the patient.

I think we tend to sort of play it by ear, so I'll, I'll talk about a life limiting condition which is near as I can get, but I'll madly backtrack (Ellen, N).

These actions demonstrated a reluctance from healthcare professionals to provide patients and care givers the information they need to cope with their illness.

Subtheme 1b: Conversations should happen; however they do not

Patients and care givers have described experiences of not being able to access sources of information that is needed to enable them to manage their symptoms and care choices. They expressed a need for there to be resources available to access, when they require it. Andrew described his experiences of unobtainable information at a time when his symptoms were unstable:

there's nothing you could you could tap into, and at a time when I probably needed that (Andrew, P).

Likewise, Haley expressed a need for healthcare professionals to be open with their patients, to enable them to cope with their changing condition. This desire for information is preferrable whilst the patient is well enough to make care decisions.

I think we should be a lot more open about it. And know exactly what is around for us, what is available. Who can help us. We tend to leave it too late. You know it's always at the end when you're not as healthy as you could be, or you're not set up for it (Haley, P).

The request to be informed has been described by both patients and care givers. With participants expressing a need for their healthcare professional to share information with them.

Heart failure nurses, patients and care givers all acknowledge a need for information giving to be an ongoing process. Nurses describe the importance of providing gradual information to their patients to improve recall and understanding, preventing the negative emotional impact end-of-life conversations will have. For example Laura said

if you really are surprising them, they're not going to take a lot on board beyond you telling them that anyway. So you need to follow it up with some more time at in another place when they've had chance to think chance to speak to their family or you know (Laura, N).

Patients reiterated the need for repeated conversations by agreeing with heart failure nurses, that information does get forgotten. Nicola expressed concerns that assumptions are sometimes made by healthcare professionals regarding the information they give to patients and care givers, impacting on their own level of understanding.

They stop saying it... And a lot of the time you've either forgotten or you don't know it in the first place. Like it can never hurt to say something again (Nicola, P).

Shelley (a heart failure nurse) elaborated on this recommendation by discussing the timing of conversations, highlighting the importance of introducing the topic early on in the disease trajectory to improve patients and care givers understanding.

I think it's really important to make sure that you kind of eke in this information early on and in drips. Rather than just go in and go right, this is what we're doing (Shelley, N).

The opinion from nurses of a gentle, gradual information giving to patients and care givers is viewed as empowering to them. This ensures that any care decisions are made as a joint decision, and using a collaborative conversation.

It's about revisiting what you know where you're at and what we actually mean by the terminal part of heart failure… know the trajectory is very different and it's about explaining the process and what that might entail (Fiona, N).

Jenny discussed the importance of adapting information giving to the level of patient's understanding. This was felt to ensure patients were fully informed and then able to use the information given in the their decision making.

it's just making sure that it's explained to the patient clearly and checking their understanding a little bit as well (Jenny, N).

Patients, care givers and community heart failure nurses all have experience of these discussions and as such acknowledge that end-of-life conversations were difficult to undertake, and as a result rarely happen. On occasion when they are executed it is in a

suboptimal manner. The challenges associated with this task, mean they are often actively avoided by healthcare professionals who either expect other clinicians to initiate discussions or delay addressing this sensitive topic themselves. The consequences of this avoidance is patients and care givers are ill-informed to make care decisions, and feel isolated by the lack of information. There is an identified need for end-of-life conversations to take place from all participants, and recommendations that there should be repeated discussions to ensure patients understand their disease progression, thus enhancing their abilities to make decisions regarding their care. Patients and care givers want to be informed regarding their illness and know the sources of information to manage their changing clinical needs.

4.3.2 Theme 2: Interpreting information (patients and care givers)

This theme is derived from the patients and care givers interviews only. Receiving and interpretating information has an impact on patients and care giver's abilities to make individualised care decisions. Due to this participant group being the receivers of information the researcher felt this was likely to be a theme pertinent to just their experiences. The limitation of end-of-life conversations restricts participants understanding of their condition, whilst having a negative effect on them emotionally.

Subtheme 2a: Left us up in the air

Patients and care givers described the impact of not being given information by their healthcare professionals. Sue (a care giver) described the initial consultation with her relative's physician, and how inadequate information giving resulted in them, as a family needing to seek further information from alternative sources.

And so obviously you know she saw the doctor, etc. Um, [they], they then said that they thought it was heart failure... we felt we wanted to know more (Sue, CG).

This experience was similar for Phillip, who as a patient had received written correspondence from a clinic contact with his physician. Due to the limited information given to him verbally during that contact, he was unable to understand the letter causing him distress:

I have no understanding what they've written (Phillip, P).

The lack of information given to patients and care givers is described as having a continual emotional impact on their ability to rationalise and manage the disease. Polly explained the omission of information left her feeling isolated, as the symptoms she was experiencing were not explained:

I didn't know hardly anything of what I was going through was not normal… I literally have been left in the dark just to say. (Polly, P).

Likewise, Robert had a similar experience when describing the lack of conversations regarding the deterioration of his symptoms, and how this resulted in him feeling abandoned:

It probably left us a bit up in the air. I didn't realise I was just as bad as I was (Robert, P).

Participants were unable to manage their condition due to their lack of understanding, resulting in them feeling unprepared for any changes in symptoms or progression of the disease. These experiences extended to both patients and care givers. For example, Stella (a care giver) stated whilst recalling conversations regarding their relative's heart failure and its deterioration. The lack of information has caused anxiety for her, as she is unable to rationalise symptoms:

Since then, I have not moved from here because I won't leaving [them]. You know unless there is our [relative] or [relative] other than that I won't. Um, but that was the devastation that we had Christmas just before Christmas, and I believe that is what they do say, because I found since 2 of the people who was told the same thing. So, it, it wasn't no build up, and there wasn't no explaining (Stella, CG).

Similarly Thomas (a patient), described his experience of receiving information as the symptoms worsened. When questioned if he had been told what to expect as his disease advanced, he felt that information had not been given to him or not in a way that was clear for him to understand:

No they didn't seem to go into that technicalities, or if they did, I missed it (Thomas, P).

Patients expressed belief that healthcare professionals had deliberately withheld information from them. This idea was captured by Andrew (a patient) who described his experience of a hospital admission due to his sudden deterioration of heart failure symptoms. At the time he felt he was not fully informed of his condition. The lack of information impacted on his ability to rationalise his illness, his symptoms and recovery:

they didn't say much at the time, you know. We'll see how you react to that. See where we can get you. I couldn't understand why, just having something wrong with your heart made the rest of my body just completely useless. I just couldn't understand it. You know but yeah, so I was you know the just the fact that you had to get up and move you had to. You can't just lie there you're never going to get well, are you? (Andrew, P).

These experiences were replicated in care giver's accounts. Sue described an occasion whilst their relative was actively dying, that even though the healthcare professional had conversed with them there was information that was missing which would have enabled them to cope a little easier

my [relative] had a couple of conversations with the district nurse who, who was basically saying you know it's quite likely that your [relative] hasn't got very long, but... they didn't really discuss any options (Sue, CG).

Subtheme 2b: I don't remember

This subtheme encapsulated the patient and care giver's experiences of recalling the information given to them by their healthcare professional. Participants described the influencing factors on their ability to remember information, and experiences of receiving information. Some participants were able to recall the information given to them, and the impact of how this was conducted had on them. For example, Andrew discussed the experience of receiving information when he was in an emotional state. This impacted on his ability to retain the conversation, which then heightened his anxieties.

I didn't take any of it in. I just, just, burst into tears (Andrew, P).

The emotional impact of not receiving information was reflected by Stella, a care giver. She described the event of being present with her relative whilst they both took part in an end-of-life conversation. She felt the lack of preparation, and bluntness of the conversation had a negative effect on them both.

And it was the most, we've both experienced life, and it was the most devastating um.. (Stella, CG).

Some participants have been emotionally affected by the way information was given to them, which impacted on their ability to retain information, others have described not being able to recall receiving the information at all. Haley was unable to recount being informed of her condition or how the disease will progress:

I don't remember anybody actually saying, you know the heart's failing, and this is what's going to happen (Haley, P).

Patients and care givers have described their experiences of receiving information regarding their condition, it's progression and discussing their end-of-life preferences. As they are the receivers of end-of-life information these themes have not be experienced by phase 2 participants of community heart failure nurses. Patients and care givers have described a lack of information given to them is a basis within this theme, which has resulted in participants feeling uncertain, and unprepared to make end-of-life care decisions. Whilst some expressed a concern that information was being withheld from them, others described an inability to recall if information had been shared with them. This demonstrates a need for patients and care givers to be provided with information, and the need for ongoing conversations to allow them to process the information given and adjust to their changing needs.

4.3.3. Theme 3: Influences on initiating end-of-life conversations (heart failure nurses)

This theme is derived from the nurse interviews only and describes 'information giving' from a healthcare professional perspective. As the providers of information this theme and subthemes were relevant specifically to this participant group. The heart failure nurses described their experiences and potential barriers that may influence the introduction of this sensitive topic. The theme examines the influences that impact heart failure nurse's abilities to initiate, and provide ongoing end-of-life conversations with their patients and care givers. Subthemes describe the perception of end-of-life care, and heart failure as an illness cause reluctance from nurses to initiate discussions.

Subtheme 3a: Everybody immediately thinks the worst

Nurses shared experiences that inhibited them from initiating conversations about care preferences. They expressed trepidation associated with society's opinions of death, dying and the terminology used in end-of-life care. It was felt this lack of understanding inhibited patients when considering their care needs, resulting in nurse's reluctance to initiate these conversations. For example, Shelley discussed the potential impact of using end-of-life terminology and alternatives available; unable to provide a substitution:

I don't know how you could overcome it because I think whatever term you give it, people are always going to think that it's the end (Shelley, N).

In particular the term palliative care was felt by heart failure nurses as being negatively viewed, with its association with death, and dying. Participants felt that as soon as palliative care was mentioned patients and care givers assumed death was imminent. Laura discussed how the interpretation of terms used in healthcare are related to death, which impacted on clinicians reluctance to introduce this aspect of care into a patient's treatment. She felt this had a detrimental effect on patient's understanding when discussing care options:

I don't think it's just heart failure. I think it's it's, it's everywhere. Unfortunately, palliative care has become synonymous with dying. Like hospices, like how people's faces change. If you suggest they go to the Hospice (Laura, N).

The limited understanding of terminology extends beyond palliative care to the condition of heart failure itself. Nurses describe how a lack of awareness relating to the condition results in patients and care givers not appreciating it's terminal aspect, and relation to end-of-life care. Ellen discussed the lack of public awareness, and how conversations can be a shock as the condition does not have the platform of familiarity as other diseases such as cancer:

heart failure not understood it's not like cancer, which everybody immediately thinks the worst if I get a diagnosis (Ellen, N).

Patient's lack of understanding and appreciation that heart failure is a long term, incurable condition resulted in a reluctance from healthcare professionals to have end-of-life discussions with heart failure patients. Concern was expressed that patients and care givers would be uncomfortable to acknowledge their deterioration, and as such they would not want to discuss their care. Jenny explained that the perception that patients do not want to discuss their end-of-life care, resonates through to the opinions of healthcare professionals, and this inhibits the initiation of conversations

I think it can be sometimes when people don't want to talk about it. That makes people feel uncomfortable (Jenny, N).

Subtheme 3b: Not enough time

This subtheme encapsulated heart failure nurse's experiences of service provision. Participants describe the allocation of time for clinic appointments and that this has an impact on end-of-life conversations. Many felt the standardised practice of a 10 minute appointment was insufficient to allow clinicians to conduct sensitive conversations.

I think the cardiologist or even GP, they get 10 minutes. Which is not enough time to tell somebody that they've got heart failure (Shelley, N).

Beth elaborated on the effect a lack of time can have on how the conversation is conducted. Limited contact with patients can result in clinicians addressing matters that they feel is essential information and them appearing rushed and abrupt.

the consultants got 10 minutes. I've got 10 minutes to see you and this is what you've got. I don't know why you've been referred here. You know you're gonna die. Go away. Leave me alone. Sort of thing (Beth, N).

Historical and standardised practice in clinic timing allocations has been discussed by nurses as not fit for practice. It is believed by the heart failure nurses that the current set up of clinic timings is not conducive to enable end-of-life conversations.

So if you're going in and you've got 15 minutes or half an hour or whatever your template is, it's not long to be able to speak to someone, deliver that news and support them (Laura, N).

Subtheme 3c: Gradually build that trust

Whilst highlighting the inadequate clinic times for conducting end-of-life conversations, recommendations were made on how discussions should be conducted. The provision of time during patient contact was felt to be important in having these sensitive conversations as it allowed the formation of trust between patient and clinician. Building relationships between patients, care givers and their healthcare professional was felt to be important in cultivating an environment where both parties were comfortable in discussing this sensitive topic. Joanna explained the importance within clinic practice to have the facilities to spend time to build a relationship with their patients.

It's time we have a lot more time. To have with patients and we, we know them better (Joanna, N).

Spending time with patients extended beyond the provision of individual contacts. Having regular visits, and ongoing contact with patients provided opportunities to develop a working

patient – healthcare professional relationship. Laura described the importance of spending time with patients to form a bond, and build a trust between patients and their nurse.

And just gradually build that trust (Laura, N).

Likewise, Fiona reiterated the importance of regular, ongoing conversations to prepare patients and care givers for the progression of their heart failure. In providing regular contacts, and forming a trusted relationship with their clinician, patients were able to have the confidence to make care choices at a sensitive time of life, which enhanced the patient's ability to make individualised care decisions with the support of their heart failure nurse.

I don't think it's a bad thing to talk about when you first meet a patient and you're talking about heart failure the nature of heart failure. I think it's important to sow the seeds that it's an it's an unpredictable journey. And we can't necessarily cure the journey, you know, cure the symptoms. What we can do is manage the symptoms and we work alongside them to help manage those symptoms (Fiona, N).

The data demonstrates there are factors that influence healthcare professional's ability to initiate end-of-life conversations. A perception of public opinion and understanding relating to the terminology used cause a reluctance in providing these sensitive discussions. The availability of time, or lack of, adds to the challenges of providing this aspect of care. Heart failure nurses recommend the standardised length of healthcare clinic appointments, being 10 to 20 minutes is not long enough to undertake these conversations. Indicating that clinical contacts with heart failure patients are not fit for purpose. It is recognised that patients and care givers need ongoing conversations to allow them to understanding disease progression, and treatments available. The provision of a patient-nurse relationship will give patients the confidence and support to make care decisions.

4.3.4 Theme 4: Influences on palliative care delivery (heart failure nurses)

This theme is derived from the nurse interviews only, and encapsulates the challenges associated with providing palliative care within clinical practice. Heart failure nurses have discussed aspects within current practice that enhance or inhibit this aspect of care. The three subthemes identified examine which clinician is ideally placed to offer this care, how current care priorities influence the provision of palliative care, and how care can be improved.

Subtheme 4a: Just as long as someone does it

Heart failure nurses discussed identified healthcare providers who are ideally placed to provide palliative care. Some participants felt it should be any clinician that had a working relationship with the patient, as Laura described

whoever knows them best and you know, it could be the heart failure nurse. It could be the GP. It could be the cardiologist, I don't think there's a right and a wrong. It's just as long as one doesn't think the other's doing it (Laura, N).

Most participants felt it should be the heart failure nurse that provided ongoing palliative care. Many felt it was part of their role, as they viewed themselves as heart failure nurses, and palliative care nurses. Jenny discussed how she viewed her professional role, and believed the palliative aspect of heart failure was very much blended with her provision of heart failure care

we are essentially palliative care nurses just that we are specialised in heart failure (Jenny, N).

The importance of regular patient contact, and care provision was apparent when discussing the ideally place clinician to offer this care. Nurses expressed the importance of regular interactions with these patients when offering palliative care to ensure patient's changing

needs were addressed. Beth explained the importance of expertise and confidence when offering palliative care. She felt as they were the ongoing providers of care to her patients, she was best placed to deliver this care:

a heart failure specialist nurse because we have the experience, the knowledge there. That's what we do on a daily basis (Beth, N).

Although this stance was a popular view from six nurses, there was also an opinion expressed that the consultant or patient's doctor should lead their care. Mary discussed the lack of guidance available on who should provide palliative care to heart failure patients. Due to this she felt historical practice should prevail, and the patient's doctor should lead any care decisions. As a heart failure nurse her belief was to support the physician, and not initiate end-of-life discussions and care.

I do think they need to hear it from a consultant or a doctor that this is a life limiting, deteriorating condition. And I think they need to hear it from them. I don't. I think we could support it. I don't think it's my role to say to a patient who is unaware that this is a terminal illness personally (Mary, N).

The uncertainty of who should provide this care continued through this subtheme. There are also variations in opinion of what is ideal palliative care, and a lack of unified attitudes from clinicians. Shelley considered the differences in acute clinical areas, and those within the community setting when prioritising care provision. She explained that acute areas focused on treating symptoms, and fail to address the palliative stage of heart failure. In contrast, the majority of community heart failure nurses view palliative care as a pivotal part of their role.

[they've] been into hospital several times to be off loaded, and no one there has told [them] that [they're] palliative. So it makes it look like we're just saying, saying it in the community, but because we're not doctors, it's not being accepted by [their relative] and it's

making it very, very difficult because this [patient] is, is dying and [they've] not got the support in place that [they] need (Shelley, N).

The lack of a unified approach to palliative care is also discussed by Joanna. She reiterated Shelley's observations that there are differences between medical led and nurse led care. The different care priorities between these disciplines exacerbate the challenges of delivering sensitive care.

I think they're told often very different things from us, from the consultants, from the GP. And it's they're given very different opinions. And that's very hard (Joanna, N).

This subtheme demonstrated a lack of guidance, and unified approaches to providing palliative care. As a result nurses describe disjointed care, and the omission of ownership taken by clinicians when providing heart failure patients with palliative care.

Subtheme 4b: Prioritisation and variation of end-of-life conversations and palliative care

The importance attached to end-of-life conversations and palliative care is influenced by the priority placed on it by healthcare providers. This subtheme discusses the reluctance from healthcare professionals towards these discussions and to offer palliative care. These views extends to clinician's perception of palliative care in comparison to curative medicine. Heart failure nurses feel that medical practice does not place priority on this form of care. Mary discussed the attitudes within clinical practice that palliative care takes second place to curative therapies, resulting in a lack of importance associated with it:

I think you know it's not a particularly dynamic to other people, it is to us, but a dynamic form of medicine either and it's the mainly older, older by-group. I think it doesn't sometimes get the attention (Mary, N).

The influence of healthcare professionals' attitudes towards palliative care has been described by participants as highly influential in the provision of successful end-of-life care. In contrast to the low priority many clinicians give to palliative care, some of the nurses describe how important it can be to provide good quality palliative care.

it's readdressing in your own mind what your role is within a patient's journey and if you see you are still adding value and palliative care isn't a failure. It's just a further extension of what you're able to offer this person. Then you see the value in what you're adding, and you're not actually seeing it as failing. But if they die at home comfortably knowing they're going to, everything's sorted, I think. Well, that's a job well done (Laura, N).

Beth offered a rationale for the inconsistencies in care provision, by describing how personal opinion can motivate care due to the lack of standardised guidance:

I think you have to be comfortable to be able to talk about palliative care. And what it means. And it's not always as straightforward (Beth, N).

Nurses describe the variations in practice between healthcare providers. The acute settings for care are focused on curative medical practice, which takes precedence over end-of-life care. Due to this the organisation of care provision focuses on delivering therapeutic treatments.

in acute settings don't necessarily focus on that because they're more focused on the acute episode that's happening in that situation. And I think that sometimes we know it's a palliative condition from the minute we see them (Jenny, N).

Likewise, this is the view of Mary who believes the attitude towards palliative care influences clinician's opinions. The lack of priority at an organisational level filters down to those

providing the care, resulting in an embedded stance that palliative care is a community based service only

and that's soft stuff, I think as it's thought of, thought to be more appropriate for community services (Mary, N).

The prioritisation of palliative care is thought to influenced by funding decisions dictated by the organisation of healthcare services. Participants felt the allocation of funding for care services was predetermined by financial gain to the healthcare providers, and palliative care was not viewed to be commercially viable.

the concept of palliative care and the ethos behind it. Isn't supported with financially, so until as much money is put into end of life care as other aspects of medical care, there's always going to be this lacking... (Ellen, N).

It has been recognised that the organisational influence on funding for palliative care provision results in a variation in practice. Jessica discussed the differences in services available to patients, whilst acknowledging that heart failure patients have the same condition, and therefore would require a similar package of care. Offering a nationalised guidance on the services provision was felt to be a solution to improve the priority of palliative care and provide a unified approach.

maybe we're all doing a bit more of the same thing, but then that's very, that's very different in different areas because they've got different services like some places haven't got community teams, they've only got hospital teams, the funding's different, you know, some places have got huge teams, other places haven't… I think it should be more of a nationalised approach (Jessica, N).

The variation of providing end-of-life conversations and palliative care provision within geographical areas, results from a lack in national guidance. There is a recognised need that this group of patients require palliative care, however due to the deficiency in recommendations, responsibility of the task remains open to interpretation of healthcare providers. This in turn causes disparities in the care given, service availability, and ownership taken in who provides palliative care.

4.3.5 Theme 5: Autonomy

This theme is derived from both interviews with patients, care givers and nurses although some of the subthemes are different between the two groups. The initial subthemes appraise patients and care giver's experiences in controlling their decision making process relating to their care needs. The encapsulate the emotional impact of this care and the need of having control over their illness and care. The subsequent subthemes discuss the practical aspects of having control and ownership of delivering the care, and the nurse's needs to enable them to feel self-sufficient in initiating discussions. The subthemes their identified requirements such as educational needs and the impact of training on their own abilities to take control and initiate end-of-life conversations and provide palliative care.

Subtheme 5a: Emotional impact (Patients and care givers)

Both patients and care givers have had experiences that resulted in them feeling they were losing control of their care decisions. Sue (a care giver) described how her relative's unmet care needs impacted on their ability to make care choices. Unexplained care decisions made by healthcare professionals, limited information given to her and her relative, and inconsistent care providers all exacerbated feelings of being unconfident in their care decisions.

just kind of felt that, particularly for my [relative] it just kind of felt that her needs were not her needs in that situation (Sue, CG).

Likewise, Nicola described the emotional impact of not receiving the information she felt she needed to manage her condition. The lack of information given to her, despite regular contacts with healthcare professionals resulted in apprehension and anxiety regarding her symptoms and disease progression.

you kind of feel a bit up in the air, waiting for an answer you don't really want but kind of need (Nicola, P).

The emotional effect of not receiving adequate information and an inability to make care decisions has been discussed by participants. Both patients and care givers have experienced emotional unrest as a consequence of unfulfilled information giving. Phillip described an incident during his initial admission to hospital, when he was given his diagnosis. He felt the limited information provided prevented him from rationalising his preceding experiences, and inhibited him from making future care choices.

I felt vulnerable and very lonely at that very stage (Phillip, P).

Likewise, Andrew had a similar experience during his admission to hospital. The lack of information given to him resulted in confusion over care choices, and alarm when healthcare professionals advised him of his plan of care.

And that scared the hell out of me. I was like woe, woe! What's going on I thought I'd come here to try and lose weight (Andrew, P).

The experiences of receiving inadequate information impact on participant's abilities to make care choices. Not all patients and care givers have received suboptimal information. Some participants described experiences where they have taken the lead in sourcing information to enable them to make care decisions, and take control of their care plan. Thomas acknowledged that healthcare professionals are reluctant to have conversations with patients regarding their deteriorating symptoms, and therefore he feels he has to take control of conversations

I think sometimes I have to bring this subject up. I think they're a bit coy about mentioning it (Thomas, P).

Likewise Haley said due to the limited information she received regarding her symptoms, she sought her own source of information. This enabled her to be adequately informed so she was able to make care decisions.

Nobody went any further so, I went to my GP, and I said, what's going on, you know? (Haley, P).

Patients describe a loss of control and inability to make care decisions due to the lack of information given to them. This has resulted in them experiencing distress and abandonment. There is a need for patients and care givers to be informed so they can take control of their illness and symptoms.

Subtheme 5b: Rationalising illness (patients and care givers)

The provision of information allowed participants to rationalise their illness. The experiences of waiting for information and the anticipation associated with that, resulted in patients feeling liberated that they were able to justify their symptoms with a diagnosis once they finally did receive a diagnosis which explained their symptoms. Nicola described waiting for a formal diagnosis from her clinician, and when she officially received it felt comforted that she was able to manage her condition

when that conversation did finally come, it felt like a bit of a relief, because it was like. I've been waiting a long time to know that it's definitely that (Nicola, P).

Likewise, Polly described a similar experience. Expressing relief that her diagnosis was severe enough to justify her symptoms

that it was actually something serious, that was a gift in itself (Polly, P).

Participants have expressed a want to receive information regarding their diagnosis and symptom progression. The information assists them to rationalise their experiences and plan any future deterioration. The requirement for information extends to discussing death and dying, with participants describing a need to acknowledge this to enable them to plan their future care. Thomas recognised their pending demise, and felt healthcare professionals should not avoid discussing it. He said

... and sooner or later, as we are all going to, I am going to die (Thomas, P).

Patients have rationalised their illness to enable them to take control of their disease. Instead of patients being fully informed of their illness, and the management of their symptoms they

are left to justify the seriousness by the relief of having a diagnosis. Patients are not being given the information they need to control their care needs.

Subtheme 5c: Competence and confidence (heart failure nurses)

This subtheme discusses the needs of healthcare professionals to take control of end-of-life conversations and palliative care decisions. Descriptions of educational training were said by nurses to provide competency in delivering this care. Fiona described a unified approach would ensure the delivery of end-of-life care to a national standard preventing variations in practice.

I think we've got to be competency driven to make sure we're all achieving a certain standard. And while following guidance and communicating in the same way, so we're all coming from the same page in a way. So we're all given the same information (Fiona, N).

These recommendations are felt to be generalised to all disciplines within healthcare. Nurses expressed it should be generic training to ensure all patients, not just those with heart failure have their end-of-life needs addressed.

I think that's a big, big educational thing. And I think that's across all medicine. It's not just cardiology, it's, it's everywhere. It's your surgeons, it's, it's, it's everybody (Laura N).

The experience of receiving education was felt to influence clinical practice. However, participants explained that standardised training does not ensure they feel competent in initiating end-of-life conversations. Joanna described that even though she has received recognised communication training, this did not provide her with the confidence to offer this aspect of care.

We've all been trained in advanced communication. They recently paid for all the [staff members] to complete the advanced care training and now they're saying right, you need to go and write ReSPECT form [recommended summary plan for emergency care and treatment form]. So it's like well actually hold on a minute. We haven't actually had any training in that.. (Joanna, N).

The provision of education did not provide healthcare professionals with confidence to take part in this sensitive care provision. Fiona reiterated this view, whilst acknowledging the training in advanced communication skills was accepted within the profession as a standardised education requirement, this did not provide clinicians with the confidence for initiating end-of-life discussions.

it's about advanced communication skills, having the competence and confidence to be able to have those conversations and not shy away from them (Fiona, N).

Laura felt that training should go beyond standardised courses, healthcare professionals should have education to meet the individual's requirements. This would ensure they had the belief in their abilities to instigate end-of-life care. She discussed the need for training to prepare clinicians before they are placed in a position of necessity, or they actively avoid undertaking the task.

we don't educate people well enough to give them the confidence to, to, to deal with the deal with the issue. Unless they're forced to, which is a shame. So I do think education, confidence and you know to a certain extent time, but I think it can easily be made an excuse time (Laura, N).

Heart failure nurses have identified a need to feel confident in their abilities to initiate end-of-life conversations. Education has been identified to contribute to nurse's confidence, however competence is viewed as an additional requirement. There is no nationalised

education guidance on this topic, and as a result some nurses feel more equipped than others. A program of training and competency assessment would provide clinicians with the skills and experience they need to undertake end-of-life discussions, increasing their confidence to provide this aspect of care.

4.3.6 Theme 6: Support delivery

This core theme is derived from both interviews with patients, care givers and nurses. The theme encapsulates experiences of participants from both sections of the study, relating to their support needs, the types of support available and the impact of receiving support. There are four subthemes identified, with three overlapping between the patients and care givers, and heart failure nurses. The subthemes identified from both study sections were 'sources of support', 'the impact of having a collaborative relationship', and 'the emotional impact of receiving support'. The remaining subtheme was pertinent to the patient and care giver group, which described the 'identified support needs'.

Subtheme 6a: The types of support available

This subtheme was described by all participants from both sections of the research. Patients and care givers discussed the consequences of having accessible support. Verbal communication with a healthcare professional is viewed as preferable as a source of assistance. Andrew described the importance of having telephone contact with his heart failure nurse. The ability of being able to call them enabled him to be reassured and manage his symptoms in a timely manner.

She [heart failure nurse] kept me out of hospital many, many times when I started to panic, and I thought things were going wrong, I could just call and say, look, this is happening. Five minutes chat and I was calm down again, (Andrew, P).

Verbal support was discussed by Phillip. He was describing how he accessed his support network, and felt by simply being able to call his nurse provided him with reassurance and confidence to confront any challenges his condition may provide.

It was just verbal support, which was great, offered (Phillip, P).

Likewise, Haley reiterated this opinion by describing a telephone contact that provided her with confidence to manage her illness. She felt it reassuring that there was a form of support available when she was concerned.

It was reassuring that there was at least somebody there that could ring up and say, you know the hearts not doing very well (Haley, P).

The provision of support from their clinician allows patients to cope with their illness and manage their unpredictable symptoms. They have identified the importance of collaborative support to have control over their heart failure.

Heart failure nurses discussed the types of support available to them. They described verbal communication between different services was a preferable source of help. This type of assistance was not available to all heart failure nurses and for those that did have multi-disciplinary team (MDT) meetings, they described it as ‘lucky’, acknowledging the rarity of this support.

we're very lucky we have regular MDTs with our cardiology consultant and our renal consultant as well. So we can always discuss patients, you know with them if we're sort of struggling with management (Jessica, N).

MDT support was not accessible to all heart failure services. Jenny acknowledged that this was a preferable source of support, if it were available. She felt it would not only provide the heart failure nurses with confidence to make care decisions for their patients, it would also improve communication between collaborative care services and improve patient care.

maybe having like a joint MDTs, so we can discuss the needs together because there'll be times where they're kind of under both of our services (Jenny, N).

The development of relationships between clinicians provides other benefits whilst having conversations. Nurses described that having regular discussions and receiving support from fellow clinicians impacts on the quality of care they are able to offer. Jenny described the importance of regular support from other members of the MDT to provide individualised care for their patients and care givers.

I think having those good relationships in that good communication means we're all on the same page. There's that continuity of care and the person who's at the centre of that is the patient (Jenny, N).

Likewise, Beth expressed similar experiences, and emphasised the provision of safe care, in supporting each other collaboratively.

It enables it to take place in a safe in a safe way, in a safe manner, in a supportive way and you know if you've got collaborative work (Beth, N).

Patients and care givers have described how accessible verbal communication with their healthcare professional provides them with confidence to seek assistance and make care decisions. Telephone conversations were a simple form of support for them to be reassured.

Heart failure nurses also sought support from verbal communication in the form of MDT meetings with fellow clinicians. This enabled them to seek assistance when making care decisions for their patients and provide them with confidence due to a collaborative approach.

Subtheme 6b: Identified support needs (patients and care givers)

This subtheme was described by patients and their care givers, when considering their own support requirements. A common theme from the data was the need for support for care givers, as well as the patients themselves. Sue (a caregiver) described experiences of caring for her relative. She felt the support was there for the patient, however for the care givers this was limited. Providing ongoing communication and support for the carers she believed would enable them to emotionally cope with the changing needs of their relative.

I think I think there's a lot that can be done for care for the carers (Sue, CG).

The identification of care giver support was reiterated by Polly (a patient). She said that knowing her relatives were supported would assist her emotionally as well. Polly discussed the distress of her dying, and her relatives not having adequate support. She felt the knowledge that they had a working relationship with a healthcare professional as well would ease her anxieties.

I would deal with it better if I knew my family members was leaving behind had more support in a way, emotionally (Polly, P).

Some patients described receiving support from their clinician, and how this gave them confidence to cope with their illness. Andrew discussed the importance of his working relationship with his community heart failure nurse. He described this as invaluable, allowing him to manage his condition and make individualise care decisions.

we got home from [hospital], she came. I didn't even know they were coming. [Hospital] done all that, [hospital] had organised all that, and you know I, I needed, I needed that nurse. She was absolutely amazing (Andrew, P).

These experiences were not always shared by other participants. Some described the lack of support available to them, and how this made them feel. For those not privy to this experience patients and care givers felt abandoned by the lack of support. Polly described her experiences after the healthcare professionals had exhausted all curative medical therapies. She reported feeling abandoned as she felt there was nothing else that could be treated. The lack of information given to her regarding the provision of palliative care resulted in her feeling alone.

I have no support, because I've just been left, because there is nothing more he can do (Polly, P).

Subtheme 6c: The impact of having a collaborative partnership

All participants described the importance of having a working partnership with healthcare professionals to provide individualised care. Patients and care givers discussed how a partnership with their clinician allows them to receive trusted advice, regarding their symptom management. The knowledge that patients had regular visits from a heart failure nurse provided Sue (a Care giver) reassurance that decisions were being recommended by a clinician who knew their relative:

it was generally collaborative, as I say, the, the heart failure nurse was clearly had the overall I guess decision making, and you know was clearly a specialist in her field (Sue, CG).

The familiarity of their clinician provided participants with support in managing their illness. Andrew described the instability of his symptoms and how a working partnership with his

heart failure nurse enable him to make decisions regarding treatment options. The collaborative partnership gave him the confidence to cope with his changing condition and together they were able to decide on the appropriate plan of care.

we together… We both knew what kept me straight a little diversion either way, and I would fall off so, so finely balanced (Andrew, P).

Heart failure nurses discussed how collaborative working with fellow clinicians allowed them to support each other. Jenny described how the supportive relationship with other care services eased the undertaking of end-of-life conversations with patients. In discussing the care needs of patients, she and her colleagues were able to determine, what care plan was appropriate for individual patients.

the main thing is supporting each other as healthcare professionals to have those conversations (Jenny, N).

Likewise Shelley expressed similar experiences, and discussed the importance of providing patients with individualised end-of-life care plans, whilst acknowledging the unpredictability of heart failure.

I think very much in our area it is 2 teams that collaborate together to ensure that the patient and their family get the best palliative care scenario possible really (Shelley, N).

Some heart failure nurses discussed the variation in heart failure services extended to disparities in being able to provide individual patient care. Fiona acknowledge that there must be a personalised care plan for each patient. However the availability of different services was necessary to adapt to the needs of patients and their care givers.

it's not one-size-fits-all, it's, it's a, it's a collaboration, a different team (Fiona, N).

The participants who have experienced collaborative working between the heart failure team and other palliative services have discussed the impact this had on care provision. Nurses have described the importance of the professional relationships, and this offers a unified approach.

when they all work together and it works well, it's brilliant. When you're all on the same page. It's, it's great. And you know you giving the same message (Laura, N).

Patients, care givers and heart failure nurses agree that conversations should also be collaborative. They have expressed a want to be involved in these discussions to enable them to make personalised care decisions. Sue (a care giver) described the experience of having ongoing conversations regularly with their nurse. The process of repeated discussions enabled them to cope when their relative deteriorated; as the patient, themselves and the nurses all had the same understanding of what was happening, and they were all prepared

that was that was good, I mean we, we knew at that point that this condition was going to deteriorate over time (Sue, CG).

This preference is reflective of the views of heart failure nurses. They acknowledged that ensuring everyone is informed when discussing the sensitive topic of end-of-life conversations provides confidence within both parties.

I think it's important to have those kind of conversations so that people know what they're facing and will cope. I think we all cope better when we know the sheer hard facts rather than whatever our minds imagining might be (Laura, N).

Subtheme 6d: The emotional impact of receiving support

Patients who described not having a supportive network were unable to have confidence in their care decisions. Nicola discussed her lack of support, and how she had to

organise her own care plans. The lack of clinician support resulted in her having to take ownership in managing her symptoms which caused her anxiety due to her feeling ill prepared to take the lead in her care.

I really struggled. Because I, I'm the one that has to do everything (Nicola, P).

Those participants who did have a supportive working partnerships with their healthcare professional experienced confidence in making collaborative decisions regarding their unstable symptom management. Thomas described this as challenging on occasion and having the support from a familiar source provided trust in the choices made.

Oh yeah... they do balance things up between all the different err medications I'm taking and got to work it out... Um, and they've got to work this out and that out. They're going to do a lot of juggling with the drugs. Um, oh no, they're very good (Thomas, P).

Additionally, collaborative working with heart failure nurses enabled patients to have confidence in their support network. Nurses felt that in forming partnerships with all care services, patients and care givers would have the self-assurance to decide which source of support they required. Jenny described the consequence of patients experiencing relationships with their healthcare professionals, and how this will impact them emotionally once they are confident in everyone's abilities to support them.

that will give them the confidence about going to palliative care and kind of, you know, seeing that it's not just all doom and gloom, it's actually so much more to it (Jenny, N).

Working partnerships between services provided heart failure nurses the confidence to initiate end-of-life conversations, and introduce palliative care to their patients. Regular meetings

with other care providers increased heart failure nurse independence to make these care decisions. Reducing the reliance on others to take on that role.

we come out of that meeting every week and all say, oh, we've learnt something again this week. Yeah, it just gives you more confidence (Jessica, N).

Collaborative working for all participants provides confidence to make care choices. The importance of having support networks to take part in end-of-life conversations provides them with confidence to have discussions and make care choices relating to this unpredictable illness.

4.4 Chapter summary

This chapter has provided evidence of patients, care givers and community heart failure nurses' experiences and preferences of taking part in end-of-life conversations and palliative care provision (during phase 1 of the study). These themes were then presented to community heart failure nurses (during phase 2) to gain their experiences and obtain an insight into how the findings can be implemented into clinical practice (phase 3 of the study). The next chapter will discuss these findings in more detail in relation to the wider literature.

Chapter 5. Discussion

5.1 Introduction

The aims of this research were to identify heart failure patients and care giver's preferences and experiences relating to end-of-life conversations and palliative care provision. This chapter will identify the key findings and relate them in the context of the wider literature that has been discussed in the introduction and literature review chapters of this thesis.

Figure 5 demonstrates the key findings from both phases of this study, and identified whether the themes originate from patients and care givers, healthcare professionals, or both. These themes will be discussed in more detail below.

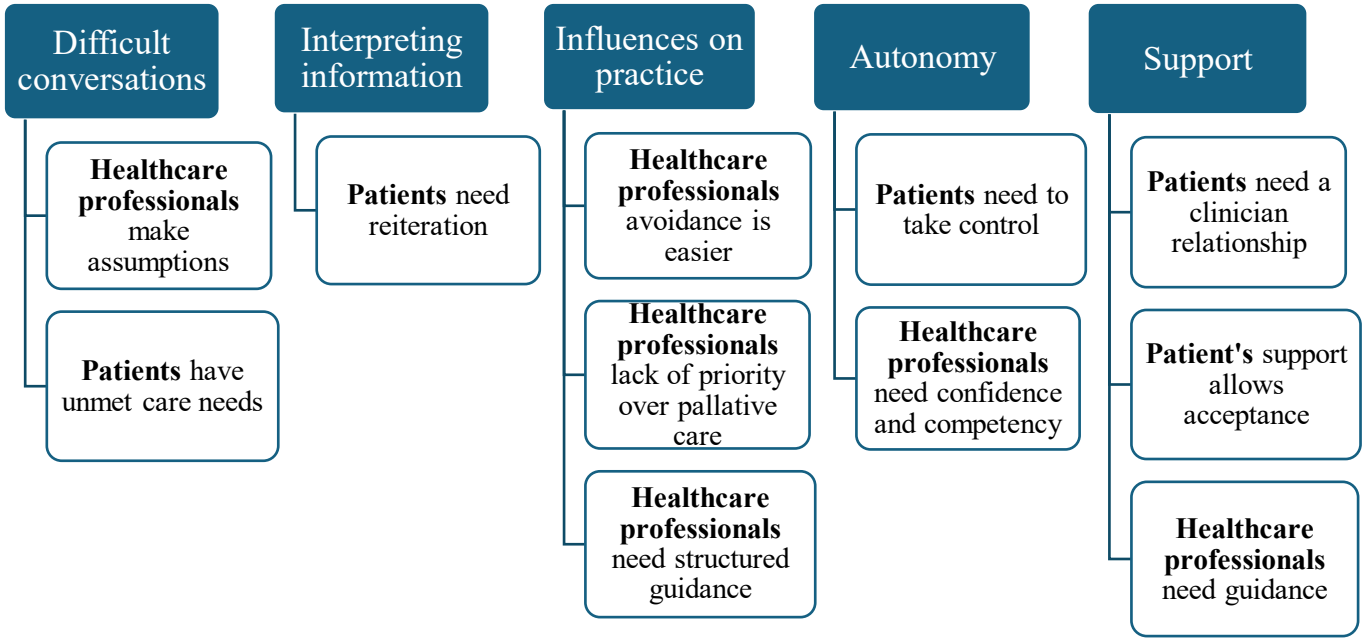

Figure 5. Discussion themes

5.2 Conversations are difficult

The objective of this research was to obtain experiences and preferences of taking part in end-of-life conversations from those patients, care givers and healthcare professionals who had already been involved in these types of discussions. This theme relates to the challenges associated with undertaking these conversations and the emotional impact of being involved or not having the opportunity to discuss this topic.

5.2.1 Healthcare professionals make assumptions

The need for end-of-life discussions were identified as necessity in the previously reviewed literature (in chapter 2). The premise of this theme continues to be relevant in the data of the current study. This research has found that assumptions are made by clinicians regarding patient's preferences. The notion that patients do not want to know their condition has a terminal aspect or want to address their end-of-life preferences due to the taboo nature associated with death inhibits conversations taking place. This finding was reflective of the work by Ziehm *et al.*, (2016). In their study healthcare professionals provided data on palliative care provision for heart failure patients, the evidence showed clinicians were unwilling to discuss the patient's demise. There were concerns by professionals that initiating these conversations would have a negative emotional impact on their patients, and they would lose hope in the final phases of life (Higginbotham, Jones and Johnson, 2021b). Clinicians viewed the approach of avoidance as 'emotionally protecting' their patients (Caldwell, Arthur and Demers, 2007).

This current study found that there was a reluctance by clinicians to discuss this sensitive topic as they believed patients would even question their professional integrity. Fear of not being able to articulate themselves during a sensitive conversation and apprehension that

discussions would cause patients to lose confidence in the clinician's persona resulted in healthcare professionals avoiding the topic rather than addressing it (Hanratty, 2002).

There is recognition in the current research by healthcare professionals that end-of-life conversations were a complex task to undertake. The balance of providing understandable information pertinent to the individual's illness versus protecting them from the distress of the topic resulted in evasion (Hanratty, 2002), and as such opportunities to discuss the end-of-life preferences were often missed (Glogowska *et al.*, 2016). The wider literature has reported that the views of healthcare professionals may not necessarily be similar to those of the general population (Nelson, A *et al.*, 2021).

5.2.2 Patients have unmet care needs

The presumptions made by clinicians that having end-of-life conversations would have a negative impact on patient's and care giver's stance are contradictory to the findings in this current research. The data showed patients and their advocates *did* want their healthcare professional to initiate discussions regarding its terminal element and disease progression. In fact it was the omission of these discussions that triggered the emotional turmoil of uncertainty, concern and isolation rather than the taking part in the conversation.

The findings of this research contradict the assumptions made by healthcare professionals in the wider literature, that initiating end-of-life discussions would have a detrimental effect on the emotional state of their patients. The evidence from patients and care givers describe the avoidance of these conversations are a cause of anxiety. Patients expressed that they require the initiation of end-of-life discussions to allow them to understand their illness and future care options, thus reducing the fear of the unknown. However, to do this they expressed a need to have accessible information.

5.3 Interpreting information

Occasionally patients and care givers were provided with limited information regarding the progression and changing symptoms relating to their condition. There were acknowledgements in the wider literature review that the lack of end-of-life conversations prevented patients from making care choices. This theme of interpreting information provides an insight into the process and influences on how patients and care givers receive knowledge regarding their disease and its progression. The findings of the current study are obtained from patients that have already undertaken end-of-life discussions and therefore been identified as being in the latter stages of their condition.

5.3.1 Patients need reiteration

Patients and care givers reported that there is a lack of understanding about heart failure as a disease. The work by Browne *et al.*, (2014) discussed this topic and identifying there are gaps in knowledge from heart failure patients relating to the incurable nature of their condition. They concluded that conversations failed to address the terminal aspect of this disease, as it is thought that heart failure is not viewed as fatal and openly discussed as such, unlike other malignant conditions (Selman *et al.*, 2007). Due to these misconceptions the current research found that on occasion where end-of-life care needs were mentioned there was no warning of the severity and the experience of conversations felt abrupt, with patients describing the emotional impact of feeling shocked.

Patients and care givers in this study recognised that there was a reluctance from healthcare professional to engage in end-of-life discussions, with few recalling having conversations or been provided with the opportunity to be part of them (Rogers *et al.*, 2000). A conclusion that had also been identified in the work by Young *et al.*, (2017). Their research aim was to

establish if heart failure patients had been given opportunity to express their end-of-life preferences. They reported a sample of 400 participants only 17% recalled having previously discussed their wishes. A finding which they discussed was either due to end-of-life conversations not being a routinely undertaken or patients were unable to recall the event while discussing their work. Stocker *et al.*, (2017) described the emotional distress of receiving a diagnosis of heart failure may influence a patient's capacity to retain further information due to the patient concentrating on the term 'failure' and assuming they were near death. Irrespective of the conclusions drawn from these sources of evidence when analysing the recall of information both authors made recommendations to increase the frequency of end-of-life discussions to aid retention of information. The regularity of conversations was a theme in this research, with patients and care givers describing the need for information to be repeated and having ongoing discussions to adapt information to their changes in symptoms and individual needs. The findings found conversations needed to be an ongoing '*drip feed'* of a gentle introduction to this sensitive topic, preventing patients and care givers from experiencing shock and distress due to feeling ill prepared. A theme reflected in the work of Caldwell, Arthur and Demers, (2007) who concluded that information giving for heart failure patients needed to be conducted in a gentle and regular manner to aid understanding.

The timing of initiating conversations was another element discussed in this study. Despite clinicians' belief that it was 'cruel' to provide patients with negative information near the time of receiving their diagnosis (Stocker *et al.*, 2017), patients in the current research expressed an opposing opinion. They wanted to be part of end-of-life discussions and be informed about the changes in their condition early on in the disease trajectory. This finding was replicated in the work by Strachan *et al.*, (2009) who found that patients favoured direct

communication from their physicians to inform them of their condition. This lack of candour by staff was elaborated on by Stocker *et al.*, (2017). They found patients who had an introductory conversation regarding their prognosis described the information given to them as limited, and their subsequent follow up questions were not directly addressed by healthcare professionals causing them anxiety and uncertainty (Molzahn, A *et al.*, 2020).

Additional influences that impacted a patient's ability to remember information were related to the quantity of information about their condition. In this study patients described actively sourcing information themselves via their healthcare support network to fulfil their requirements and reduce anxiety due to a lack of knowledge. Emotional descriptions of isolation and abandonment were given due to inadequate knowledge and poor access to end-of-life conversations. The current research has offered additional insight into the impact and resolution of negative experiences associated with poor information giving as there is limited data within the wider literature from this perspective to collaborate these findings.

The theme of interpreting information has provided an insight into the emotional impact patients and care givers experience due to the lack of adequate knowledge. The omission of sufficient, timely, regular information results in patients feeling shocked by the blunt approach when end-of-life conversations are addressed; anxiety due to the gaps in knowledge; a lack of understanding regarding their disease progression; and isolation as a consequence of unresolved questions regarding their illness. This evidence suggests end-of-life conversations are suboptimal however, healthcare professionals recognise that these discussions are influenced by alternative factors other than the clinician expected to initiate them.

5.4 Influences on end-of-life conversations and palliative care provision

Having examined the evidence of influences that clinicians have over end-of-life care provision this theme discusses how organisational structures in healthcare influence conversations and care provision. As described in the previous themes, end-of-life discussions are complex and multi-faceted this research has gained evidence into the influencing factors on this aspect of care.

5.4.1 Healthcare professionals avoidance is easier

Initiating sensitive discussions take time (Browne *et al.*, 2014) and this study has provided data to reiterate this. Heart failure nurses examined how structured clinical appointments can hinder conversations relating to end-of-life decisions and inhibit the building of collaborative relationships between patient and clinician, which have been identified as advantageous in conducting sensitive discussions (Remawi, Gadoud and Preston, 2023). The work by Ecarnot *et al.*, (2018) and Remawi, Gadoud and Preston, (2023) both analysed evidence from a clinician's perspectives highlighting the complexities around the practicalities of undertaking these conversations. Data suggested general practitioners take a passive role in patient's care and leave decision making to the specialist clinicians (Remawi, Gadoud and Preston, 2023), whereas the position of the cardiologist was more definite. Ecarnot *et al.*, (2018) concluded that cardiologists use insufficient clinical time as an excuse not to contemplate a patient's terminal care needs with their findings suggesting these physicians actually dislike discussing end-of-life issues and actively avoid taking part in them. These doctors describe their role as curative (Ziehm *et al.*, 2016) and felt their participation in a patient's care ended when end-of-life considerations were made (Stocker *et al.*, 2017).

5.4.2 Healthcare professionals lack of priority over palliative care

The current study found a cardiologist's role in heart failure patient's care was complex, with a small sample of heart failure nurses suggesting that a cardiology physician's reluctance to take ownership in initiation end-of-life discussions hindered other healthcare professional's confidence to take the lead of this task. As the identified 'specialist' in a patient's care, it is reported that if the cardiologist had not consider the patient to be in the latter stages of their disease then it prevented others doing so as well due to their lack of confidence to take on this role (Higginbotham, Jones and Johnson, 2021b). The work by Singh *et al.*, (2020) reiterated this finding by reporting that cardiologist were viewed as the 'gatekeeper' to palliative care. However, the consensus in this current research is any healthcare professional who knows the patient best is ideally placed to lead end-of-life discussions for this patient group. Although the wider literature reported that nurses were reluctant to take the lead on this role, the sample was of 'general cardiology nurses' and not from a heart failure specialist background (Ecarnot *et al.*, 2018). A majority of community nurses in this study viewed themselves as palliative heart failure nurses, and as such had the confidence to take control of providing this care.

5.4.3 Healthcare professionals need structured guidance

The complexities of providing this care continued as a theme when discussing the lack of national guidance and local variation in services available to these patients. This study found in the absence of specific advice on how and when end-of-life conservations should be conducted there was a tendency to leave the discussions until the patient was actively dying, by which time the patient was unclear of the services available to them or unable to make care decisions themselves due to symptom deterioration (Strachan *et al.*, 2009). This uncertainty was found to be exacerbated by the misconception that palliative care

cannot be introduced alongside aggressive medical therapies. By introducing it in conjunction with prognostic medicines heart failure nurses found it to be a natural part of patient care (Barrett and Connaire, 2016). The negative impact of delaying access to palliative care services have been reported in the work by Singh *et al.*, (2020) who found that in deferring a referral resulted in suboptimal care, whereas early contact with alternative services allowed time for planning and relationship formation.

The discussions on variable specialist palliative care provision was highlighted in the current study, as a lack of accessible services were felt to not only impact patients, they also inhibited the clinician's ability to provide optimal care. An unfamiliarity of local specialist teams and uncoordinated facilities result in patients unable to recognise the expertise of their healthcare professional (Hanratty *et al.*, 2006), whilst clinicians felt unsupported and uncertain in their decision making abilities due to the lack of collaborative working between services (Higginbotham, Jones and Johnson, 2021b).

The impact due to a lack of organised multi-disciplinary care for heart failure patients was felt to be exacerbated due to the unique disease trajectory of heart failure (Singh *et al.*, 2020). These individual experiences were discussed in the wider literature, it was recognised that care had to be adapted to the patient's own needs due to heart failure not having a linear deterioration that is commonly associated with other terminal conditions (O'Leary *et al.*, 2009). Not only was it believed this influenced the service need of each patient, it was also viewed as a barrier to initiate end-of-life conversations and palliative care referrals as clinician's struggled to identify when was the right time to instigate the discussion (Glogowska *et al.*, 2016). The consensus from the community nurses within this current study are there is never a right time to introduce end-of-life preferences however, early

initiation prepared the patient for changes in their condition. A finding that was reiterated by Siouta *et al.*, (2018) when they sought evidence from clinicians to improve palliative care for heart failure patients.

The theme of influences has highlighted the complexities of initiating end-of-life conversations and providing palliative care. The findings of this research have demonstrated a lack of national guidance; inadequate organisational structures such as restricted clinician-patient contact in the form of clinic appointments; poorly defined clinical roles result in an absence of priority for this aspect of care and as such result in avoidance of undertaking the conversations. This lack of importance is also reflected in end-of-life care commissioning and as a consequence there is variability in service provision. These influences have a negative impact on delivery of end-of-life care and as a result is not associated with any precedence. The delivery of this care can have a positive impact on patients and care givers, if undertaken.

5.5 Autonomy

The theme of autonomy was described by patients, care givers and healthcare professionals, enablers that allow participants to make decisions on end-of-life care choices have been demonstrated to impact positively on everyone involved when conversations promote an increase in knowledge.

5.5.1 Patients need to take control

The current study found that patients and care givers wanted to be informed regarding the progression of the disease. This enabled them to cope with the unpredictability of the illness and have control over their care decisions, to undertake this they described a need for

honest, and accessible information with their clinicians. The work by Remawi, Gadoud and Preston, (2023) reiterated these findings by reporting patients preferred regular updates on their disease progression in a format that was understandable as this offered them reassurance. It is recognised that in providing clear and concise knowledge maximises a patient's control over their decision making (Caldwell, Arthur and Demers, 2007). This research reported a lack of conversations between patients and their healthcare professional patients resulted in them actively seeking information themselves, for those patients who were fully informed of their unpredictable symptoms and changes in condition were able to rationalised their diagnosis. Patients also described being prepared for potential deterioration made the end-of-life conversations less shocking, and distressing. They had the ability to justify their experiences which provided patients with confidence and competence to manage their illness. Due to the limited evidence within the wider literature, these findings provide an additional insight into the management and support for this patient group, which endorse the work by Remawi, Gadoud and Preston, (2023) who highlighted that those patients who had sought information allowed them to become experts of their own condition.

5.5.2 Healthcare professionals need confidence and competency

The need for a network of support was relevant to healthcare professionals in being autonomous in delivering end-of-life care. In the current study they described the positive impact of having regular contact with other clinicians, which provided them with educational opportunities and time to discuss complex patient care. It is recognised that collaborative working with colleagues and specialist palliative care services was imperative in making the best care decisions for their patients (Ziehm *et al.*, 2016). The work by Ecarnot *et al.*, (2018) also provided insight into nurse's practice, discussions around patient care with their peers gained affirmation regarding care decisions. The community heart failure nurses within the

current research reflected on previous experiences and shared learning with colleagues ensured all clinicians were competent in discussing this sensitive topic. Those nurses who felt confident to make end-of-life care decisions described being able to use their intuition when making clinical choices for their patients, this intuitive knowing was a finding from the work by Higginbotham, Jones and Johnson, (2021) who demonstrated healthcare professionals who were experienced in offering this care used their 'gut feeling' to guide them in addressing a patient's care needs.

The theme of autonomy has discussed evidence from a patient perspective. To enable them to be autonomous in their care decisions they expressed a need for regular access to information regarding their unpredictable disease. The provision of this had a positive impact on them emotionally and resulted in feelings of confidence to make care choices. Autonomy relating to healthcare professionals involves having access to collaborative working relationships when making challenging care decisions for their patients, by increasing their confidence and competency through support and education enabled them to pro-actively introduce this sensitive topic to patients. The provision of knowledge relating to end-of-life care choices adds to the positive experience however, support is identified as an additional requirement in ensuring everyone is fully informed.

5.6 Support delivery

The theme of support in the current study provided evidence that collaborative working for all participants has a positive emotional impact. By working collaboratively with healthcare professionals impacts the ease of having these sensitive conversations.

5.6.1 Patients need a clinician relationship

This research demonstrated that patients had variable access to their clinicians. Those who had an available community heart failure nurse service described experiences of having a close working partnership and accessible sources of information which allowed the patient to have confidence in managing their condition. They had little concerns for their loved ones if, and when they should become increasingly ill as they felt confident they would be adequately supported. The positive experiences of patients with specialist heart failure support was reiterated in the work by O'Leary *et al.*, (2009). They reported highly valuing the care from these clinicians, and expressed the importance of being able to access well known key nurses at times of apprehension. The current research demonstrated that there was a need for consistent healthcare professional support. This provided a clinician-patient relationship that allowed collaborative working to control an unpredictable disease trajectory. The knowledge of who and when a patient or care giver could access this support allowed them to manage their day-to-day existence (Remawi, Gadoud and Preston, 2023), and a reliable, familiar healthcare team provided opportunities for information to be given alongside treatment options. In a changing condition, as treatment options became more scarce patients were able to understand their deterioration (Caldwell, Arthur and Demers, 2007).

5.6.2 Patient's support allows acceptance

Patients who had built a strong partnership with healthcare professionals were able to accept that sensitive discussions could take place due to the comfort of the patient-clinician relationship (Glogowska *et al.*, 2016). There is limited evidence in the wider literature to reiterate the impact for those patients who do not have that professional specialist support. The patients who did not have access to this commissioned service reported in the recent

study a sense of anxiety and concern relating to the deterioration of their condition, apprehension of who would assist family carers and what would happen when symptoms became more complex. These findings add to the current body of evidence on this topic which is from the perspective of patient's support experiences.

5.6.3 Healthcare professionals need guidance

The current study described available support for community heart failure nurses as a positive experience. Those who had access to multi-disciplinary meetings to discuss the complex care needs of their patients felt this to be beneficial, not only to the patients who would have a robust plan of care, to themselves as clinicians. These opportunities allowed the nurses to be educated by palliative care experts, whilst gaining a level of knowledge and competency. The recommendation that care planning should include all disciplines was echoed in the work by Singh *et al.*, (2020). They reiterated that an adequate care team for this multifaceted disease should include professionals from health and social care disciplines.

The evidence provided by this research and the wider literature has described the positive impact support has for patients, care givers and healthcare professionals. The additional insight gained from a patient perspective who does not have access to community heart failure nurse support has provided evidence into the negative impact this has on the individuals and their care givers. Adequate support impacts on patients, care givers and clinician's confidence to address care needs and provide the competence to make care decisions. This has highlighted the need for everyone involved in heart failure end-of-life care to build collaborative working relationships to share knowledge and be educated in disease progression whilst being supported.

5.7 Chapter summary

This chapter has presented the findings of this current research in relation to the wider literature. It has described the emotional impact poor healthcare can have on patients and care givers, and the variation in practice due to the lack of importance placed on end-of-life conversations and palliative care.

The perceived negativity associated with this aspect of care and the assumptions made by clinicians influences their approach, resulting in the undesirable emotional impact that they seek to avoid when addressing it. The evidence demonstrates a need for repeated, gentle sharing of facts to allow patients and care givers to absorb the information they need.

It is documented that end-of-life conversations are a complex task and there are multiple influences when undertaking them. The findings from community heart failure nurses have offered an insight into the changes needed to improve clinical practice. When discussions occur and patient's information needs are met they describe being fully informed, confident, competent and have identified a need for all of those involved to have a healthcare support network.

The data from this current research has reported findings that are lacking in the wider literature. Evidence from those who have experienced end-of-life conversations have provided an additional insight into the emotional impact of patients and care givers who receive suboptimal care. The researcher will address these preferences in the following chapter, and make recommendations to improve future care.

Chapter 6. Recommendations

6.1 Introduction

This chapter will make recommendations for future practice based on the themes discussed in the previous chapter. The recommendations will be made in relation to changes in practice, alterations in policy and the educational needs of those involved in heart failure end-of-life conversations. Once these proposals have been made the latter part of this chapter will examine; the role of the researcher who has a clinician background, changes in the researcher's knowledge on this topic, the strengths and limitations of the current study, the recommendations for future research and dissemination of findings.

6.2 Changes to current practice

The current research and the wider literature has demonstrated that end-of-life conversations are described as complex and as a result rarely happen (Caldwell, Arthur and Demers, 2007), whilst there have been several identified factors as to why the discussions are not undertaken; death being viewed as a taboo topic therefore avoidance is viewed as protecting the patient's emotions, difficulty in identifying an appropriate time to initiate these conversations, or confusion over clinician's role in patient care, there is a strong emphasis on healthcare professionals assuming patients preferences (Ecarnot *et al.*, 2018). This study has provided an insight from the perspective of heart failure patients and their care giver's needs which contradict these misconceptions, indicating there needs to be a change in practice to prioritise this task.

The research advocates that those diagnosed with this condition require a support network to meet their individual requirements. The findings demonstrate that appropriate support for patients and care givers needs to be accessible, and consistent in allowing the important

clinician-patient relationship to be developed. The specialist healthcare professionals who have been identified as ideally placed to fill this void are community heart failure nurses (Glogowska *et al.*, 2016). This profession is thought to be well placed due to their organisational structures of working; provision of home visits allowing unstructured time spent with their patients, as well as offering multiple opportunities to give comprehensive advice and address questions patients or care givers may have (Boyd *et al.*, 2004). The frequency of contacts is thought to cultivate a collaboration of trust and bond between clinician and patients, both of which have been highlighted as necessary to provide ongoing conversations and an environment where sensitive discussions can take place.

It is recommended by this research and the wider literature that end-of-life conversations start early on in the patient's disease trajectory (World Health Organization, 2023). This allows patients to be aware of the changes in symptoms and progression of their illness which may indicate they are entering the latter stages of their disease. Community heart failure nurses would be ideally place to offer that consistent and long term care needed to undertake this aspect of care (Hanratty, 2002).

For those patients where a community heart failure service has not been commissioned alternative arrangements must be put into place in the form of a clinician who has a similar work schedule; facilities to review patients without the constraints of timed appointments, abilities to review patients at their home at a time of symptom deterioration, healthcare professionals who are able to form a collaborative working relationship, and have the expertise to manage this unpredictable disease. The expectation would be the patient's general practitioner, who is generally viewed as the 'overseer' of patient's care (Remawi, Gadoud and Preston, 2023).

The recognition of healthcare professional support is not just recommended for patients and their care givers, this extends to the community heart failure nurses themselves. In providing a multifaceted approach all the clinicians involved have the same perspective of formulating personalised care specifically tailored to the patient's needs and gain an awareness of the healthcare services available to ensure collaborative multi-disciplinary care. Although this source of support was identified within the current research as a prerequisite in providing heart failure nurses with confidence and competency to initiate this aspect of care, it was apparent that not all heart failure services were privy to this arrangement. A majority of community nurses within the current research described a variation in support networks available to them, highlighting the lack of collaborative partnerships between healthcare services. This unified approach was viewed as preferable within the wider literature (Ecarnot *et al.*, 2018), with research reiterating the benefits clinician support has to offer (Ziehm *et al.*, 2016a). The researcher's recommendations are for community heart failure nurses to coordinate heart failure palliative care, with the support of multi-disciplined clinicians. This will not only ensure patient care is individualised with an understanding of available services, it will provide all clinicians the opportunity to learn and gain confidence, and competence in their palliative care skills.

6.3 Changes to current policy

The national policies and guidance on providing end-of-life conversations and palliative care to heart failure patients is currently tokenistic with no priority of practice attached to it (NHS England, 2022a). Alterations need to be made to increase the priority of this care. Current end-of-life communication within the UK is under scrutiny with the second reading of the assisted dying bill being pushed through Parliament in late 2024. The summary by Leadbeater, (2024) described the proposed bill as allowing adults with a terminal illness to

request assistance in ending their life. This summary offers clinicians guidance in undertaking end-of-life discussions related to assisted dying, highlighting the lack of such advice for other aspects of terminal illness namely heart failure conversations and care. Heart failure being a terminal illness is pertinent to these potential changes in end-of-life policy and therefore demonstrates the importance of this research which has made recommendations to actively improve national guidance for this patient group.

The evidence from this study has recommended that national guidance will reduce the variations in practice. Standardised recommendations should provide direction on early end-of-life conversations alongside prognostic medical therapies, the need for leadership on care provision from identified clinicians who can accommodate time within their workload to provide ongoing discussions and definitive guidance on collaborative multi-disciplinary support for patients, care givers and healthcare professionals. The lack of emphasis on this care for heart failure patients has a negative impact on the services commissioned for patient care and as such results in suboptimal services are currently available for these sensitive conversations to take place (Beattie, Higginson and McDonagh, 2020b).

6.4 Changes to education

The lack of priority associated with end-of-life care has been demonstrated in this research and the wider literature. Although there is recognition in the wider literature that advanced communication skill training is thought to enhance a clinician's abilities to initiate end-of-life conversations (Barrett and Connaire, 2016) the findings from the current literature dispute this. Evidence from this study demonstrate the clinicians who have multi-disciplinary support have access an educational resource in the form of their colleagues, they also gain confidence in providing end-of-life conversations through collaborative working with their

peers. Nurses who had experienced the multi-disciplinary team working described receiving education and confidence in their decision making abilities especially due to the uncertainty associated with the heart failure disease trajectory. The community nurses in this research who did not have access to this support described hesitation in instigating end-of-life discussions. To address these inconsistencies in care provision the use of multi-disciplinary meetings would allow healthcare professionals from all levels to meet and discuss shared patient care (Glogowska *et al.*, 2016), something that community heart failure nurses in the current literature identified as a source of education due to the breadth of specialties taking part in their meetings.

Table 4 below summaries the recommendations from this research. It address the action needed to improve end-of-life conversations and palliative care, whilst acknowledging the impact on care and the individuals involved in this aspect of care.

Recommendation	Action needed	Impact on care	Impact on individuals
All patients to have a community heart failure nurse service, or similar health provider advocate.	Ensure commissioned services provide this support.	• Co-ordinated care. • Increased awareness of service available. • Long term consistent care provided. • Someone to 'oversee' patient's care.	• Consistent support network. • Confidence in care provided. • Facility to build a patient-clinician relationship. • Informed practice. • Collaborative partnership working.
Improvement to current policies and national guidance.	National organisations to provide clear and concise guidance of care commissioning.	• Increase prioritisation of end-of-life discussions. • Reduction in variations of practice. • Reduction in avoidance of addressing care needs.	• Confidence to provide end-of-life care. • Competency to initiate sensitive conversations. • improve collaboration of services.
Improve the priority of educating healthcare professionals	Education of end-of-life care in educational institutions, and provision of multi-disciplinary learning.	• Provide a unified approach to address care priorities. • Address gaps in knowledge and improve care.	• Increase confidence of all involved due to a collaborative approach. • Confidence to address sensitive topics. • Clear understanding of care needs.

Table 4. Summary of recommendations

The identified recommendations needed to improve end-of-life discussions demonstrate the changes required are not straight forward. Structured policy changes to define who is responsible for leading this care, co-ordination of service and healthcare support for all those involved have been identified as a requirement in addressing end-of-life preferences for heart failure patients. These alterations to clinical practice would provide the confidence, competence and collaboration to ensure this aspect of care is prioritised.

6.5 Changes in knowledge of the researcher

The researcher came to this research with experiences of end-of-life conversations and palliative care provision from the perspective of a care provider. They acknowledged the need for discussions to occur and the reluctance associated with acknowledging a patient's deterioration from their fellow clinicians. They knew that there was an undisputed need for this care to improve for their patients.

In undertaking this research they now appreciate the importance of healthcare professional support for patients, care givers and clinicians, whilst it seem obvious to them as a nurse their role was to support, inform and education the patient in their changing needs. It was not so apparent the impact healthcare support had on their colleagues. It was a task carried out in clinical practice in an informal way which may have accounted for the lack of emphasis associated with it. This research has highlighted the importance of collaborative working in providing opportunities for education and improved competency, which results in greater confidence. It is these emotion promote action and conversation and should not be underestimated.

6.6 The clinician as a researcher

This section will examine influences the researcher has brought to this research due to their clinical background and previous experiences of taking part in end-of-life conversations and palliative care provision.

6.6.1 The dual role of the researcher

The researcher has considered the impact of their clinical background, and the potential bias they bring to the study. In considering their individual roles of clinician and researcher descriptions will provide transparency of their overall impact on this research.

6.6.2 Researcher versus nurse

The quality of qualitative research is often judged on the researcher's ability to provide transparency in relation to the systematic analysis used (Smith and Noble, 2014). The experiences, beliefs, and preconceptions of the researcher are thought to result in research bias (Noble and Smith, 2015). However, by addressing these in advance helps to improve the transparency and reduce the risk of bias (Smith and Noble, 2014).

The researcher will address their clinical background and in doing so, discuss their experiences of having the dual roles of being a nurse and researcher, and how they felt this impacted on the research process.

6.6.3 Background

The researcher has been a registered nurse for over 30 years, and spent the last 12 years working as a community heart failure nurse. Their responsibilities included identifying the change in patient's symptoms and treating them accordingly. This included recognising the need for end-of-life conversations and providing general palliative care. Yet their experiences of fellow clinician's reluctance to acknowledge patient's deterioration and avoidance of having end-of-life conversations raised questions regarding the quality of care heart failure patients were receiving. It was these experiences that have been the motivation in undertaking this research.

Whilst the researcher is confident in having sensitive discussions with heart failure patients and their care givers, there was an awareness on how their opinions could influence the research and the reliability of the study's findings. The use of reflexivity was felt to be an important process in demonstrating credibility within the research (Arber, 2006). The researcher considered how their dual role of being a nurse may impact their ability to also be a researcher.

6.6.4 Principles of the nurse

The definition of nursing is to ultimately provide collaborative and autonomous care for everyone in all environments. In providing health promotion, prevention of illness, and provision of care to those who are ill, have a disability and are dying, nurses are to act as advocates for their patients (World Health Organization, 2020). They are commonly viewed as 'caring' and 'kind' individuals who are there to listen, respond and be supportive to their patients. The philosophy of this profession is reflected within the professional guidance, which is to provide high standards of care (Nursing and Midwifery council, 2015). In providing specialist and complex care, their ethical priorities are to ensure the safety of patients by managing risk to avoid harm (Royal College of Nursing, 2024).

6.6.5 Principles of the researcher

The researcher's role is to gather, analyse, and report data to provide evidence and understanding of the phenomena being studied (Jack, 2008). Researchers have a responsibility to ensure that research undertaken, is conducted within ethical guidelines (Remenyi, Swan, and Van Den Assesm, 2011), with the main consideration being that no one taking part in the research comes to any harm from the activities associated with the study (Remenyi, Swan, and Van Den Assesm, 2011, Liaw and Tam, 2015). It is recognised that the

welfare of any patient taking part in a research study should take priority over the advancement of science (Greaney *et al.*, 2012). Adhering to ethical considerations provide autonomy, non-maleficence, beneficence, and justice towards participants (Beauchamp and Childress, 2019).

6.6.6 Dual role of nurse and researcher

It is argued that individuals cannot be a researcher and clinician simultaneously, despite there being overlap when practicing each profession (Lanza and Satz, 1995). Researchers view the people taking part as a participant and provider of information, whereas nurses will view them as patients (Wilkes, 2001). However, McIntosh, (2023) refute this opinion by describing that if professionals with dual roles observe the ethical principles of clinician and researcher the two roles will merge together. This is felt to not be a simple process, and execution of it can produce conflict of values to nurses causing moral anxieties (Clarke and Clarke, 1991).

6.6.7 Identification of the nurse role

The researcher has considered the forementioned concerns whilst adhering to the ethical principles of both being a nurse and researcher. An example of this was the relevance of the researcher's nursing role, and the implications this divulgence would have on the participant and researcher relationship. Jack, (2008) described the negative impact the awareness may have on participant's behaviour during the interview. Participants may consciously withhold information relating to experiences, due to a recognition of nurses' professional responsibilities. Alternatively, they may use the interview as an opportunity to discuss clinical concerns.

In adhering to ethical guidance of transparency during the research process, the researcher disclosed relevant information relating to their professional background. It was felt that due to the sensitivity of the topic being discussed participants should be informed of the previous nursing role, however guidance was provided to those taking part regarding the active position the researcher would be taking during the research (Dempsey *et al.*, 2016). Whilst the nurse would not be offering any clinical advice, each participant was offered a follow up contact post interview to discuss any concern the conversation may have triggered. The purpose of this was to establish sources of support from the participant's own network rather than counselling from the researcher (Holloway and Wheeler, 1995).

6.6.8 The use of reflexivity

Reflexivity has been undertaken throughout the research process. The practice of reflexivity has enabled the researcher to consider how their position will influence the research progression, the dynamics between patients and co-producers, and the needs of the participants (Warwick-Booth, Bagnall and Coan, 2021).

An example of dual role conflict was during the recruitment stage. A participant had expressed an interest in taking part in the study. However, due to their age and the clinical history available to the researcher there was concern alternative treatments *potentially* were available to them, resulting in the patient's condition not requiring palliative care or them having had an end-of-life conversation. As a nurse there was an understanding of treatment options, as a researcher there was an awareness of sample bias if the participant was excluded from taking part. In addressing the dual roles of both nurse and researcher considerations can be made regarding their positionality. Reflexivity is thought to bring the two professions closer together (English, Gott and Robinson, 2022), whilst aiming to conduct an unbiased

research (Ritchie *et al.*, 2014). In an attempt to accomplish objective research, an informal conversation with the potential participants reiterated their experiences ensuring they did fulfil the inclusion criteria and therefore recruited to take part in the study.

6.7 Dual role – ethical considerations - the researcher's thoughts

This subsection has been written in the first person to enable the reader to not only sense the personal challenges associated with the dual roles, but also to allow the reader to differentiate between the nurse and researcher role when describing the separate experiences of the author.

6.7.1 Nurse versus researcher

My nursing career has now spanned several decades, with my most recent position providing specialist care to heart failure patients and their care giver. As a nurse, I felt comfortable in my decision making abilities and continually strived to deliver safe care under the guidance of the nurse's governing body the Nursing and Midwifery Council (NMC) (Nursing and Midwifery council, 2018a). My priorities have and always will be the welfare of my patients, even at the more challenging times of care planning, when there were no definitive treatment options available. It was during this time as a specialist nurse, that I explored the world of research by completing a Master's degree. This experience, and the motivation to improve end of life care for a patient group urged me to immerse myself further and embark on a full time research project to enhance end of life and palliative care.

This progression from specialist nurse to researcher has been challenging, more so than I had anticipated. The potential influences of how my epistemological views, clinical experiences and identity impact qualitative data collection, are well documented within the wider

literature (Hay-Smith *et al.*, 2016). Although I was clear in the expectations demanded of each role, I experienced concerns regarding how I would maintain a balance between providing safe interactions with patients in keeping with my nursing ethos, whilst fulfilling the commitments of my academic obligations, in adhering to ethical expectations of causing no harm to participants during the research process.

Reflecting on the nursing and researcher role, I recognised there were particular areas when collecting data that have highlighted the challenges associated with my own positionality.

The areas I had identified were:

- The underpinning ethos of both clinician and researcher.
- The formation of relationships between clinician / researcher and participant.
- The impact of beneficence and nonmaleficence on data collection.
- The primary purpose of a nurse or researcher.

By comparing the experiences of undertaking research, with my clinical background I gained an insight into the requirements and expectations of each role, and establish whether being both a nurse and researcher would complement or contradict each other. This provided me with an understanding of how to negotiate each role ensuring that patient safety *really* is at the centre of each interaction.

6.7.2 The ethos of Nursing versus Researcher

When an individual takes up a subject position there is a certain discourse which is associated with that identity (Fahy and Smith, 1999). I agree with Leslie and McAllister, (2002) who associate a nursing role as a person who is ‘caring’ and ‘kind’, who listens,

responds and is supportive to their patients. This ethos of nursing is reflected in the guidance set out by the nurse's governing body. The Nursing and Midwifery council, (2018a), state that the nursing profession is to provide care, and to be an advocate for patients and carers following the basic principle of beneficence ('to do good') (Valizadeh *et al.*, 2022). However, this protective nature and the practice of beneficence, was put into question when I became a researcher interacting with vulnerable patients. I felt a need to protect patients who had agreed to take part in my research even though they have a limited life expectancy, within the wider literature questions are raised of whether it is ethical to include such frail participants into research at all (Bloomer *et al.*, 2018). My study findings are reflective of the current narrative of involving patients requiring palliative care. Responses such as 'therapeutic', 'privilege' and a 'want' to take part have been expressed by participants, reiterating my view that there is a need for this type of research (Vlckova *et al.*, 2021), and contradicting the literature that expresses concern, that it would be more harmful than good (Kars *et al.*, 2016). As I navigated my way through the researcher role, beneficence appeared less significant. Ethical processes are intended to ensure that no one taking part in the research comes to any harm from the activities associated with the study (Liaw and Tam, 2015), adhering to the ideologies of non-maleficence (Ingham-Broomfield, 2017). This did however, provoke my want to protect participants. Having spent many years practicing beneficence as a nurse, to curtail this and concentrate on non-maleficence did not feel natural to me. The principle of beneficence from a researcher's perspective must incorporate the wellbeing of the participant (Greaney *et al.*, 2012), which is something that comes more naturally to me due to my expertise from years as a clinician. Conversely, non-maleficence is also commonly practiced within my nursing role (Nursing and Midwifery council, 2018a). The challenges associated with the complex nature of heart failure as a disease, and indeterminate treatment plans that may be ineffectual, result in potential adverse effects being

considered on an individual basis. This combined approach of using both beneficence and non-maleficence in nursing is transferable into my researcher role, with beneficence referring to the benefits of the research participant and non-maleficence referring to the possible risks to participants taking part (Ford and Reutter, 1990).

In transferring both principles throughout the research process, assurances are made that individuals will benefit from participating and (as I have already mentioned), experience a cathartic effect from sharing their experiences (Doody and Noonan, 2016). Patients experience the sense of trust that is associated with the cultural identity of a nurse, (Martin *et al.*, 2007). However, now identifying as a researcher I experienced concerns that participants would either not feel comfortable in discussing their experiences during the research interview, or in acknowledging my clinical background would confide personal events which were not relevant to the research topic, and may have a negative impact on their emotions. It is due to these concerns that I have considered the creation of the patient – researcher relationship.

6.7.3 The formation of relationships between clinician / researcher and participant

Historically, medical professionals are seen as 'experts' in their specialist fields and are viewed as the source of knowledge and influence when informing clinical decision making for patients (Kaba and Sooriakumaran, 2007). This is certainly an experience I have encountered previously when discussing treatment options with patients in the clinical setting. Providing the pros and cons of each potential care plan in accordance with the principles of beneficence and non-maleficence, a number of patients have expressed that I am the 'expert' and they will be 'guided by me' in their decisions. As a nurse there are opportunities of building relationships with patients and providing them with confidence to

work collaboratively in planning care (Leslie and McAllister, 2002). However, as a researcher I was aware of the limited contact between myself and participants, and the impact this can have on qualitative data collection (Jack, 2008). In being open with participants regarding my clinical background and expertise, broke down the non-clinical researcher – participant barriers. This became apparent during data collection where patients shared personal information that has not been pertinent to the research topic. These experiences concerned me due to their potential maleficent nature. However, using my clinical skills I negotiated my roles to ensure participants were in a positive mind when discussing these events in an attempt to make the discussion a positive experience. I was able to incorporate my clinical skills from my nursing role to provide a valuable awareness into the research process by practicing the principles of both beneficence and non-maleficence due to my clinical, and ethical awareness. In failing to disclose my clinical background may contradict the philosophy of nursing and adherence these principles (Martin *et al.*, 2007).

These situations have not always been effortless. Discussing the sensitive subject of end-of-life care, has on occasion resulted in participants becoming distressed. This caused me conflict in adhering to both beneficence and non-maleficence as a researcher. At what point should I have intervened and allow participants time to collect themselves without impacting on the quality of data collected? In discussing their experiences it was acknowledge that this was therapeutic for them, and should I interfere with this process? The work by Jack, (2008) recommends that there are certain circumstances when the nurse will have a legal and ethical responsibility to intervene and even halt the interview. My clinical expertise guided my decision making in these situations. I felt that if a participant felt comfortable to discuss personal stories that are emotive, this showed they trust my abilities to support them. Implementing the principles of both beneficence and non-maleficence as a researcher showed

that the welfare of individual participants were at the forefront of my research rather than the research itself and the data collected (Ashton, 2014).

6.7.4 The impact of beneficence and nonmaleficence on data collection

The techniques I used to obtain experiences was also influential on the quality of research data. As a nurse obtaining relevant clinical data it is imperative to ensure the correct diagnosis and treatment plan are prescribed (Bramhall, 2014, Nursing and Midwifery council, 2018) reducing the risk of harm. Pattern recognition is utilised when making an assessment of patient's symptoms, based on a few pieces of information (Manias, Aitken and Dunning, 2004). 'Focused' questions obtain the specific information, and are directed on previously generated hypotheses (Barratt, 2019). This approach, can be characterised as a form of hypothetico-deductive reasoning, which allows the use of clinical knowledge through pattern recognition to aid my diagnosis (Barratt, 2019). During the decision making process I consider each possible outcome and assigned a value, reflective on the desirability of each individual effect (Harbison, 1991). This method is relevant in the management of heart failure symptoms, where there are potentially several treatment avenues, all of which may have both beneficial or negative impact on the patient's health. In comparison my researcher role adopted the use of open-ended questions during the data collection, guiding the participant to describe experiences in their own words (Quick and Hall, 2015b), and enabled them to talk freely, with the intention that feel they are able to express themselves (Braun and Clarke, 2006b). The collection of qualitative data in the form of an interview attempted to understand the world from the subjects' point of view, to unfold the meaning of peoples' experiences, to uncover their lived world prior to scientific explanations (DeJonckheere and Vaughn, 2019). The purpose of this inductive approach was the allowance of findings to emerge from identified common, overriding themes without the limitations imposed by

hypothesis driven forms of enquiry (Thomas, 2006). The use of open-ended questions guided the participant to describe experiences in their own words (Quick and Hall, 2015b), leaving them open to discuss emotive and personal experiences. It is here that by practicing the principles of both beneficence and non-maleficence as a researcher ensured that the wellbeing of the participant was not being compromised. The purpose of research should always come second to the individuals participating. It may be necessary to accept and concede that there are going to be certain limitations to the research to achieve this (Beaver, Luker and Woods, 1999), to protect the welfare and safety of the patient.

6.7.5 The primary purpose of a nurse or researcher

The nursing profession is regarded as a caring occupation, with a focus on helping patients and their carers to adapt to their illness (Cheraghi *et al.*, 2023). This includes health promotion, and prevention of illness (World Health Organization, 2020) by providing evidence based care. I am expected by my governing body, the public and my employer to fulfil this legal requirement (Royal College of Nursing, 2018), and in doing so will maintain the principles of both beneficence and non-maleficence as set out within the Nursing and Midwifery council's guidance (Nursing and Midwifery council, 2018a). The question that arises from these expectations is when does the responsibility of a nurse end? I always have a duty to provide safe care to patients, and all service users (Nursing and Midwifery council, 2018b), and I believe this was inclusive of my interactions with patients and carers participating in my research. Considering my new role as a researcher, this is someone who generates new knowledge, that will support health organisations to enhanced care provision in the longer term (Fathalla and Fathalla, 2008). There is a necessity for evidence to inform care and this is recognised as essential in guaranteeing that we provide the most effective provision of care and interventions (Watmough *et al.*, 2010). Ensuring I adhered to ethical

guidance in my researcher role maintained the principle of non-maleficence. However, I felt that by providing evidence that will enrich care for individuals, the practice of beneficence applies indirectly to this role as well, especially in the long term care. Maintaining the expectations of both roles, I feel there is overlap in both being a researcher and nurse. Using the experiences and expertise I have gained ensured that the principles of both beneficence and non-maleficence are upheld.

The process of undertaking this research has been a challenging, and thought provoking experience for me. I was very aware throughout the whole process that it was my experiences in clinical practice that had motivated the topic of research, my opinions and my views that the practice of end-of-life conversations needed to improve. Patients who took part had been identified by their healthcare professional as requiring palliative care, and as such could be viewed as being on 'borrowed time', and yet they still wanted to help others by taking part. I had a responsibility to ensure the study was conducted in a manner worthy of the participants time. I felt I had a duty of care to these participants who were sharing their experiences. The use of participatory methods ensured the research perspective remained that of the patient, and reassured me that there was a need for this research.

The use of the framework thematic analysis methods even though were thorough and as I thought never ending, provided transparency and replicability in producing robust research for such an important topic. The ongoing reflective process throughout this research has enabled me to keep returning to the purpose of this research, not my opinion but those of the population it affects.

I found phase 2 of the study, when community heart failure nurses were involved more challenging than phase 1. Where I had patient participant involvement (PPI) to assist me in remaining focused and true to the aims of the study during the research process in phase 1, I then struggled to detach myself when gathering experiences of the community nurses in phase 2. It felt harder to not visualise myself in their role having been there myself previously. Through reflecting on the process and regular meetings with my supervisors to discuss my experiences. I was able to differentiate between my nursing role and that of a researcher.

This section has considered the influences of having a dual role when the researcher has been a clinician and gained first hand experiences of the phenomena being studied.

Throughout the research the researcher has considered their impact on the process due to their dual role of both nurse and researcher through the use of reflexivity. To ensure the research was as bias free as possible, co-production with a national heart failure charity enabled the research process to be from a patient perspective. The researcher has discussed the implications of both roles and how beneficence and non-maleficence intertwines between the two. All researchers bring experiences and beliefs to each study, which if considered and acknowledged in advance, enhances the transparency of the study and possible research bias (Smith and Noble, 2014).

Beneficence and non-maleficence flow between both roles of nursing and researcher, to ensure there is minimal influence on data collected. It is important to be honest with participants and ensure they are aware of my remit as a researcher. The provision of professional boundaries will provide participants with a safe environment to express their

experiences (Richards and Schwartz, 2002). The researcher's knowledge and clinical expertise will ensure that the benefit of taking part in the study will outweigh the potential risks associated with being involved (West, 2019).

The researcher has considered their influences on the current study, and will now consider the strengths and limitations of this research.

6.8 Strengths and limitations of the research

6.8.1 Strengths – the patient's voice

Involving patients in research, who have been identified as nearing the end of their life is reported to be challenging due to their vulnerability (Anderson and Hatton, 2000), and unstable symptoms (Casarett and Karlawish, 2000). It was previously assumed within the wider literature that this patient group do not want to participate due to their limited survival and the burden of taking part (Anderson and Hatton, 2000). However, with careful planning and flexibility it is felt to be unethical not to approach participants who are end-of-life (Vlckova *et al.*, 2021) and recent evidence reiterates the notion that this group should not be excluded (Bloomer *et al.*, 2018). Due to the continued negativity and perceived challenges associated with this type of research (Chatland *et al.*, 2023), there remains limited research involving heart failure patients who have been identified as being end-of-life. This study provides evidence to fill this gap in current research. It was undertaken by a researcher with clinical experiences of caring for this patient group which enabled them to adapt the research process and use their clinical skills to ensure the patient's changing physical and psychological needs were met. The vulnerability and limited life expectancy of these participants were a consideration for the researcher and as such the priority of this study was to ensure it represented the patient's voice. Therefore, a participatory research approach was

used to ensure the community assisted in shaping the design and make sure it was from the perspective of heart failure patients (Hotze, T., 2011).

6.8.2 The use of community based participatory research

There is a lack of research in the wider literature that used participatory methods for the minority group of heart failure patients and their care givers. The method of community based participatory research (CBPR) was utilised in this current study which also added to the limited literature involving vulnerable participants in use of co-produced research. It is recognised that CBPR is used to provide research representative of minority groups (Holkup *et al.*, 2009), to ensure it is relevant to the community being studied (Springer and Skolarus, 2019). Due to the minimal amount of evidence using this method, this research provided occasion for heart failure patients to collaborate and participate in research which will gained an insight into their end-of-life experiences, and ultimately provide recommendations to improve current care.

6.9 Limitations of the sample

6.9.1 Diversity of patients and care givers

Efforts were made by the researcher to obtain a national sample which was inclusive to all ethnic groups. It is noted that the sample for this research was mainly of white British descent. In view of identified minority groups, such as those from a south Asian background having a higher cardiovascular risk and therefore being increasingly likely to have heart failure, a sample that included this ethnic background would have been more representative of the general population (Banerjee, 2020). This limitation is thought to restrict experiences of accessing palliative care services and as such does not provide generalisable findings. The

inclusion of minority groups would have also addressed the already recognised inequalities for these patient receiving end-of-life care (Aker *et al.*, 2024).

6.9.2 Diversity of the community heart failure nurse sample

There are limitations associated with the recruitment of this study which was pertinent to the community heart failure nurses. They were nurses who were sourced from a national sample that responded to an email invite. Even though the researcher attempted to attract nurses from all community providers there was a possibility of omitting some services due to lack of online presence in promoting their care provision. The self-identified community nurses who participated may have represented those clinicians who had a particular interest in palliative care, or were confident in their abilities to initiate end-of-life conversations with their patients. A further limitation associated with the recruitment of the nurses was a lack of ethnic diversity. As the researcher has already mentioned the sample identified as white, British and all of the nurses were female. Due to the lack of diversity of this sample and the small participant numbers the findings cannot be viewed as generalisable.

6.9.3 Heart failure care givers sample

The current research has included 2 participants in this study who were care givers, and had experienced end-of-life conversations. It is already acknowledge that there is a lack of evidence from participants who have already taken part in these discussions. The deficiency in representation of this participant group has not provided rich evidence and insight for this group.

This study has provided evidence from heart failure patients, care givers and clinicians who have taken part in end-of-life conversations which is limited in the wider literature. The use

of participatory methods has ensured it is relevant to the population being studied and from their perspectives. The limited sample of care givers, and diversity of ethnic minority groups means the results are not replicable to the general population however, do add to the current resource of evidence. The recommendations for further research will be documented in the forthcoming section.

6.10 Recommendations for future research

Currently there is limited literature on the preferences of heart failure patients and care givers when taking part in end-of-life conversations and palliative care provision. This research provides an insight into those preferences specifically relating to this disease, where previous studies have made comparisons or assumptions based on other terminal illnesses. Having addressed the limitations of this work, the researcher has identified a need for further research to be done on this topic.

There is a requirement for further research into the provision of palliative care by community heart failure nurses. Work is needed to identify the availability of these nurses nationally, and the commissioning practice for those patients that do not have access to a community heart failure service. This will establish how this speciality can easily incorporate this aspect of care into their working practice or the organisation of practice for those that do not have a specialist support.

Further research is also required regarding the practice of undertaking end-of-life conversations. In gathering data, the frequency of these discussions within different clinical areas will offer an insight into current practice and provide evidence for best practice to ensure these discussion take place. If the assisted dying bill, which is currently being pushed

through parliament is successfully passed the importance of end-of-life conversations with heart failure patients will become even more relevant in the provision of clinical practice.

The current lack of participatory research methods used in heart failure palliative studies has demonstrated how co-produced research is largely sidelined when undertaking this type of research. There is evidence to suggest the benefits of a collaborative patient – researcher partnership from the inception throughout the research process into the dissemination of findings (Warwick-Booth, Bagnall and Coan, 2021). The benefits of using this method in the current research has allowed vulnerable participants, such as those with experiences of heart failure to work collaboratively with the researcher. This ensured the terminology used was non medicalised and understandable for potential participants, as well as making sure the interview questions were from a patient perspective and gaining an insight from those who have experienced the phenomena being studied (Schubotz, 2020). Working collaboratively throughout the research process provided equality between service users and care providers (Schubotz, 2020), and reassurance to the researcher that their own professional experiences weren't influencing the data collected. The recommendation for future research is that by engaging with patient and public involvement will not only add validity to findings (Vaughn and Jacquez, 2020), but will improve those exposed to health inequalities (Schubotz, 2020).

Finally there is a need for further research in end-of-life conversations experiences of ethnic minority groups, focusing on those from south Asian backgrounds where there is a higher level of prevalence of heart failure. This evidence would complement the current research in providing a sample that was more representative of the general population (Banerjee, 2020).

6.11 Dissemination of findings

The researcher has presented their findings to researchers, patient and public involvement members and academics in the form of online and in-person presentations associated with the Applied Research Collaboration, East of England. The importance of involving participants with terminal illness has been a regular source of interest. The researcher believes this should be prioritised in future research to ensure lived experiences and preferences are collated to formulate healthcare services.

The proposed sharing of these findings will be undertaken in the form of a highlight report. This will be shared with the participants and the co-production charity who have collaborated with the researcher throughout the research process.

The study will also be submitted to peer reviewed scientific journals for publication.

6.12 Conclusion

The aim of this research was to improve understanding regarding the experiences and preferences of end-of-life conversations and palliative care provision for heart failure patients and care givers.

The current study has approached this research in applying a co-production method to ensure the process and findings were from the perspective of the minority group involved. The ultimate findings from the evidence is heart failure with its unique deterioration of inconsistent episodes of deterioration and instability of symptoms are not similar to other incurable diseases. Even though it is acknowledged that end-of-life symptoms and care needs maybe similar to those of other terminal illnesses, such as cancer (Beattie, Higginson

and McDonagh, 2020a), the specific trajectory of heart failure is very different. This non-malignant illness requires its own guidance and end-of-life approach to be prioritised. The unpredictability of its disease trajectory means this cannot and should not be slotted into current guidance of end-of-life care. Acknowledgement of its distinctiveness and addressing the care needs will ensure patients and care givers receive the care that will meet their individualised requirements.

The evidence has also highlighted the negative emotional impact this lack of care provision has on patients, care givers and healthcare professionals demonstrating a need to improve current guidance and practice. Enhanced patient – clinician relationships, increased prioritisation through changes in current policy and guidance and the education of all involved in caring for heart failure patients through collaborative working will provide confidence, competency and collaboration that is needed to improve end-of-life conversations and palliative care provision.

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Appendices

PICo Framework	**Application of the framework**
P (Population)	• Heart failure patients • Heart failure care givers • Community heart failure nurses
I (phenomena of interest)	• Experiences of taking part in end-of-life conversations • Experiences of palliative care provision
Co (context)	• Association specific to heart failure

Appendix A. PICo framework

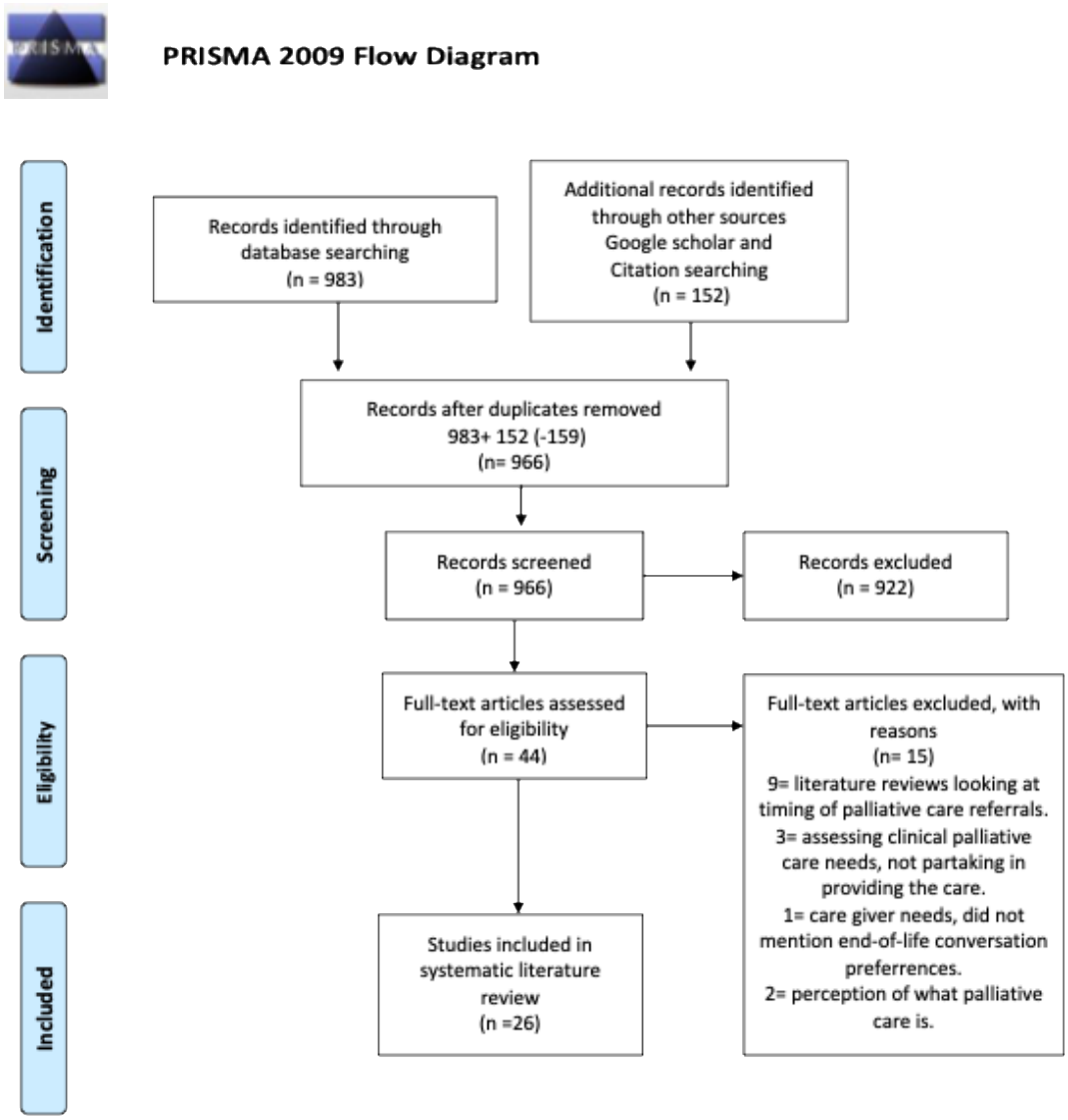
Search History/Alerts

Print Search History | Retrieve Searches | Retrieve Alerts | Save Searches / Alerts

Select / deselect all | Search with AND | Search with OR | Delete Searches | Refresh Search Results

Search ID#	Search Terms	Search Options	Actions
S6	S1 AND S2 AND S3 AND S4 AND S5	**Expanders** - Apply equivalent subjects **Search modes** - Proximity	View Results (893) | View Details | Edit
S5	(patients or clients or client or patient or individual or service user) OR carer* OR care giver* OR advocate*	**Limiters** - Publication Date: -20240731; English Language; Human; English Language; Human **Expanders** - Apply equivalent subjects **Search modes** - Proximity	View Results (9,152,683) | View Details | Edit
S4	discuss* OR convers* OR decision*	**Limiters** - Publication Date: -20240731; English Language; Human; English Language; Human **Expanders** - Apply equivalent subjects **Search modes** - Proximity	View Results (2,093,319) | View Details | Edit
S3	end of life care or palliative care or death or dying or terminally care or support* care	**Limiters** - Publication Date: -20240731; English Language; Human; English Language; Human **Expanders** - Apply equivalent subjects **Search modes** - Proximity	View Results (1,160,180) | View Details | Edit
S2	(congestive heart failure or chf or heart failure) OR chronic heart failure OR cardiac failure	**Limiters** - Publication Date: -20240731; English Language; Human; English Language; Human **Expanders** - Apply equivalent subjects **Search modes** - Proximity	View Results (243,249) | View Details | Edit
S1	experienc* OR view* OR perception* OR attitude* OR feel*	**Limiters** - Publication Date: -20240731; English Language; Human; English Language; Human **Expanders** - Apply equivalent subjects **Search modes** - Proximity	View Results (2,946,708) | View Details | Edit

Appendix B. The literature search results



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009) *Preferred Reporting Items for Systematic Reviews and Meta-Analyses*: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Appendix C. Prisma flow diagram

CASP Checklist:
For Qualitative Research

Reviewer Name:	AF
Paper Title:	Healthcare professionals' attitudes regarding palliative care for patients with chronic heart failure: an interview study
Author:	Ziehm, J. Farin, E. Siebel, K. Becker, G. Köberich, S.
Web Link:	https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-016-0149-9
Appraisal Date:	07/02/2023

During critical appraisal, never make assumptions about what the researchers have done. If it is not possible to tell, use the "Can't tell" response box. If you can't tell, at best it means the researchers have not been explicit or transparent, but at worst it could mean the researchers have not undertaken a particular task or process. Once you've finished the critical appraisal, if there are a large number of "Can't tell" responses, consider whether the findings of the study are trustworthy and interpret the results with caution.

Section A Are the results valid?	
1. Was there a clear statement of the aims of the research?	☒Yes ☐ No ☐ Can't Tell No previous studies for the German health care system that has this study aim. Aim: to assess HCPs attitudes regarding palliative care of CHF patients, to identify barriers and facilitators for these patients.
CONSIDER: • *what was the goal of the research?* • *why was it thought important?* • *its relevance*	
2. Is a qualitative methodology appropriate?	☒Yes ☐ No ☐ Can't Tell Collect experiences with and attitudes towards palliative care.
CONSIDER: • *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants* • *Is qualitative research the right methodology for addressing the research goal?*	
3. Was the research design appropriate to address the aims of the research?	☒Yes ☐ No ☐ Can't Tell Design discussed reasoning to capture a range of health care professionals who are involved in caring for this patient group.
CONSIDER: • *if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)*	
4. Was the recruitment strategy appropriate to the aims of the research?	☐Yes ☒ No ☐ Can't Tell A limitation of the study, recruited from a localised sample. Used a high proportion of healthcare professionals who had a robust elaborate palliative care infrastructure.
CONSIDER: • *If the researcher has explained how the participants were selected* • *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study* • *If there are any discussions around recruitment (e.g. why some people chose not to take part)*	
5. Was the data collected in a way that addressed the research issue?	☒Yes ☐ No ☐ Can't Tell Interviews face-to-face or via phone, interview guide consisted of questions about heart failure, care and palliative care for these patients. Interview was piloted to ensure comprehension. Interviews were audio recorded and transcribed. Saturation of data not mentioned.
CONSIDER: • *If the setting for the data collection was justified* • *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)* • *If the researcher has justified the methods chosen* • *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)*	

• *If methods were modified during the study. If so, has the researcher explained how and why* • *If the form of data is clear (e.g. tape recordings, video material, notes etc.)* • *If the researcher has discussed saturation of data*	
6. Has the relationship between researcher and participants been adequately considered?	☐ Yes ☒ No ☐ Can't Tell They acknowledge they recruited healthcare professionals they knew, but have not considered the potential bias on the data. Acknowledgement made on the small geographical area of recruitment.
CONSIDER: • *If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location* • *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*	
Section B: What are the results?	
7. Have ethical issues been taken into consideration?	☒ Yes ☐ No ☐ Can't Tell Limited ethical consideration made. Ethical approval was gain, and informed consent. No further details on how participants were supported pre and post interview. No mention of confidentiality.
CONSIDER: • *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained* • *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)* • *If approval has been sought from the ethics committee*	
8. Was the data analysis sufficiently rigorous?	☒ Yes ☐ No ☐ Can't Tell Analysis process discussed, covering each step of the stages. No mention of researcher bias.
CONSIDER: • *If there is an in-depth description of the analysis process* • *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data* • *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process* • *If sufficient data are presented to support the findings* • *To what extent contradictory data are taken into account* • *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*	
9. Is there a clear statement of findings?	☒ Yes ☐ No ☐ Can't Tell Findings are discussed and displayed clearly with adequate discussion on clear and unclear consensus of findings.

	Translation of findings from German to English occurred by one author for the write up. 3 authors were the analysis group
CONSIDER: • *If the findings are explicit* • *If there is adequate discussion of the evidence both for and against the researcher's arguments* • *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)* • *If the findings are discussed in relation to the original research question*	
Section C: Will the results help locally?	
10. How valuable is the research?	☒ Yes ☐ No ☐ Can't Tell Provides an insight into healthcare professional's views and practices when providing palliative care.
CONSIDER: • *If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature* • *If they identify new areas where research is necessary* • *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*	

APPRAISAL SUMMARY: *List key points from your critical appraisal that need to be considered when assessing the validity of the results and their usefulness in decision-making.*

Positive/Methodologically sound	Negative/Relatively poor methodology	Unknowns
• **Appropriate methodology for this data collection.** • **Provided clear insight into healthcare professional's experiences.** • **Provided some recommendations of how this care can be improved.** • **Comparable to the wider literature on this topic.**	• **First of this type of research in Germany – may not be relevant in the UK.** • **Was unable to provide a definitive definition of when palliative care should be started.** • **Participants recruited from a clinical area with a robust palliative care service.**	• **Consent process.** • **Support offered to participants.** • **Number of participants from the same clinical area = potential bias.** • **Participants were recruited via existing contacts of the authors – unknown what those relationships were.**

Appendix D. Critical appraised literature

CASP Critical Appraisal Skills Programme

Paper for appraisal and reference: End-of-life conversations with heart failure patients: a systematic literature review and narrative synthesis. Barclay, S. et al. (2011) *British Journal of general practice,* pages e49-e62.

Section A: Are the results of the review valid?

1. Did the review address a clearly focused question?

Yes	x
Can't Tell	
No	

HINT: An issue can be 'focused' In terms of
- the population studied
- the intervention given
- the outcome considered

Comments: End-of-life conversations needed to be developed specifically for heart failure patients. Conclusions: conversations rarely happen.

2. Did the authors look for the right type of papers?

Yes	x
Can't Tell	
No	

HINT: 'The best sort of studies' would
- address the review's question
- have an appropriate study design (usually RCTs for papers evaluating interventions)

Comments: To certain degree. There were papers included that were aimed to gaining insight into communication needs of HF, but not specifically related to end-of-life discussions.
A majority of papers were from the perspective of healthcare professionals rather than patients themselves.

Is it worth continuing?

3. Do you think all the important, relevant studies were included?

Yes	x
Can't Tell	
No	

HINT: Look for
- which bibliographic databases were used
- follow up from reference lists
- personal contact with experts
- unpublished as well as published studies
- non-English language studies

Comments: Papers were sorted into high and medium weight of information relating to the topic being reviewed.
Major medical search platforms were used to cover a vast search area. It was acknowledged there is a limit quantity of literature relating to this topic of interest.

Dissertations were not included, which may have limited the search of current unpublished research.

4. Did the review's authors do enough to assess quality of the included studies?

Yes	x
Can't Tell	
No	

HINT: The authors need to consider the rigour of the studies they have identified. Lack of rigour may affect the studies' results ("All that glisters is not gold" Merchant of Venice – Act II Scene 7)

Comments: Two reviews read the abstracts of the articles search, this may have impacted on the quantity of literature as some are not clearly defined to the research methods and aims. Any discrepancies between the 2 reviews were discussed. There is no clear definitions of how this was done, or if a framework was used.

5. If the results of the review have been combined, was it reasonable to do so?

Yes	x
Can't Tell	
No	

HINT: Consider whether

- results were similar from study to study
- results of all the included studies are clearly displayed
- results of different studies are similar
- reasons for any variations in results are discussed

Comments: The results were presented in a standardised format and clearly displayed. Results showed similar findings, the literature was mainly qualitative apart from one that looked at quantitative data analysis.

Section B: What are the results?

6. What are the overall results of the review?

HINT: Consider

- If you are clear about the review's 'bottom line' results
- what these are (numerically if appropriate)
- how were the results expressed (NNT, odds ratio etc.)

Comments: Results were presented in a clear format, with multiple papers referenced as evidence for the conclusions made. The themes drawn from the evidence was replicated from multiple sources.

7. How precise are the results?

HINT: Look at the confidence intervals, if given

Comments: In relation to heart failure patients, the findings were not necessarily specific to heart failure. It was acknowledged in the findings that conversations rarely happened, therefore evidence around experiences of these discussions were limited.

Section C: Will the results help locally?

8. Can the results be applied to the local population?

Yes	
Can't Tell	
No	x

HINT: Consider whether
- the patients covered by the review could be sufficiently different to your population to cause concern
- your local setting is likely to differ much from that of the review

Comments: Findings were mainly end-of-life papers not necessarily pertinent to heart failure, and more generalised end-of-life preferences / conversations.

9. Were all important outcomes considered?

Yes	x
Can't Tell	
No	

HINT: Consider whether
- there is other information you would like to have seen

Comments: Both patient and healthcare professionals' experiences were considered in the findings. Barriers and enablers to end-of-life conversations were considered and the consequences of this lack of care was drawn from the reviewed evidence.

10. Are the benefits worth the harms and costs?

There was no mention of risks relating to the individual papers, no associated risks to this research as no human participants. However, some general findings have been concluded relevant to HF patients.

Yes	
Can't Tell	x
No	

HINT: Consider
- even if this is not addressed by the review, what do **you** think?

Comments:
This paper does not offer any new knowledge to the topic being researched. Any relevant papers have been included in this literature review have been used in their primary form as part of the systematic approach literature review.

Are you a **Patient** with a diagnosis of Heart Failure**?**

Have you been a **Carer** for someone who has a diagnosis of Heart Failure**?**

Have you ever been advised by a healthcare professional…

- that the treatment priorities for your care are to now keep you comfortable?
- that there are no further treatment options available to improve the heart function?
- that your heart failure symptoms are increasingly unstable?

Invitation to Participate in a Research Study

Participation will involve being interviewed by **Amanda Farwell** (a **former Heart Failure Nurse Specialist with over 13 years' experience** of caring for heart failure patients and carers and a PhD student at the University of Essex).

It is funded by the National Institute for Health and Care Research - Applied Research Collaboration for the East of England, and the University of Essex.

The interviews will be undertaken over Zoom video call with Amanda, and will last approximately one hour. Participant confidentiality will be maintained throughout the research.

For further information regarding Amanda's professional experience or this study please either scan the QR code or email Amanda on the details below.

If you are over 18 years of age and are interested in taking part please email Amanda on the details below.

Information for **patients** | Amanda's Professional Biography | Information for **carers**

amanda.farwell1@nhs.net

Version: 2.0 Date: 12.09.2023
IRAS Reference Number:

Appendix E. Promotional poster for patients and carers

Patient Participant Information Sheet

Project Title

Improving heart failure supportive and palliative care.

Invitation

My name is Amanda Farwell, and I am a PhD student in the School of Health and Social Care at the University of Essex and the Applied Research Collaboration for the East of England. I would like to invite you to take part in a research study. Before you decide whether or not 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.

Purpose of the study

The aim of this study is to obtain heart failure patients and carers experiences of having conversations about the progression of their condition with healthcare professionals, their experiences of receiving ongoing care relating to these discussions, and how this care can be improved. This information may be used to help enhance current care for heart failure patients who are requiring supportive care due to a progression in their condition.

The project is being undertaken as part of a PhD qualification and will run until October 2024.

Why have I been invited to participate?

You have been invited to participate as you have experienced a conversation with a healthcare professional, regarding the progression of your heart failure. This may have included discussions about your worsening symptoms, the increased frequency of hospital admissions (due to your heart failure), the need to keep you comfortable due to your declining symptoms and how there is a lack of treatment options now available to you.

Do I have to take part?

It is up to you to decide whether or not you wish to take part in this research project. If you do decide to take part, you will be asked to provide written consent. You can withdraw without giving a reason, and any information that you have already provided will be destroyed.

Whether you decide to take part or not, or if you take part and then withdraw will have no impact on your future care provided by any healthcare professional, within or outside of the National Health Service.

Appendix F. Patient participant information sheet

What will happen to me if I take part?

You will initially be contacted by the primary researcher (Amanda Farwell), after you have confirmed that you would like to participate via email. This informal discussion will arrange a time and date convenient to yourself for the interview to take place, and allow you to ask any questions or queries you may have regarding the participation of this study.

The interview will last approximately one hour, and will be conducted by the primary researcher – Amanda Farwell via an internet video call, called Zoom. This will allow yourself and the researcher to see and hear each other. There will be a set of interview questions used, but these are to guide the conversation whilst allowing you to describe your experiences in your own words. Written notes may be taken during the course of the interview, but these will not contain any personal information, and will only be available to the primary researcher conducting the interview. Whilst the interviews are in progress an audio recording will be taken. This recording will be transcribed by the primary researcher, who will provide your interview with a randomly allocated identification number and all personal and identifiable information (such as names of people, places or healthcare providers) will be removed to ensure the transcript has been anonymised.

Anonymised extracts from the interview transcript will be used in the analysis of the data, and direct quotes may be used in future publications of this research.

What are the possible disadvantages and risks of taking part?

The aim of the research study is to improve supportive care for heart failure patients. To achieve this participants will be asked to describe their experiences, which you may find uncomfortable or emotional. The primary researcher has a vast experience of undertaking these conversations, and caring for heart failure patients and their carers, and will endeavour to ensure it is performed in a sensitive manor. If you feel distressed in any way you will be given the opportunity to discontinue, or postpone the interview. The primary researcher will offer an informal discussion with you to determine if you require further support from those healthcare professionals within your network of care.

What are the possible benefits of taking part?

Although you may not benefit personally from this research, it will enable a better understanding of the topic and provide information that may improve heart failure end of life conversations and palliative care provision in the future.

How will we use information about you?

The primary research (Amanda Farwell) will need to use information from you for this research project.

This information will include your

- Name
- contact details
- Age
- Gender
- Ethnicity

Appendix F. Patient participant information sheet

- Occupation
- Geographical area

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

The primary researcher will keep all information about you safe and secure.

Once the primary researcher has finished the study, they will keep some of the data so they can check the results.

The primary researcher will write their reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, and any information that you have already provided will be destroyed.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team by sending an email to: ajfarw@essex.ac.uk
- by sending an email to dpo@essex.ac.uk (the Data Protection Officer at the University of Essex).

For further information a copy of the HRA 'Patient and data research' leaflet can be found at www.hra.nhs.uk/patientdataandresearch

Will my information be kept confidential?

The information collected will be stored in a secure, encrypted database within the University of Essex. Any notes that have been made during the interview will be scanned and stored in the same way. Once the document has been copied and securely saved, the paper version will be destroyed. Audio recordings of the interview will be transcribed and anonymised by the primary researcher (Amanda Farwell), this transcription will also be saved securely. All electronic data will be password protected and will only available to the primary researcher (Amanda Farwell). During the project the anonymised transcripts may be shared with the primary researcher's academic supervisors (named below).

Once the project has been completed the data will be retained for a period of ten years. At the end of the ten year period all data collected relating to this research will be destroyed.

Your safety is paramount during this research study, and should any information be disclosed that leads the primary researcher to believe that you or others are at risk of harm, the primary

Appendix F. Patient participant information sheet

researcher may have a duty of care to inform the appropriate authority. It is only during this scenario that anonymity cannot be guaranteed.

What is the legal basis for using the data and who is the Data Controller?

In providing your consent, in signing the Consent form, you are agreeing to the processing of your data.

Any queries regarding this can be directed to the Data Controller at the University of Essex. The contact details for the University Information Assurance Manager are: dpo@essex.ac.uk

What should I do if I want to take part?

If you wish to take part in the research study please advise your heart failure clinician that you agree for them to pass on your name and contact details to Amanda Farwell (the primary research) directly via the secure email below.

What will happen to the results of the research study?

The results of this study will be used in the primary researcher's thesis as part of their PhD. In keeping with the Research repository policy at the University of Essex, the thesis will be retained indefinitely for public viewing.

Results will be published as a journal article and may be used to inform Clinical Commissioning Groups in future heart failure care service development.

All information used within the results of the research project will be anonymised, and will not be identifiable.

The findings of the study will be available to participants and you are welcome to apply for a copy by emailing the primary researcher – Amanda Farwell on the details below.

Who is funding the research?

The research project is being funded by the National Institute of Health Research, Applied Research Collaboration for the East of England.

Who has reviewed of the study?

The research has sought ethical approval from the University of Essex Ethics Sub-Committee 2, Essex Partnership University Trust Research and Innovation department and Wales REC 7, Health and Care Research Wales.

Concerns and Complaints

If you have any concerns about any aspect of the study or you have a complaint, in the first instance please contact the principal researcher of the project, Amanda Farwell, using the contact details below. If are still concerned, and you think your complaint has not been

Appendix F. Patient participant information sheet

addressed to your satisfaction or you feel that you cannot approach the principal researcher, please contact the Director of Research within the School of Health and Social Care who responsible for this project, this will be Dr Camille Cronin (camille.cronin@essex.ac.uk). If you are still not satisfied, please contact the University's Research Integrity manager Dr Mantalena Sotiriadou, (e-mail ms21994@essex.ac.uk). Or contact Essex Partnership University Trust's local PALS team on the details below. (Please include the IRAS reference which can be found at the foot of this page).

Patient Experience Team (PALS)
Freepost RTAG-HYGH-KYUY
EPUT NHS Foundation Trust
The Lodge
Lodge Approach
Wickford, Essex
SS11 7XX
Tel: 0800 0857935
Email: epunft.pals@nhs.net

Where can I receive a paper copy of this Participant Information Sheet?

If you have sourced this Participant Information Sheet via the promotional poster QR code. A paper copy is available and can be obtained from your local heart failure nurse or by emailing the primary researcher, Amanda Farwell (amanda.farwell1@nhs.net).

Research Team Members

Primary researcher:	Amanda Farwell amanda.farwell1@nhs.net
Academic supervisor:	Professor Ewen Speed esspeed@essex.ac.uk +44 (0) 1206 872847
Academic supervisor:	Professor Gill Green gillgr@essex.ac.uk +44 (0) 1206 874144

Appendix F. Patient participant information sheet

Are you a community heart failure nurse?

Would you like to.....

improve end of life conversations and palliative care provision for heart failure patients and their carers?

be involved in discussing how data from heart failure patients and carers can be implemented into clinical practice?

Invitatio to Participate in a Research Study

Participation will involve taking part in a focus group or individual interview with **Amanda Farwell** (a former Heart Failure Nurse Specialist, and a PhD student at the University of Essex).

It is funded by the National Institute for Health and Care Research - Applied Research Collaboration for the East of England, and the University of Essex.

The focus group or interviews will be undertaken over Zoom video call with Amanda, and will last approximately one hour. Participant confidentiality will be maintained throughout the research.

For further information regarding Amanda's professional experience or this study please either scan the QR code or email Amanda on the details below.

If you are over 18 years of age, currently a Community Heart Failure Nurse and are interested in taking part please email Amanda on the details below.

Information for **Community heart failure nurses.**

Amanda's professional biography

ajfarw@essex.ac.uk

Appendix G. Promotional poster for community heart failure nurses

The research question

What are heart failure patients' and carers' experiences and expectations of end of life conversations and palliative care provision? And how can this be implemented clinical practice?

Interview Questions

ID number:
Date of Interview:
Patient or Carer or both:

General Background Questions

- Age
- Gender
- Geographical area
- Profession
- Ethnicity
- Date of heart failure diagnosis
- Type of heart failure

1. Tell me about when you were diagnosed with heart failure.

2. Do you remember if you were told that this is a life-long condition and was potentially life limiting?

3. Did anyone speak to you about end of life care? Were you able to make sense of that phrase 'end of life'? Did anyone talk to you about what they might have called palliative care?

- If yes, what do you remember about the end of life conversations? What about your experiences of talking about and receiving palliative care?
  (For example, where were you when you were told this? Were you with someone or alone? Which professional gave you this information? Was it done in a sympathetic way? Who provides your palliative care?)

4. Do you feel being told that you were now required end of life care was helpful to you?
   If yes, how was it useful? If no, why not?

- If no, would you have liked to talk to your doctors, nurses or someone at an organisation such as Marie Curie or a palliative care charity about end of life care? Why?

Appendix H. Interview schedule for patients and care givers

5. Are there aspects of end of life care that you would you like to discuss with your doctor or nurse? (For example, management of symptoms, location of preferred place of care or death, advanced care planning).

6. Are you currently receiving palliative care? If yes, what aspects of receiving palliative care are important to you? If no, what would you think your requirements to be?

7. Is there anything that you think we should have covered, but have not yet?

8. Is there anything you would like to add or ask?

Appendix H. Interview schedule for patients and care givers

Focus group – heart failure nurses

Vignette

Fred is in his mid 70s. He has been a carer for his wife since her diagnosis with heart failure, 5 years ago. Fred says he was involved in an end of life conversation between the heart failure nurse and his wife when she was first diagnosed. Since then he describes feeling unsupported, and ill-informed about his wife's condition and care.

- Do you think this is a common experience among care givers for heart failure patients?
- How do you think Fred can be more included in his wife's care?
- Who do you think is best placed to deliver this support?

Vignette

Ginny is in her late 50s. She was diagnosed with heart failure 4 years ago. Near the beginning of her diagnosis she received written correspondence from cardiology clinic appointments, but does not recall having a conversation with anyone - of what heart failure is, and that it is a condition that is often terminal.

She said she was advised of the terminal aspect out of the blue, about 2 year ago, when her heart failure nurse mentioned a palliative care referral. She thinks having conversations earlier on may have been helpful.

- Do you this is a common experience among heart failure patients?
- How do you identify patients that are entering the palliative stage of their condition?
- When do you think it would be the best time to discuss this?
- Who do you think is best placed to deliver this support?

Vignette

Molly is in her mid 70s. She was diagnosed with heart failure several years ago. Molly and her husband attended a heart failure clinic appointment 6 months ago, when her end of life preferences were discussed. She describes the conversation as a shock, and felt the conversation was conducted in an abrupt manor. She thinks a gentle introduction to the topic may have been helpful.

- Do you this is a common experience among heart failure patients?
- How do you think conversations like this can be initiated, and when would be the best time to instigate it?
- Who do you think is best placed to deliver this information?

Vignette

Jim is in his late 60s and was diagnosed with heart failure 4 years ago. He said he had an end of life conversation with his heart failure nurse, who thought support from the palliative care service would help him. Jim's view of palliative care is associated with dying, and he has negative views of the term palliative care.

- Do you this is a common experience among heart failure patients?
- How could this negative opinion be overcome?
- How can the term palliative care be introduced to prevent negativity?

Main themes

Inclusivity for *all*.

Patients and care givers reported a need for those directly involved in patient end of life care to be included in end of life conversations and ongoing care discussions.

Appendix I. Interview schedule for community heart failure nurses

- In your experience, do you think patients and care givers end of life conversations are inclusive?
- How do you think inclusivity for patients and care givers can be achieved?
- What barriers would prevent this from happening?
- What would help improve this?

Social isolation.

Patients reported exclusion, wanting to know more, and confusion when receiving and interpreting information relating to their end of life care. These emotions leading to social isolation.

- In your experience, do you think heart failure patients receive suboptimal information relating to their end of life care?
- How you think heart failure patients can informed about their end of life care?
- What barriers would prevent this from happening?
- What would help improve this?

Take control and conquer

Patients reported a need to take control, and a fear of the unknown relating to their end of life care.

- In your experience, do you think heart failure patients are not in control their end of life care?
- Do you think patients want to be in control of their end of life care decisions?
- What barriers would prevent this from happening?
- What would help improve this?

Mixed messages

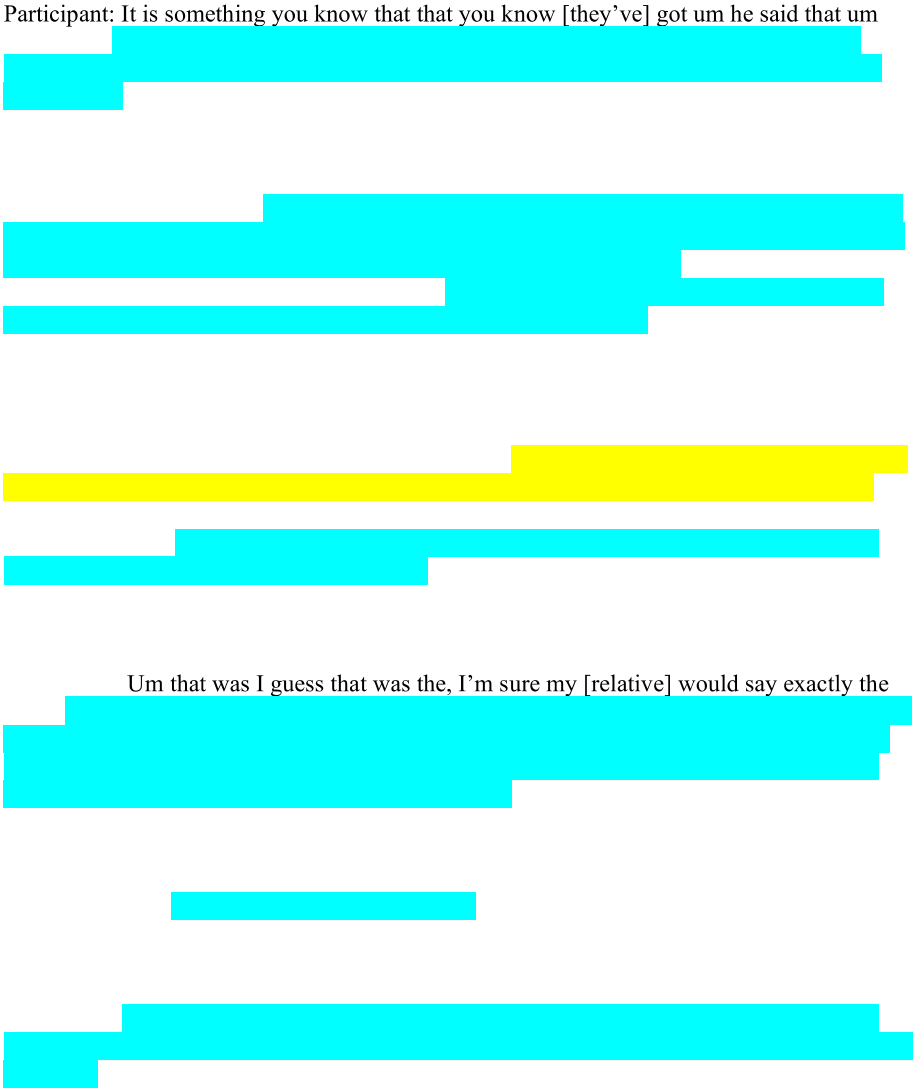
Patients reported receiving mixed messages regarding their end of life conversations, and information given. Some felt well informed, recalling conversations and clear explanations, whilst others reported having no recollection or information given at all.

- Do you think heart failure patients do receive inconsistencies in end of life conversations and information given?
- Do you think all heart failure patients want to be fully informed about their end of life care?
- What barriers would prevent this from happening?
- What would help improve this?

Appendix I. Interview schedule for community heart failure nurses

Interview extract

Participant: It is something you know that that you know [they've] got um he said that um



Um that was I guess that was the, I'm sure my [relative] would say exactly the

Appendix J. Interview transcript

Heart failure research feedback form

Participant's quotations	**How do these quotations make you feel?**	**Do the quotations feel like your experiences? Is so, how?**	**What word would you use to sum up these quotations?**
Giving patients and care givers information: • It probably left us a bit up in the air. I didn't realise I was just as bad as I was. • didn't take any of it in. I just, just, burst into tears. • it was just assumed, I knew. • wasn't no build up, and there wasn't no explaining.			
Having end of life conversations: • It needs to be more than a one off especially to a lot of people that don't understand what's going on. • Could have been introduced a little bit easier. • No one has been honest with me. • Given time to have a discussion.			
Having control what happened next in terms of illness and care: • I have to bring this subject up. I think they're a bit coy about mentioning it. • Scared the hell out of me. • Felt vulnerable and very lonely. • There's no good trying to hide it, it's there.			
Receiving support: • I needed that nurse; she was absolutely amazing. • How she [the nurse] explained things. She explained things very well. It, it was very good. • if they get to know me, they get to know what I can deal with. And it's that relationship. • I have no support, because I've just been left, because there is nothing more he can do.			

Appendix K. Data analysis feedback

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Mrs Amanda Farwell
PhD student

Email: HCRW.approvals@wales.nhs.uk

06 February 2023

Dear Mrs Farwell

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Working in partnership with heart failure patients, and carers to improve end of life conversations and palliative care provision with clinicians.**
IRAS project ID:	**320970**
Protocol number:	**N/A**
REC reference:	**23/WA/0024**
Sponsor	**University of Essex**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

Appendix L. NHS ethical approval form

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **320970**. Please quote this on all correspondence.

Yours sincerely,
Sue Byng

Approvals Specialist

Email: HCRW.approvals@wales.nhs.uk

Copy to: *Ms Sarah Manning-Press*

Appendix L. NHS ethical approval form

Decision - Ethics ETH2122-1346: Mrs Amanda Farwell

E

ERAMS <erams@essex.ac.uk>

To: Farwell, Amanda J

09/06/2022

Mrs Amanda Farwell

Health and Social Care

University of Essex

Dear Amanda,

Ethics Committee Decision

Application: ETH2122-1346

I am pleased to inform you that the research proposal entitled "Working in partnership with heart failure patients and carers to improve end of life conversations and palliative care provision with clinicians." has been reviewed on behalf of the Ethics Sub Committee 2, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

Appendix M. University ethical approval form

Decision - Ethics ETH2122-1346: Mrs Amanda Farwell

E

ERAMS <erams@essex.ac.uk>

To: Farwell, Amanda J

Extensions and Amendments:

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

Covid-19:

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

Beverley Pascoe

Ethics ETH2122-1346: Mrs Amanda Farwell

This email was sent by the University of Essex Ethics Review Application and Management System (ERAMS).

Appendix N. University ethical amendment approval form

Participant Consent Form

Project Title

Improving heart failure supportive and palliative care.

Research Team Members

Primary researcher:	Amanda Farwell Amanda.farwell1@nhs.net
Academic supervisor:	Professor Ewen Speed esspeed@essex.ac.uk +44 (0) 1206 872847
Academic supervisor:	Professor Gill Green gillgr@essex.ac.uk +44 (0) 1206 874144

		Please initial box
1.	I confirm that I have read and understood the Participant Information Sheet dated 02.02.23 for the above study. I have had an opportunity to consider the information, ask questions and have had these questions answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw from the project at any time without giving any reason and without penalty.	
3.	I understand, if I chose to withdraw, the research team will keep the research data about me that they already have.	
4.	I understand the identifiable data provided will be securely stored and accessible only to the primary researcher (Amanda Farwell) and that confidentiality will be maintained.	
5.	I understand that should any information be disclosed that leads the primary researcher to believe that I or others are at risk of harm, the primary researcher may have a duty of care to inform the appropriate authority. I understand it is only during this scenario that my anonymity cannot be guaranteed.	
6.	I agree to the interview being audio recorded.	

Appendix O. Consent form for participants

7. I agree for my anonymised direct quotes to be used in publications. ☐

8. I understand that my fully anonymised data will be used for the purpose of the research thesis, journal publications and to inform Clinical Commissioning Groups in the future development of heart failure services. ☐

9. I agree to take part in the above study. ☐

Participant Name	Date	Participant Signature
_____	_____	_____
Researcher Name	Date	Researcher Signature
_____	_____	_____

Participant Copy * ☐

Chief Investigator copy * ☐

(*Please tick to indicate copies provided to both parties).

Participant ID Number. ☐

Appendix O. Consent form for participants

Appendix P. Interview check list